

### **Maintaining and Terminating Human Life**

Life support refers to treatment that maintains vital body functions during disability or illness. It is often provided short-term to support patient recovery. However, life support may also be used indefinitely, until a decision is made to discontinue it. This decision may be made if a patient is considered brain dead—where the brain ceases to function. In such cases, a life support system can continue to run the body’s organs when the brain cannot. More than one doctor is required to complete a formal brain-death assessment.

In Canada, the difficult decision to stop life support is generally made by the family when brain death has occurred. In rare cases, a patient’s family may disagree with the diagnosis of brain death and request that life support be maintained. A legal case may ensue as a result, as health-care professionals may object to continuing life support when there is no moral or ethical reason to do so at a cost that may deny other patients care.

### **New research and new questions**

Greater ethical issues arise when considering discontinuing life support for patients in a long-term coma or a vegetative, nonresponsive state with no hope of recovery. Dr. Adrian Owen of Canada’s The Brain and Mind Institute is a renowned neuroscientist. For over 25 years, he has been studying nonresponsive brain injury patients who are considered to be in a vegetative state.

Using pioneering techniques and neuroimaging technology such as fMRI (functional magnetic resonance imaging) scanners, Dr. Owen has shown that about 20 percent of such patients are aware mentally. They are just unable to communicate their thoughts. Dr. Owen has been able to record patient brain activity patterns in response to instructions, such as imagining playing tennis, and even questions, such as are they in pain. His work has expanded and challenged our understanding of consciousness. It also brings up new questions about maintaining and terminating human life.

### **Heartbroken Parents Take 2-Year-Old Off Life Support**

It was Christmas 2015 when Dylan Askin’s parents experienced their worst nightmare. They rushed their son to the hospital as the toddler struggled to breathe. There, they received terrible news.

Doctors diagnosed Dylan with Langerhans cell histiocytosis (LCH) — an extremely rare type of lung cancer. As a result of the disease, cysts covered the poor boy’s lungs, causing one of them to collapse. The odds were not in his favor and things got even worse after he contracted pneumonia.

“They told us things were looking bleak and that we weren't going to get him back," Dylan’s mom, Kerry Askin, explained. "All the settings on all the machines were at their highest and he was still struggling. All his family came from all over to say goodbye, including his big brother."

Devastated, Dylan’s parents soaked in what was expected to be their son’s final hours.

"I hadn't slept for days building up to it," Kerry recalls. “I was crying all the time. They had actually closed off part of the unit so we could both stay with him overnight because they thought he could go at any minute. All the while we were singing to him and talking to him and saying goodbye."

By Good Friday of 2016, the 2-year-old’s condition was dire. Doctors said they couldn’t do anymore. The next day, Dylan’s family made the tough choice to pull the plug. Doctors began taking him off of life support. But then, something completely unexpected happened. The little boy’s heart rate actually returned to normal!

“Stop! There is still fight in him!” Kerry told the doctors.

With amazement, Dylan’s doctors and family watched him grow stronger and stronger.

"Then his oxygen levels started to pick up, and he started coming back to us," Kerry said.

“By Easter Sunday, he was stable enough that I felt comfortable enough to have a lie-down. I was strong in that belief that he was our Easter miracle,” she says.

In fact, the whole family recognized they’d witnessed a miracle!

A month after waking up from his coma, Dylan was well enough to go back home. And two years later, he’s happy, healthy and cancer-free!

### **Rachel’s Story**

My smart, dynamic 55-year-old sister Natalie was diagnosed last summer with stage 4 cancer. She was given a few months to live and offered palliative care. The diagnosis hit her and us like a thunderbolt. Always active and full of life, Natalie was a loving wife and the affectionate mom of three grown kids. She had a rewarding job and was excited about the upcoming birth of her first grandchild. It seemed impossible that she would lose it all in just a few short months. Her one wish was to be at home, and we all arranged our lives, jobs, and schedules to help make that possible.

The palliative team did their best to care for Natalie’s physical and medical needs, and we adjusted to this new “normal,” hoping with all our hearts that “months” meant “many months.” But with each passing week, we could see the illness progress rapidly, and Natalie’s pain getting worse. We cried a lot, but we also hugged a lot, and told each other all the important things. My sister let us know she wanted to die at home, surrounded by her loved ones, and we agreed to help make that possible.

Natalie faced the end of her life as she had lived: realistically and with no desire to prolong the indignities, or the agony. Our family had experienced several deaths over the decades, as our parents and then our in-laws passed away in different hospital rooms. The final stage always involved days, sometimes weeks, of watching them suffer, waiting for the inevitable to happen. My sister didn’t want that and asked me to get more information on medical assistance in dying (MAID). I contacted Dying With Dignity Canada staff members, who were very helpful and put me in touch with the MAID care coordination service. From there, we were immediately connected with a registered nurse who handles MAID cases.

Natalie was afraid she would suffer a medical crisis and end up in hospital before the assessment process was complete, but everyone on her MAID team went out of their way to make sure things would be in place as soon as possible, and that all our questions and concerns were fully answered. The MAID doctors, nurses, and everyone we met, treated Natalie and the rest of us with the utmost respect and compassion. However, we were surprised to find that support for MAID was lacking in much of the rest of the medical community.

Two of Natalie’s doctors tried to dissuade her after she expressed her wishes. One stressed that her life “had meaning to the end,” implying that Natalie was throwing it away if she chose a medically assisted death. Another presented what he thought was a better alternative, which involved dying in a hospice after several days of receiving larger and larger doses of morphine. Our family is not religious and to Natalie and many of us, these reactions and suggestions seemed nonsensical, but even among some of our family members, Natalie’s choosing to die on a certain day was a difficult concept to come to terms with.

Natalie knew that not everyone could be told of her plans. Elderly relatives with deep religious beliefs were not informed, so the truth had to be kept from most people outside of our close family circle. Natalie picked her death day carefully, based on how long she thought she could bear the pain without huge doses of morphine, while ensuring it would be a date after her new grandchild was born.

But what is it about humans that we’re willing to accept something if it happens by chance, but not when it’s a well-thought out action? Some in the family wondered why it had to be that day and not another — why couldn’t she wait one more week, or two? Most of this was kept from Natalie because we did not want to distress her, but at the time it hurt me deeply, mainly because I was the one driving the MAID bus that we were now all on. I was the one who made all the phone calls, who arranged the various appointments, who acted as the in-between. Natalie had asked me to help her with this important task and I did it with all my heart. Although no one said anything directly, it was clear some were uncomfortable with that role. Now, several months later I have a better understanding of the powerful emotions of love and loss that were causing us to bump into each other like that.

On the day of Natalie’s death, we were all with her. We spent the morning doing what she loved best, holding hands with Friends playing in the background. The nurse who came to put in the IV ports was warm, friendly, and efficient. The doctor was the same. From the moment we met him and saw him interact with Natalie, we knew we were in good hands.

After being at the bedside of several loved ones who passed away, I can truly say that none of those deaths were as gentle, dignified, or emotionally healing for the family as my sister’s passing. We are all so thankful we live in a country that granted Natalie the ability to choose to die on her own terms, to be with us, present and alive to the last, instead of having to face a prolonged agony, alleviated only by higher and higher doses of drugs. I will never forget saying goodbye to my sister as she went to sleep, in the arms of her husband, surrounded by everyone who loved her best.

1.) Why was life support required for Dylan?

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2.) How long was life support provided for Dylan?

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3.) Who made the decision to discontinue life support for Dylan and why was it made?

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4.) What is the difference between temporary and permanent life support?

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5.) Do you think life support should be used on a permanent basis or only temporarily? Explain your reasoning.

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6.) Technology cannot solve all problems in society, and in some cases, it can even create new ones. What is the problem that life support creates?

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7.) In June 2016, the Parliament of Canada passed federal legislation that allows eligible Canadian adults to request medical assistance in dying. Why do you agree or disagree with this?

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