

REGIONAL HOSPICE

No parent ever wants to outlive their child, but for some of us, it is a reality that we have no choice but to accept.

Our beautiful twin boys Michael and Matthew were born on May 21 2006. Michael was diagnosed with athetoid cerebral palsy. He had little motor control, was in a wheelchair and required a feeding tube. Although he was cognitively normal, he was nonverbal but communicated through a device, head nods, and facial expressions. Michael was considered medically fragile, had daily nursing care for 16 hrs a day, and a hospital set up. However when he required intensive care, he was in and out of the hospital for weeks or months at a time.

When he was 13, Michael suffered a terrible fall that fractured his jaw, needing multiple surgeries. This was too much for Michael's already compromised body to handle. Michael lost weight and was not able to thrive.

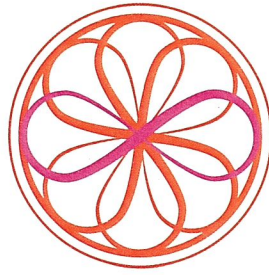
My husband and I consulted a palliative care doctor who led Michael's care. At this point his death was certain, and we had to make plans for this. The doctor put us in touch with a hospice that usually cares for adults. After speaking several times, they agreed to take on Michael's case when the time approached. I was told to reach out to them when Michael was closer to actively dying.

When that time came, several months later, I was told that they could no longer help. We were devastated and lost. I asked who I could contact, and had no guidance. The hospital tried to help, but they also didn't have an answer.

Because of hospital bureaucracy, Michael's palliative care doctor was limited with what he could do. His regular nurses could only provide lifesaving care, so I was the one who had to administer morphine to my own child. I knew the morphine was just to make him comfortable while he dies. I had to do this while I was emotionally dealing with the impending death of my child. It actually ripped my heart to shreds to do so. No parent should ever have to do this. On top of this, I had to deal with a system that could provide me with no help.

Ultimately, we were able to find support from a local convent, where Sister Catherine helped us find Regional Hospice for Michael. I wish we found them sooner. Regional Hospice staff were wonderful, however, he died two days after they took his case.

Making the Best of Every Day[®]



Connecticut is in dire need of a children's hospice. I do not want any parent to have to provide end of life care to their child without support as we were forced to. It is so unfair to the parents and the child. Imagine for a moment if you had to make the same decisions for your child. Everyone deserves to die with dignity.

Again, I want you to imagine being in our shoes and being told that the hospice isn't willing to help your child. You are helpless and numb. No one helped with our child, even though Hospice is readily available for adults.

Every hospital should have resources available to guide parents on options to care for their medically fragile or dying child. Regional Hospice never turns away a dying child. We should have been provided with this information long before we were. It is inexcusable that we were not.

It made the most devastating time in our life even more unbearable. I am here today because this cannot happen to another child.