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PAPERS

THE ALFIE EVANS CASE: HOW NOT TO APPLY CATHOLIC TEACHING ON WITHDRAWING LIFE-SUSTAINING TREATMENT

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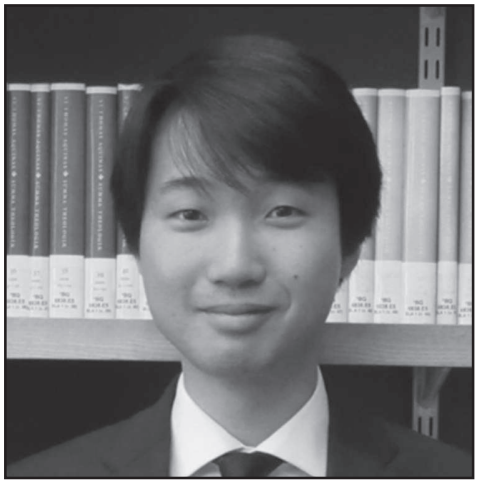
A version of this paper was delivered at 'A Panel Discussion on the Alfie Evans case and its Implications', hosted by the Catholic Union at Notre Dame University, London on 11th September 2018.



Beginning with the Person

When we come to consider the tragic events of the Alfie Evans case, it is imperative that we begin by remembering that we are dealing not with a subject in the abstract, but a real-life human person: Alfie Evans, who died in April this year following the removal of his ventilator by court order.

There is much to be said about the merits of the various court judgements dealing with Alfie Evans's medical treatment, but I want to begin by asking you to consider the image of a young child on life support, in contrast with the image of an adult on life support. How, and why, do they seem so different – if indeed they do? Why is it that the subject of withdrawing life-sustaining treatment, which is never an easy one, seems particularly difficult when it comes to children and infants?

One reason may be that we have a more instinctive tendency to protect the youngest members of our society. But in my opinion, there is something else at work: With adults, we are easily struck by the horror of autonomy that is lost, especially if the patient is also unconscious. With children and babies, however, they are in general more obviously dependent on the help and support of others anyway, and so life-sustaining treatment appears less unnatural or invasive. Somehow, it is their dependence, in fact, that accentuates our sense of their humanity, and we are better able to see them as whole persons, compared with adults on life support. And therefore the language language that has been known to be applied to adults in a persistent vegetative state (PVS) in the context of removing nutrition and hydration – 'a passive prisoner of medical technology' (from a justice of the US Supreme Court), 'the shell of his body' (in relation to Tony Bland in this country)[1] – would have been met with great repugnance if applied to Alfie Evans, who was said to be in a 'semi-vegetative state'.[2] Children, it seems, awake in us moral sensibilities that we more easily let slide with adults.

To be clear, I am not saying that we should never withdraw or withhold life-sustaining medical treatment. Even assisted nutrition and hydration, which is in Catholic teaching is not medical treatment but ordinary care, can be withdrawn in extreme circumstances – though the fact of PVS alone does not suffice.[3] The Catholic moral tradition does not tell us that we are obliged to do everything we can to preserve life whatever the cost. But decisions about withdrawing treatment must be made in view of the whole person – their whole humanity, their intrinsic dignity and worth – rather than by focusing on what seems like 'mere bodily existence', as may be the temptation when we come face-to-face with an adult on life support, compared with a child. We can make judgements about the worthwhileness of a particular treatment, but what we must never do is make such a judgement about the worthwhileness of someone's life itself, including our own. This, however, was a problem in the way the Alfie Evans case was decided.

Ordinary and Extraordinary Means

But first of all, when might life-sustaining treatment cease to be worthwhile?

Catholic medical ethics has long made a distinction between ordinary and extraordinary means in medicine. Ordinary means are those which are not futile and not overly burdensome; we therefore have a moral duty to undertake them as part of our more general duty to protect and preserve our own lives, which have inherent worth. Extraordinary means by contrast are those which are futile, or excessively burdensome, or which promise little benefit in relation to the burdens they entail. They are, therefore, not obligatory. These burdens could include physical, emotional, psychological and even financial burdens. And why are we not obliged to undertake these, even though they might extend our lives? It is because medicine must serve the whole human person, and medical means become extraordinary when they become disproportionate for the person to bear, taking into account their whole life.

Indeed, medicine must not just serve the whole person but also the whole community. And that is why even resource allocation, a lack of resources, can be a reason for a hospital or a patient to refuse life-sustaining treatment, if it has been carefully assessed that the limited resources available are needed more urgently elsewhere and will be of greater benefit there. This justification must not, of course, be abused and turned into an evaluation of patients' lives by cost and cost savings. It would not be respectful of some

one's dignity to judge them primarily or solely in terms of their cost to the taxpayer; at the same time, the reality of the limited resources and an overstretched NHS should not be forgotten.

It is worth clarifying two things here. Firstly, the question of whether a particular treatment is ordinary or extraordinary is, in general, relative to the patient and their context. It is a moral and not a medical judgement. [4] The same course of antibiotics can be ordinary for one person and extraordinary for another. Secondly, although our moral judgement must have the treatment as its object, and not our own life (or the patient's, if we are making a decision on their behalf), that it is not to say that one's underlying condition plays no role whatsoever in the judgement. Obviously, one's condition might affect how much benefit can be derived from the treatment in question, and this would have an impact on an assessment of its benefits and burdens.

But here, there is potential for confusion: The suffering that comes from a disease or condition is not the same thing as the suffering brought about by treatment. Yet the two are easily mixed up, as when a particular treatment is said to 'prolong the suffering' of a patient even when the treatment itself poses few or no burdens at all. The patient's suffering caused by their condition is not by itself a reason to withdraw or refuse treatment; otherwise we come very close to judging the worthwhileness of the person's life.

The Alfie Evans Case: Judging Life or Treatment?

It is clear, then, that making a judgement about ordinary and extraordinary means is not all that straightforward a matter. We might therefore ask whether this distinction was properly applied in the Alfie Evans case.

Interestingly enough, in the High Court judgement of 20 February 2018, the judge in the Alfie Evans case quoted a letter by Pope Francis precisely on the subject of withdrawing life-sustaining treatment. Personally, however, I would be cautious about making too much of that. The fact of the letter being cited may indicate, perhaps, that the judge was accepting of the distinction between ordinary and extraordinary means in medical treatment, and that of course is to be welcomed. But the letter itself does not do the work of telling us whether in this case, the treatment in question – continued ventilation – was indeed in the realm of extraordinary means. In fact, Pope Francis's letter contains these words of caution regarding making judgements about ordinary and extraordinary means:

> To determine whether a clinically appropriate medical intervention is actually proportionate, the mechanical application of a general rule is not sufficient. There needs to be a careful discernment of the moral object, the attending circumstances, and the intentions of those involved.[5]

It was precisely where the moral object was concerned that I think the High Court judge, Mr Justice Hayden, went wrong in this case. It seems to me that what he was judging was the worthwhileness of life, rather than the worthwhileness of continued treatment. It is true that at various points in his judgement, Hayden J refers to continued treatment as being 'futile', but it is when he cites guidance on withdrawing life-sustaining treatment produced by the Royal College of Paediatrics and Child Health (RCPCH) that he truly gives some conceptual clarification as to what he means by 'futile' and why exactly he thinks this is the case. (I should note that this piece of guidance was also referred to by the High Court judge in the Charlie Gard case.) The importance of this piece of guidance should not be understated, for the judge explicitly states, 'It is necessary here to root my own conclusions… within the available guidance' in relation to it.[6]

The portion of the RCPCH guidance that Hayden J quoted in particular reads:

> Lack of ability to benefit; the severity of the child's condition is such that it is difficult or impossible for them to derive benefit from continued life…[7]

This is no judgement about the futility or burdensomeness of treatment, properly understood. It is a judgement on the worthwhileness of Alfie's life, albeit rather circuitously phrased. The idea that life is something we can 'derive benefit' from or not suggests a rather utilitarian form of thinking – as if life is something we own, analogous with other possessions, rather than something constitutive of who we are as persons at a fundamental level. Human life becomes valued for its 'use' to its 'owner', rather than for its own sake. This thought was, sadly, also at work in the Bland judgement of 1993, when Lord Keith referred to a large body of medical opinion as holding that 'existence in a vegetative state with no prospect of recovery is… regarded as not being a benefit'.[8]

Simply put, what is being said here in the Alfie Evans judgement is, 'This is a life no longer worth living'. This is dangerous, slippery territory for medical ethics, and in particular for those who live with profound disabilities, for life is no longer regarded as having intrinsic worth by this judgement. [9]

Valuing Life as Intrinsically Good

The idea that life is something we own, rather than a constitutive part of who we are, is popular with advocates of euthanasia. But if there is anything that disabuses us of this notion, it is reflection on the level of dependence so inherent in infancy and childhood, as mentioned earlier. We do not own life, and that is why dependence is nothing contrary to our humanity but in some ways a fulfilment of it, since we are by nature interpersonal beings and dependence is part of the fabric of our social life. This applies equally to adults, even those in PVS. Children such as Alfie Evans help us understand that even being in a state of near-complete dependence on medical technology, with limited conscious experience, does not render a life meaningless or worthless. Life always remains an intrinsic good.

But in all fairness to the judge in the Alfie Evans case, I would like to add that, where criticisms of 'euthanasia' or 'court-sanctioned killing' are concerned, I do not think it is indisputably the case that those charges are true. The ruling may have been made based on a judgement on the worth of Alfie's life, and this is deeply problematic, but this does not necessarily translate into an intention to deliberately end life. A charitable interpretation of the judge's ruling might hold that its fault lies, rather, in an

insufficient appreciation of the obligation to preserve life. It is analogous to a patient with advanced cancer who decides to stop chemotherapy because he thinks, 'I want the suffering from my cancer to end quickly'. I am not saying this is a legitimate way of reasoning about withdrawing treatment, but we would not be hasty about calling such an intention 'suicidal' either. While it is clear to me that there is something deeply wrong with the way the Alfie Evans case was decided, we should be cautious about criticising anyone as intending euthanasia or suicide unless such an intention is demonstrably present.

Yet it is not difficult, of course, to see why such criticisms were made. If Hayden J was cautious in his choice of words in the High Court, sticking largely to the language of the futility of treatment (though he justified that futility incorrectly), Lord Justice McFarlane in the Court of Appeal was more explicit about his characterisation of the case, saying that the judge has concluded 'it is not in the best interests of the individual to carry on living'.[10] That is polite-speak for 'better off dead'.

Hence, in summary, one of the key questions we must consider when looking back at this case is this: Was this a rightful application of the ordinary-extraordinary means distinction in medical ethics? I have suggested that it was not. Life-sustaining treatment can, no doubt, be legitimately withdrawn in some cases – it may well have been a legitimate conclusion to come to with Alfie Evans's situation, leaving aside the question of whether the courts should have given the parents' views more weight, which was another problematic aspect of the case. Cases of this kind are precisely those where reasonable people can come to different conclusions, and there should be a high bar to be cleared before parental decisions are overruled. But in any case, even the right thing or the permissible thing must still be done for the right reasons, and this excludes judging the worth of someone's life, as unfortunately the High Court judge in this case did.

Even as we go about the often difficult task of weighing up burdens and benefits, we must remember that prolonging life should always be regarded as a benefit in itself. And we can look to children to reawaken our sense of the preciousness of each life which goes beyond utilitarian calculations, and how there need be no shame in dependence.

Michael Wee is the Education and Research Officer of the Anscombe Bioethics Centre.

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[1] Airedale NHS Trust v Bland [1993] 1 All ER 821 at 832.
[2] Alder Hey Children's NHS Foundation Trust v Evans [2018] EWHC Fam 308 [24].
[3] John Paul II (20 Mar 2004), 'Address of John Paul II to the Participants in the International Congress on "Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas"', HYPERLINK "https://u.btmail.bt.com/cp/ps/Mail/ExternalURLProxy?d=btinternet.com&u=atreloar&url=http://w2.vatican.va/content/john-paul-ii/en/speeches/2004/march/documents/hf_jp-ii_spe_20040320_congress-fiamc.html&urlHash=-2.195660906770255E163" \n http://w2.vatican.va/content/john-paul-ii/en/speeches/2004/march/documents/hf_jp-ii_spe_20040320_congress-fiamc.html. Accessed 18 Sep 2018.
[4] Nicanor Pier Giorgio Austriaco, OP, Biomedicine and Beatitude: An Introduction to Catholic Bioethics (Washington, D.C.: The Catholic University of America Press, 2011), p. 142.
[5] Letter from Pope Francis to the President of the Pontifical Academy for Life, cited in Alder Hey [2018] EWHC Fam 308 [52].
[6] Alder Hey [2018] EWHC Fam 308 [46].
[7] Larcher V, Craig F, Bhogal K, et al., 'Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice', Archives of Disease in Childhood 2015;100:s5, cited in Alder Hey [2018] EWHC Fam 308 [46].
[8] Airedale [1993] 1 All ER 821 at 861.
[9] I note that Hayden J, in an earlier part of the judgement, also quoted a doctor's report as saying, 'I believe that given Alfie's very poor prognosis with no possible curative treatment and no prospect of recovery the continuation of active intensive care treatment is futile…' (Alder Hey [2018] EWHC Fam 308 [25]). While this does not go so far as to make a judgement about a life not worth living, it is clear that such an idea of ventilation being 'futile' fails to take into account that it is still prolonging life, and that is not a futile thing to do, but an intrinsic benefit of such treatment. Ventilation was not going to cure Alfie in terms of his underlying neurodegenerative condition, but this fact alone does not make it futile.
[10] Thomas Evans v Alder Hey Trust [2018] EWCA Civ 964 [32].

NEW TECHNOLOGIES: NATURAL CYCLES APP FOR NATURAL FAMILY PLANNING

CHRISTINE BERGESS

This article first appeared in the NFP Teachers Association newsletter

The NFP Teachers Association received an email request to their website from Jack Pearson, a clinical embryologist employed by Natural Cycles as a Medical Science Liaison based in the UK

On behalf of the Association I contacted Jack and scheduled a telephone call for 1.10.18.

Resume:

Jack's original email stated:

"I noticed on your website that you are currently unaware of any applications that are more accurate than charting and wanted to offer you more information about Natural Cycles. This would include the published peer review data supporting its effectiveness and our current EU and FDA approval for use as a contraceptive device".

NC app uses temperature only and predicts fertile/non fertile days on this indicator alone, with the potential, says Jack, to use LH test as an additional aid.