



END-OF-LIFE CARE FOR CHILDREN

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There is no greater joy for a parent than to bring a tiny new life into the world. You enjoy watching as your child grows and achieves all the special milestones that a perfectly normal healthy child should. Then, you notice a few things are off, but you let them slide. Then you notice more and come to realize your child is not the perfectly normal healthy child that you once had. You see doctor after doctor asking what is wrong, and they keep telling you that it is nothing. Your parental intuition knows differently, so you keep on searching for that one doctor that will have the answer. When you find that doctor, you are not prepared for the shock and disbelief when he tells you your child has a fatal disease. Even worse, it is genetic, and you are worried for your other children.

You keep hoping that a new therapy will be found and this one is going to be different, this one will work. You are hoping your child can be enrolled in the clinical trials before it is too late. The recent therapies do not work as expected, and the next clinical trial requires you to travel across the country for six months. In the meantime, your child's disease is progressing. This is when you pray for guidance for how to decide what is best for your child and your family going forward.

Your child has a fatal disease; there may be more treatments or therapies to slow the progression, but it is still fatal. The role of a parent is to protect your child and teach them life skills, not teach them end-of-life skills. There comes a point in time when parents need to say, "Enough is enough." You realize that many of these experimental treatments and clinical trials are disproportionate and that it is morally and ethically acceptable to stop searching for a miracle cure, instead opting for palliative care or hospice care where your child will be comforted and allowed to die in peace with dignity surrounded by family and loved ones.

Withdrawing Treatment from Children

Parents have the autonomous right to choose or refuse a treatment for their child, even one that is life sustaining, if it is extraordinary or disproportionate and if the choice is within the best interest and well-being of their child. Pediatric health care is practiced with the goal of promoting the best interests of the child. Treatment is generally rendered under a presumption in favor of sustaining life. However, in some circumstances, the balance

of benefits and burdens to the child leads to an assessment that forgoing life-sustaining medical treatment (LSMT) is ethically supportable or advisable.¹ Input from specialists in palliative care, ethics, pastoral care, and other disciplines enhances support for families and medical staff when decisions to forgo LSMT are being considered.

According to Part Five of the *Ethical and Religious Directives for Catholic Health Services (ERDs)*, "The task of medicine is to care even when it cannot cure. Physicians and their patients must evaluate the use of the technology at their disposal. Reflection on the innate dignity of human life in all its dimensions and on the purpose of medical care is indispensable for formulating a true moral judgment about the use of technology to maintain life."²

The ethical argument in favor of forgoing LSMT is the same for children with developmental disabilities as for those considered to be developing typically.³ To decide whether a treatment is ordinary, we must also look at the patient's condition and circumstances, and not merely focus on the treatment, the medical device, or the medicine itself.

The following questions should be considered by all of those involved in decision-making: Is this intervention going to cure the disease? Is it going to prevent progression of the disease? What impact will the intervention have on the child's quality of life? Will it improve the child's symptoms? Will it make the child feel worse? How long will the child feel worse? What will happen without the intervention? How will the intervention change the outcome?⁴

Trying every option in the face of terminal illness, pursuing all medical possibilities no matter how unlikely to succeed, and raging against death can easily become the default position in a culture that hesitates to acknowledge or discuss death openly. Yet approaching our own mortality, or in this case, our child's mortality with a greater dose of realism helps us make better decisions about when to roll back the medical interventions and focus our energies on preparing for death.

Hospice and palliative care can be important and helpful adjuncts in this process. When done well, these approaches allow us to focus on improving the remaining time for those with a terminal illness. It helps families to make these types of decisions when doctors and nurses are willing to have the hard discussions and say what they have seen. Families become willing to acknowledge death and mortality, and when spiritual preparations are allowed to hold priority of place, patients can better and more peacefully prepare for what lies ahead when they receive the summons of approaching death in the form of a terminal illness.

Shared Decision-Making

The role of parents in pediatric end-of-life care is paramount, but also fraught with difficulty in situations where grieving may influence typically clear decision-making abilities. The primary