Case #6: Give a Little Heart

John and Sue got the news no family wants to hear. They were 20 weeks into Sue’s pregnancy when the ultrasound confirmed that the fetus she was carrying, which they had already decided to name Timothy, was suffering from anencephaly. The diagnosis meant that their dreams of little league and mud pies would instead involve a funeral and possibly another try. Fetuses with this medical condition experience only the most basic of brain stem development, such that they can maintain some autonomic functions like heartbeat and breathing, but lack consciousness and typically die within a short period after birth.¹

Both John and Sue were against abortion, and thus, for the first couple of months after the news they just let nature take its course. They hoped for a miracle, but as time progressed and more tests continued to show the same abnormality, they started to wonder whether they might be able to make something positive out of their suffering. They asked Sue’s doctor about the possibility of organ donation once then inevitable happened for Tim. Their physician advised that organ donation is not a simple matter, it requires testing and coordination between multiple medical teams, but more importantly, in Tim’s situation, the degenerative nature of the death without intervention often means that the organs that might be donated are often too degraded to be of use to those in need.

John and Sue asked lots of questions—they learned that the part of Tim’s brain that is typically believed to be the source of consciousness was not present and thus, Tim would never experience consciousness nor suffering. They learned that the longest an infant had survived with anencephaly was about two and a half years, but that this only occurred with intensive medical intervention and that child was essentially in a persistent vegetative state. They continued to hope for the best, but began to prepare for the worst.

In considering organ donation, John and Sue felt like it might help them gain a sense of control over the inevitable, which they hoped might help them in the grieving process, as well as giving them some certainty in a very uncertain and painful situation. They believed that once they met Tim, face to face, they would be able to tell whether he was “there,” and over a short period, expected that they could come to terms with the prospect of donating his organs to save a baby who was out there suffering and in need of their gift.

However, they soon learned that there were barriers to such a choice, and the law had them considering the very definition of life itself. While Tim was technically alive—he exhibited breathing, excreting, and sucking (for eating), for example, as well as some reflexive movements, he did not exhibit even the most basic reactions of a newborn, such as crying and bonding behaviors that help ensure survival in the wild. While their physician wanted to help keep Tim’s life from being lived in vain, she advised them that organ donation would illegal in their state unless Tim was dead, and once dead, his organs would likely go to waste unless they found a way around the rules against such donations.

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