



The Charlie Gard Case: Who Decides “Quality of Life”

The tragic case of Charlie Gard and his parents’ fight for their rights as decision makers have given us all pause concerning the role of not only government, but also physicians in determining the quality of life of persons with disabilities. Little Charlie is an 11-month old infant who suffers from a very rare genetic disease known as mitochondrial depletion syndrome. Specialists at Great Ormond Street Hospital, where Charlie is a patient, wish to withdraw Charlie’s life support and to allow him to die. Charlie’s parents have been denied, with the support of successive courts, the ability to take Charlie home or to bring him to the United States for treatment, indicating that Charlie be allowed to “die with dignity.”

Added to the controversy is the fact that the [barrister](#) representing the court-appointed advocate for Charlie is a barrister who has advocated for a patient’s right to death with dignity. She once represented the wife of an incompetent patient in Great Britain’s High Court, who argued that her husband, who was clinically stable and had not written an advanced directive, would want to have life sustaining treatments withdrawn. The court ruled that the husband’s assisted nutrition and hydration could be withdrawn, and he died. The interesting fact is that in that case the will of the patient’s surrogate decision-maker was honored. In the case of little Charlie, the parents, who are supposed to be the advocates for their child, wish to provide their son a chance for potentially helpful treatment. Their wishes have been [obstructed](#), not only by the hospital and the court, but also by Charlie’s court-appointed advocate and the barrister who represents the advocate.

The National Catholic Partnership on Disability (NCPD) makes no judgment on this case, as it has no access to the clinical facts that have led to these decisions. But this is a tragic case, pitting parents of a child with a disability against physicians, while demonstrating the potential power of the government over the most important decisions to be made by families on behalf of a child with a disability. What is critical is the ground upon which the decisions of the medical community and the court is rendered. Determining what is an extraordinary means (disproportionately burdensome means) of protecting human life is usually the role of the patient or the patient’s surrogate. While the medical community should not be obligated to provide futile or harmful procedures

to a patient, and there are cases in which the protection of the courts should be invoked to protect vulnerable patients, the role of the physician is to advise on side effects, risks, and benefits of treatments. It is rare that decisions, concerning whether the burden of a treatment is disproportionate to any benefit to the patient, are to be made by the medical community, and more rarely by the courts. This becomes especially problematic if the government is dictating reimbursement practices for health care.

Again, the NCPD can make no judgment on the case of Charlie Gard; but when a court uses terms such as the child's right to "die with dignity," to deny parental rights to advocate for the life of their child with a disability, and when Charlie's court-appointed advocate is represented by a barrister who has advocated in a prior case to withdraw life support, grave questions need to be raised. We live in a culture in which the solution to suffering is to kill the sufferer, and there is growing evidence this is occurring in a number of cases without explicit consent. We must be diligent in our advocacy for social policy that respects the right to life, which others have deemed to have lost human dignity.

On a positive note, in the case of little Charlie, the [High Court](#) is considering allowing him to be treated by an American physician who specializes in mitochondrial diseases and genetic myopathies. The judge has agreed to allow the American physician to evaluate Charlie, and will make a decision on allowing treatment by July 25, 2017. The NCPD asks all to pray for all of those involved in these decisions, which will have an irreversible impact on the very sacred life of little Charlie Gard.