

## Reflections on the Case of Baby Joseph

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### Baby Joseph and the Right to Live or Die

Pediatrician Dr. Melanie Brown of the comfort team of Chicago Comer Children's Hospital described the case of 14-month-old baby Joseph Maraachli in this way: "It pulls at all our heartstrings when we see a baby who might be suffering. There may be times where there are things we do so a child can live out the type of life that a family wants for them." Joseph's case bears out Brown's analysis.

Moe Maraachli is a Lebanese immigrant to Canada. His wife Sana gave birth to Joseph on January 22, 2010. Joseph suffers from Leigh Syndrome, a rare neurometabolic disorder that causes the degeneration of the central nervous system. It is also known as subacute necrotizing encephalomyelopathy (SNEM). There is currently no cure for this disease and infants like Joseph rarely live longer than two or three years after the onset of the disease.

Joseph initially developed normally, but by three months of age, his parents began to notice some behavioral abnormalities. In June, 2010, Joseph was taken to Detroit's Children's Hospital with severe breathing problems. After several weeks of treatment, he was discharged in stable condition. However, he was diagnosed with a metabolic brain disease that his physicians said would cause developmental delays.

In October, Joseph again experienced breathing problems combined with a fever. His parents rushed him to a local hospital and he was subsequently transferred to London Health Sciences Centre (LHSC) in London, Ontario. There, Joseph was examined by various specialists including pediatric neurologists who ordered MRIs and brain scans. They diagnosed Joseph to be in a persistent vegetative state. The family challenged this diagnosis because on many occasions Joseph responded to touch, especially cold hands, tickled easily, moved his head when his hair was brushed, and reacted to loud noises by turning his head toward the sound. A family spokesman commented that a person in a persistent vegetative state could not display these "purposeful neuromuscular movements."

Joseph's parents requested a tracheotomy in the hope that Joseph would be more comfortable and could be discharged home where they could care for him. (Eight years earlier, Joseph's older sister Zina died from a similar progressive and fatal neurodegenerative disorder. Her death in early infancy occurred after her physicians performed a tracheotomy which enabled the family to bring their daughter home and care for her. She lived six more months before she died of her disorder). The hospital, however, refused on the grounds that it would increase the risk of infection and

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pneumonia, would prolong the baby's dying, represented futile treatment, and would cause "much discomfort." (A tracheotomy is normally indicated for patients who require a long-term breathing machine).

In response to the hospital's decision, Joseph's father stated, "My son is not a criminal ... to just let die. They are taking my baby away from me." Subsequently, they reached out to the Children's Hospital of Michigan in Detroit in the hope that Joseph could be transferred there. The hospital initially agreed to the transfer, but after reviewing Joseph's chart, they declined claiming there was nothing further they could offer baby Joseph.

In January 2011, the hospital brought the baby Joseph case to the Ontario Consent and Capacity Board seeking legal authority to have the ventilator withdrawn. The board sided with the hospital. Joseph's family appealed the decision to the Ontario Superior Court. On February 17, 2011, Superior Court Justice Helen Rady upheld the hospital's and board's judgment, basing her decision on physician testimony that Joseph was in a persistent vegetative state. The court likewise dismissed the family's request that Joseph's breathing tube be removed at home "so the boy can die surrounded by his family." An appeal to Ontario's highest court by the family kept the order from being implemented, giving the family more time.

A number of concerned American pro-life groups, including the Terri Schindler Schiavo Foundation, strongly supported the request of Joseph's parents. The foundation declared that "it is frightening to once again see government usurp the God-given rights of

parents to love and care for their child at home." The Schiavo Life and Hope Network said that "every patient, regardless of age, has a right to proper and dignified health care," naming this case a "human rights issue."

The Euthanasia Prevention Coalition declared that "the family isn't pushing for extraordinary treatment, just asking for care for their dying child at home." The coalition provided the family financial and legal support. After issuing a public call to hospitals in the United States, Priests for Life--a family of ministries with the purpose of galvanizing priests to preach, teach, and effectively mobilize others in an effort to end abortion and euthanasia--launched a grassroots campaign asking individuals to express their opposition to the "philosophy, prevalent worldwide, that says some lives are not worth caring for." They also sought to have Joseph transferred to a hospital in the United States. While several hospitals declined, SSM Cardinal Glennon Children's Medical Center in St. Louis accepted the transfer, and Priests for Life provided the financial support to air lift Joseph to St. Louis. The family believed that here Joseph would "get better care or at least a reassessment, and possibly the tracheotomy."

A spokesperson for Cardinal Glennon said that Joseph would "likely have a tracheotomy which will facilitate his transition to a skilled nursing home." After being baptized, Joseph underwent surgery for the tracheotomy on March 23, 2011. His father exclaimed, "It's a miracle. My son now has freedom. When God wants to take his life, he will take it."

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Priests for Life thanked the "tens of thousands of pro-life activists who took a stand [allowing Joseph to] receive the dignity and treatment he deserves as a human person.... (W)e have delivered a clear and powerful message to the world: while there is such a thing as a worthless treatment, there's no such thing as a worthless life." Priests for Life maintained that Joseph should not be given treatment "no matter what," nor is it "imposing any specific treatment.... All we wanted to do was give the child ... a second chance."

Some commentators and organizations have described the judgment of LHSC and the Canadian Court as a "barbaric act [which] is cruel and criminal and it cannot be allowed to happen again." This judgment is too harsh as this case raises significant moral questions about the futility of medical treatment, especially since there is debate in the literature regarding the concept of futility. The case also raises questions about who makes ultimate decisions about medical treatment, in this case, the parents or the physicians?

While some have identified a tracheotomy as "care that [the] parents are requesting," it is important to recall that while "care" is always mandatory, the usefulness and benefit of a medical treatment such as a tracheotomy must be carefully weighed against the church's teaching on ordinary or extraordinary treatment. While extraordinary treatments are not morally obligatory, the Catholic moral tradition has not ruled out the acceptability of a patient (or the patient's decision maker) deciding to have an extraordinary treatment, e.g., the patient who decides in favor of an experimental cancer treatment. The 1980 *Declaration on Euthanasia* offers several

criteria for making this decision: the type of treatment, the degree of complexity or risk, its costs, and the result that can be expected.

Joseph's family obviously reasoned that they were not requesting treatment that was futile, burdensome, or extraordinary. While Joseph is terminally ill, he will live longer and will be able to be cared for at home with a loving family. It is not clear that his dying will now be more burdensome for him, but his sister's dying process seems to have been handled well.

Joseph was discharged from Cardinal Glennon with a tracheotomy and is now at home. He is breathing on his own.