Terminal Baby at Center of Treatment Battle Returns to Canada

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After receiving a tracheotomy at a St. Louis hospital that his native Canadian government denied him, Baby Joseph, the 15-month-old terminally ill infant at the center of an end-of-life debate, has returned to his Ontario home where he is set to spend his remaining days with family.

"The tracheotomy was successful," said the Rev. Frank Pavone of New York City-based Priests for Life, Joseph's medical care at Cardinal Glennon Children's Medical Center in St. Louis. Priests for Life is an organization which lobbies against abortion rights and euthanasia and was active in advocating for Baby Joseph's further treatment in the U.S.

"We were anticipating that he would need to go to an intermediate facility after the procedure but he responded so well that he's been off the machines and breathing tubes completely for a week. He's breathing on his own," he says.

Joseph Maraachli, who has come to be known as "Baby Joseph," was thrust into the forefront of the end-of-life debate in February, when Canadian doctors told his parents, Moe and Nader Maraachli, that their baby's degenerative disease was so bad that no treatment would bring him out of a persistent vegetative state. Joseph suffers from a progressive neurological disease called Leigh Syndrome — the same disorder that claimed the life of Joseph's then 18-month-old brother eight years ago.

Though health care professionals presented Joseph's parents with a consent form that would allow doctors to take him off life support, the Maraachlis refused to sign the waiver and fought for their son to receive a tracheotomy — a procedure that would allow them to care for their baby in his final days at home.

For months Baby Joseph's life was literally in negotiations as pro-life advocacy groups fought the Canadian government to allow him the procedure, underscoring the sensitive balance many parents may face between keeping their babies alive as long as possible and pouring money and medical resources into a losing battle.

The case was brought to the Consent and Capacity Board, an independent body created by the government of Ontario, and then a supreme court judge. Both entities ruled that Baby Joseph's breathing tube should be removed. It was only after Priests For Life offered to pay for Baby Joseph's medical costs that the infant was able to get the tracheotomy on March 21. The cost of the jet to the hospital, chartered with Kalitta Air, was donated to the family.

"I would call this a success," Rev. Pavone says. "We did this based on the value of the child's life here and now, not based on any specific medical outcomes. The family wasn't looking for anything extraordinary, just to be able to have him at home."

A Heated Debate is Sparked

"From the beginning, the point of view of the family has been, 'If my child is dying, at least let us bring our child home,'" Alex Schadenberg, executive director of the Euthanasia Prevention Coalition, who has acted as a spokesman for the Maraachli family, told ABC News in March.

"They weren't asking for extraordinary medical treatment or for the government to pay for a ventilator with an in-home nurse."

Reasonable Request for Palliative Care?

The Maraachlis requested that doctors perform a tracheotomy, so that Baby Joseph's family could take him home and take care of him in his final days. While other babies in similar situations have been sent home with a breathing tube and ventilator through the Canadian health care system, Schadenberg said the family was not offered this option, and Joseph's parents did not know to ask.

But a statement given Monday from London Health Sciences Centre where Baby Joseph has been treated since October, 2010, said the contrary: "The LHSC position is consistent with the treatment plan approved by Ontario's Consent and Capacity Board as being in the best interest of Baby Joseph. It involves transferring home, on a breathing machine, and then placing him the arms of his family before withdrawing the machine."

The statement goes on to say: "The transfer would not involve performing a tracheotomy, which is not a palliative procedure. It is an invasive procedure in which a device is installed in a hole cut in the throat.

It is frequently indicated for patients who require a long-term breathing machine. This is not, unfortunately, the case with Baby Joseph, because he has a progressive neurodegenerative disease that is fatal."

The controversy has sparked heated debate throughout North America, and the hospital has even reportedly received several threats from people in the United States and Canada. Support for the Maraachlis has swelled in recent days, and people came together in at least two different Facebook groups to stand behind the family. One group, Save Baby Joseph, has more than 13,000 members, and another, Save Baby Joseph Maraachli, has more than 1,300 members.

The Ethics of End-of-Life for Infants

Some have even argued that the government overriding a parents' wishes would not happen in the United States because Americans personally pay for medical expenses, while Canada has a publicly funded medical system.

But Schadenberg said the main question here is: who really has the right to decide on this baby's fate?

Rev. Pavone says that it should not be up to medical professionals to determine whether treatment to improve a child's end-of-life is "worth it." "We respect their medical judgment but not their value judgment. The problem is that the medical people are making a value judgment on the life of the child," he says.

Felicia Cohn, Ph.D., director of medical ethics at the University of California at Irvine, told ABC News that she has been involved in similar conflicts, and an ethical process must be under way to assist both parties.

If conflict arises, a clinical ethicist or an ethics committee may assist in the decision making process. The court is a last resort and is a sign of persistent conflict.

"These cases will continue to arise as long as we value a diversity of belief systems and opinions," Cohn said. "We struggle with balancing the different values involved. Among the goals of medicine are benefiting the patient, avoiding harms to patients, respecting the autonomy of the patient and decision maker and distributing health care resources justly."