The Anscombe Bioethics Centre

Press Statement

Charlie Gard: Doing the right thing for the right reasons

On 27 June 2017, the European Court of Human Rights endorsed the judgements of the UK courts in the Charlie Gard case. The UK courts had upheld the view of the doctors caring for Charlie that it was no longer in his best interests to continue artificial ventilation. The UK courts had also ruled that it would not be in Charlie's best interest to undergo experimental "nucleoside therapy" in America as this had no realistic prospect of benefit and might have added to his distress.

This is indeed a heart-rending case. The condition from which Charlie Gard suffers is incurable and progressive: even with aggressive treatment he would be unlikely to live for more than a few months.[1] The suffering of the parents in this situation has been compounded by the long legal dispute over what form of treatment would be best for Charlie.

Ethical analysis

There are two things that need to be kept in mind in end of life care: respecting life and accepting death. Respecting life means that every person must be valued for as long as they live. One implication of this is that (at least in a medical context) death should never be the aim of our action or of our inaction. We should never try to bring about or to hasten death. On the other hand, accepting death means that we should prepare properly for death – our own and that of other people. One implication of this is that we should not deny the reality of the situation or flee from the inevitable by seeking every possible intervention, however disproportionate.[2]

While every human *life* is worthy of respect, not every *treatment* is worth pursuing. This may be

- because it no longer serves its purpose (it is *futile*),
- or because it is *excessively burdensome*: the burdens may be physical, psychological, social, or economic,
- or because it promises too *little benefit* relative to the burdens it entails.[3]

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

[2] Catholic Bishops' Conference of England and Wales. *A Practical Guide to the Spiritual Care of the Dying Person*. London: Catholic Truth Society, 2010, paragraph 2.1. http://www.bioethics.org.uk/images/user/guide-spiritual-care-dying-person.pdf

[3] *The Ethics of Care of the Dying Person* Anscombe Bioethics Centre, 2013. http://www.bioethics.org.uk/images/user/TheEthicsofCareoftheDyingPersonwebsite.pdf

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Good reasons and bad

In the case of Charlie Gard, the doctors caring for him believed that he could probably experience pain, but was "unable to react to it in a meaningful way".[4] Their evidence was that "being ventilated, being suctioned, living as Charlie does, are all capable of causing pain".[5] It was said that "even before Charlie began to suffer from seizures on 15th December 2016, the clinical consensus was that his quality of life was so poor that he should not be subject to long term ventilation".[6]

The statements that ventilation could itself be causing suffering and that it was producing only a poor "quality of life" (i.e. state of health and well-being) together constitute an argument about whether this particular treatment is worthwhile. Others may argue with the conclusion, but this way of reasoning is ethically defensible.

On the other hand, opinions were also cited in court that seem to refer not to the worthwhileness of *treatment* but to the worthwhileness of Charlie's *life*. In the High Court, Mr Justice Francis repeatedly stated, with approval, that "Charlie's parents accept that his present quality of life is one that is not worth sustaining".[7] Francis J also cited one doctor as saying that the severity of Charlie's condition was such that "it could be argued that Charlie would derive *no* benefit from continued life".[8]

At best, these are muddled ways of referring to the limited benefits of treatment relative to the burdens. At worst, they express a judgement that life with some disabilities is not worth living at all (the life is "not worth sustaining"). This way of reasoning can have dangerous and far reaching implications and should be repudiated firmly.

Another criticism which could be levelled at the way the UK courts approached this case is that they treated Charlie as if he had no parents or as if his parents had already been shown to be acting in a very unreasonable, albeit well-meaning way. In a case like this, the first question should not be "What treatment would be in the best interests of Charlie?", as though making a parental decision on his behalf, but "Are Charlie's mother and father acting reasonably or at least, not very unreasonably?" Only after parents have been shown to be acting or seeking to act very unreasonably and exposing their child to a risk of significant harm, albeit with good intentions, should such decisions be taken out of their hands.

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[4] Great Ormond Street Hospital v Yates and others [2017] EWHC 972 (Fam), 22.
[5] *Ibid*., 22.
[6] *Ibid*., 59.
[7] *Ibid*., 48, 14, 61.
[8] *Ibid*., 60, emphasis added. Such negative judgements are also reflected in problematic language used in the current guidance issued by the Royal College of Paediatrics and Child Health. See 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:s1-s23, cited in the judgement.

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Flawed reasoning, defensible decisions

There are flaws, therefore, in the way that the courts came to their decisions in the Charlie Gard case, both in negative value judgements made (or cited with apparent approval) on the worthwhileness of Charlie's life and in a failure to recognise the role and status of his parents. Nevertheless, the final decisions in this case – to withdraw ventilation and not to seek experimental treatment – are decisions that parents in this situation could reasonably make on behalf of their child. The decisions themselves are morally defensible. The Catholic moral tradition does not oblige the use of medical procedures that are burdensome, dangerous, extraordinary, or disproportionate to their expected outcome.[9]

At some point we will all die, and often we will be undergoing medical treatment before we die, and as the chances of improvement fade and the time remaining grows short, the burdens and side effects of the treatment are a reason to forego intrusive and extraordinary means and to focus on symptom control. This is true of dying children just as much as dying adults. There is a time to fight and a time to cease from fighting.

The staff of the Anscombe Bioethics Centre wish to express our solidarity with Charlie's parents as they go through this deeply painful time and assure them of our prayers for Charlie and for all those around him.

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[9] *Catechism of the Catholic Church*, paragraph 2278; see Catholic Bishops' Conference of England and Wales. *A Practical Guide to the Spiritual Care of the Dying Person*. London: Catholic Truth Society, 2010, paragraph 2.4.

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