

The case of Alfie Evans will remind people of the case of Charlie Gard last year¹. Although the medical facts differ, the fundamental ethical principles involved are very similar. Every human life is worthy of respect, and patients' lives should not be targeted deliberately, although not every treatment is worth pursuing.

Doctors should not be forced to continue treatment if they believe it offers little or no benefit relative to the burdens it entails, nor should they be forced to refer for specific treatments that they do not believe to be in the best interests of their patient. On the other hand, doctors should not prevent competent patients from seeking, for example, life-sustaining or palliative care or treatment from another doctor. Indeed, patients have a right to a second medical opinion and a general right to seek alternative treatment.

In the case of children, it is the parents who have prime responsibility for their own child and this responsibility entails the right to protect their child's interests as they see them. Parental rights, which exist for the sake of the child in the first instance, should not be taken from parents unless they have been shown to have acted unreasonably and put their child at significant risk. Doctors do not always get things right in treatment or care, and where parents have lost faith in the doctors caring for their child they may seek treatment and care for their child elsewhere. If the child can be moved without undue risk or burden, the parents should normally be permitted to transfer the care of their child to other suitably qualified doctors, whether in this country or abroad.

In this case it is not clear that the treatment itself is causing Alfie to suffer and it is not clear whether Alfie may not still be able to experience some simple pleasures such as having his arm stroked. No doubt there are good reasons to direct expensive treatments or facilities to those who are most likely to benefit (and ideally, to recover). However, if the treatment is not itself excessively burdensome and the resources are available then there is a reasonable case for continuing life sustaining treatment and care.

As a general rule, withdrawing or withholding treatment may be justified if the motive is to spare a patient unduly burdensome procedures. However, burdens caused by a procedure should not be confused with suffering caused by a particular condition or disability, even if the latter may be relevant to the patient's ability to benefit. If the motive is to end what is seen as a 'worthless' life due to illness or disability, this can never be justified. No human life is worthless, and treatment may only be withdrawn for the right reasons, such as lack of resources or undue burden in relation to its benefits.

¹ For more on Charlie Gard's medical condition see the website of Great Ormond Street Hospital. <u>http://</u>www.gosh.nhs.uk/frequently-asked-questions-about-charlie-gard-court-case



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