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A Mother's Love

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Elena Kilner, *Letters to John Paul: A Mother Discovers God's Love in Her Suffering Child* (Moorings Press, 2014).

John Paul Kilner lived a short but inspiring life. He died when he was 14 months old from a neuromuscular disease called Spinal Muscular Atrophy (SMA). SMA is a genetic disease which is the number one killer of children under the age of two. This progressive and terminal disease is caused by the lack of a protein which controls nerve-to-muscle communication. This lack results in muscle weakness and ultimately atrophy. The first groups of muscles affected are the skeletal muscles and the lung muscles. John Paul's life was impacted at two months of age. In one day he underwent three significant surgical procedures, including a tracheostomy to help him breathe and two gastrointestinal interventions to keep him nourished. Having accompanied their son through every moment of his physical suffering, John Paul's parents, Pat and Elena, have provided us with the gift of his life story.

The book *Letters to John Paul: A Mother Discovers God's Love in Her Suffering Child* has two main sections. The first contains the *CaringBridge* postings from Elena to her family and friends. (*CaringBridge* is a non-profit blog where parents or friends can keep others informed on the condition of hospitalized loved ones.) The second section of the book includes letters Elena wrote to John Paul.

The witness the book provides is timely. As St. John Paul II noted many times in his pontificate, there are significant parts of our culture that have undergone a "crisis of meaning," the loss of the meaning of human life. Elena chronicles just such a crisis, as she records the attitudes of certain health care professionals toward her son.

The doctors indicated that with SMA patients, they don't encourage the G-tube because it involves surgery, and since the prognosis is so bad, it's not worth the trouble. When I asked, "Well how do you feed them – obviously you don't starve the kid?"

The doctor's response: "Well, starvation' is a hard word..."

As the discussion progresses about the care John Paul will need at home, Pat and I have been encountering more and more nurses and doctors who question our eagerness to keep him living, and thriving as much as we can. Little by little John Paul will teach them the value of his little life, even if he isn't able to move and eat and breathe the way we do in this life. He will still learn, love, and be loved. And in

heaven he will have the body of a professional soccer player.

John Paul's life story inspires us because it is an example of the redemptive value of suffering. He endured more suffering in his short life than many people experience in decades. It is hard to imagine the suffering of his parents and siblings as they watched John Paul endure the numerous medical procedures and fight for his life each day. Yet, the book is full of hope because it provides a witness to the intrinsic dignity of each human life. In one of her letters to John Paul, Elena expressed the meaning of his suffering:

I definitely cried until my eyes were swollen shut the day I learned your diagnosis. But suffering is a necessary part of our life on earth, and we should be grateful for it, because it is the way we will be able to get to heaven someday. It is what we do with our suffering that is most important. Do we hide from it or try to avoid it at all costs – or at others' cost? Do we get angry about it? Or do we see it for what it is – an opportunity? John Paul, suffering is an opportunity. It is an opportunity to love God, to love others, and to grow in virtue. (76-77)

The book allows us to see John Paul's life within the whole truth about man. It shows us that John Paul's life had meaning because he was a member of a family and he was incorporated into the Body of Christ, the Church. His life on earth was not his final destiny. As St. John Paul II said, "The life which God bestows upon man is much more than mere existence in time. It is a drive towards the fullness of life; *it is the seed of an existence which transcends the very limits of time.*"[i] Through his smiles and eye-to-eye contact with his family and friends, he knew he was part of something bigger than himself, a family he loved and who loved him. In these common human experiences we realize Love is our final end. This is an experience so many of our young people today yearn for but have somehow missed.

The impact this little boy had on his family and friends and their response to his suffering is a shining example of the new evangelization. As Cardinal Ratzinger noted "Evangelizing is not merely a way of speaking, but a form of living: living in the listening and giving voice to the Father."[ii] This requires a conversion of heart, which for Benedict XVI entails nothing less than "to question one's own and common way of living; to allow God to enter into the criteria of one's life; to not merely judge according to the current opinions." The Kilners help us to realize that to follow Christ is to see your life through the eyes of God and that our family life is a school of virtue where "God's way of loving becomes the measure of human love." [iii]

The book would be a marvelous addition to high school and college courses by providing young people with a living example of the new evangelization and the family life we are called to by the Gospel. Benedict XVI said,

I have often affirmed my conviction that the true apology of Christian faith, the most convincing demonstration of its truth against every denial, are the saints, and the beauty that the faith has generated. Today, for faith to grow, we must lead ourselves and the persons we meet to encounter the saints and to enter into contact with the

Beautiful.[iv]

Let me be clear that I am not saying the Kilners are saints, but what I am saying is that their way of life is a path that is conducive to sanctity and continues to be a witness to the power of the Gospel which is the source of true joy.

As I finished the book it reminded me of something Malcolm Muggeridge wrote in 1981 where he noted that governments will find it impossible to resist the temptation of euthanasia.

The temptation will be to deliver themselves from this burden of looking after the sick and imbecile people or senile people by the simple expedient of killing them off. Now this, in fact, is what the Nazis did. And they did it not, as is commonly suggested, through slaughter camps and things like that, but by a perfectly coherent decree with perfectly clear conditions. And, in fact, it is true that the delay in creating public pressure for euthanasia has been due to the fact that it was one of the war crimes cited at Nuremburg. So, for the Guinness Book of Records, you can submit this: that it takes just about thirty years in our humane society to transform a war crime into an act of compassion. That is exactly what has happened.[v]

I wonder what will happen to families like the Kilners in thirty years. Our culture is becoming so dehumanized that I fear that they would be put in jail for trying to save their child's life. I pray that the example the Kilners have provided will help all to see that each human person is of infinite worth. Benedict XVI reminds us, "We are not some casual and meaningless product of evolution. Each of us is the result of the thought of God. Each of us is willed. Each of us is loved. Each of us is necessary." [vi]

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[i] John Paul II, *Evangelium Vitae*, 34.

[ii] Joseph Cardinal Ratzinger, Address to Catechists and Religion Teachers, 12 December 2000. Available at http://www.ewtn.com/new_evangelization/Ratzinger.htm.

[iii] Benedict XVI, *Deus Caritas est*, 11.

[iv] Cardinal Ratzinger, "The Beauty and the Truth of Christ": Address to CL in Rimini, 24 August 2002. Available at <http://www.ewtn.com/library/theology/ratzbeau.htm>.

[v] Malcolm Muggeridge, *Christian Married Love* (San Francisco: Ignatius Press, 1981), 28.

[vi] Benedict XVI, First Homily of His Holiness Benedict XVI, 24 April 2005. Available at http://www.vatican.va/holy_father/benedict_xvi/messages/pont-messages/2005/documents/hf_ben-xvi_mes_20050420_missa-pro-ecclesia_en.html.

