

14 February 2016

To the Special Joint Committee on Physician Assisted Dying:

As a bereaved parent of a 13 year old son, I wish to offer his story to you for your consideration as you deliberate on the appropriate recommendations on the framework for a federal response on physician-assisted dying that respects the Constitution, the Charter of Rights and Freedoms, and the priorities of Canadians.

My views:

- I believe that federal legislation should be put in place to ensure national consistency in areas of access and safeguards. It should include provisions that would allow provincial legislation to prevail in that jurisdiction when it is substantially equivalent to the federal legislation (an equivalency model as was suggested by Professor Hogg).
- I recommend that the criteria for eligibility not discriminate on the basis of age, mature minors must be included since they are capable of being competent to make such a decision. This is particularly clear for mature minors with a terminal illness. Mature minors should be able to make such a request in consultation with their parents or guardians.
- I agree with Recommendation number 17 of the Provincial-Territorial Expert Advisory Group Final Report which states that physician-assisted dying should not be impeded by the imposition of arbitrary age limits, but that it be based on competence.
- I feel it would be discriminatory to deny children access to end of life options, particularly when they are faced with a terminal diagnosis.
- I fully support palliative care, but I believe that physician-assisted dying should remain an option for end-of life care.
- I would like to state that the assertion that all end-of-life pain can be managed through palliative care is not based in reality.

My views stem from the fact that five years ago I watched my 13-year son die a very, painful death as a result of bone cancer. In November 2010, the day before his 13th birthday we received the news that cancer was once again growing

in his body and there were no more treatment options. They anticipated that he had 6 weeks to 6 months left to live. But before I tell you of his experience waiting to die, I would like to tell you a bit about the last few years of his life. As with most people who are faced with a terminal diagnosis due to cancer, it is often at the end of several years of treatments and battling to rid yourself of the disease.

Justin Ernst's Battle with Cancer

When my son, Justin, was nine years old, he was diagnosed with a Ewing's sarcoma on his right pelvic bone. Ewing's sarcoma is similar to osteosarcoma, the type of bone cancer that Terry Fox had.

CHEO (Children's Hospital of Eastern Ontario) was wonderful in starting him on chemotherapy within a few weeks. The treatment for most bone cancers is chemotherapy and surgery to remove the tumour. With Ewing's sarcoma, however, radiation rather than surgery is sometimes an option. So half way through his treatment, his father and I had to decide, whether or not to go the surgery or the radiation route. The surgery would involve removing the right half of his pelvic bone, with the result that there would no longer be a hip joint and the top of his thigh bone would rest against the base of his spine. We were advised that there was very little success with an internal prosthetic to replace the hip joint, so the only option was that he would be left with a very, pronounced limp and chronic pain.

Justin's father and I discussed the options with him and Justin clearly did not want the surgery. But as parents we had to step back and look at what would be best for him with respect to his longevity and his quality of life. In a meeting with his orthopedic surgeon and his radiologist, we were told that both options offered the same chance for long term survival. With no clear medical preference for one option over the other, we decided that quality of life was the most important. We would not have him undergo the surgery, but have him take the radiation treatment instead and allow him to retain full functioning of his leg.

He had 7 months of chemotherapy and 5 weeks of radiation, and was then cancer-free! He returned to school mid-way through grade five and quickly caught up to the rest of his classmates.

Then in September of 2009, when he was 11, we were told that they found cancer growing once again on the same pelvic bone. This time he had no pain, it was detected through one of his regular MRI check-ups. When this type of cancer returns within two years, it is not a good sign. But I remained optimistic and knew that there are always people who defeat the odds and survive – so why couldn't that be my son.

He was put back on chemotherapy, but this time it was a new cocktail of drugs. Radiation was no longer an option, so in order for him to survive he had to have his right pelvic bone removed. His 18-hour surgery was on December 1st, 2009. He was very anxious about post-surgery pain and he was assured that his pain would be controlled and not to worry. His life was never the same after that surgery.

Pain control post-surgery was extremely difficult to achieve. The normal dose of pain medication was insufficient to relieve his pain and it was obvious that his body metabolized these drugs differently than expected. This was a struggle throughout his last year of life.

The combination of the radiation he had in 2007 and the surgery left him with a lot of nerve damage. He could not move his right leg and would experience a great deal of pain when we helped him move his body. He could only be moved out of bed with the assistance of two to three people. The incision site would not heal and it needed to heal before chemo could start. He was very anxious about starting chemo again, because he did not know if he could handle the post-surgery pain and the nausea from chemo. However, chemo started again in March of 2010 and his treatments continued until the end of August.

We were working through the demands of his care - the dining room became his bedroom, complete with hospital bed, TV and Xbox. We installed a ramp up to the house for his stretcher. We went back and forth to CHEO for chemo treatments every two weeks by stretcher with patient transfer services.

He needed constant pain management with morphine and several other drugs to provide him some level of comfort.

I became his friend, his confidante, his nurse, his psychologist and his biggest advocate. We had many conversations about the meaning of life, about pain and about death. Many of these conversations challenged me to think more broadly about these issues and to look more deeply into what I believed. I wanted my son well and he was going to face many challenges, but we were going to do it.

The last time we left our house to go to CHEO, because he had spiked a fever, he thanked me for looking after him. It was one of those moments in life when everything stops, he was thanking me not just for that day but for all of it in the past and what was to come. I think he knew deep down that he was never going to come back home.

Why am I telling you this? Well because when it came to experiencing pain while he was in palliative care, pain was not new, pain had been his constant companion for the previous year and I and our family were a witness to his pain and his journey in trying to live with it.

Tolerating pain when there is hope of recovery or reprieve is bearable, but tolerating pain without hope seems to be an unnecessary evil.

When he received his terminal diagnosis, Justin wanted to go home to die, but we were encouraged to go to Roger's House for palliative care so that his pain could be managed on a 24/7 basis. Roger's House is a wonderful palliative care facility for children and our family was able to move into a suite with Justin and be there when he went to sleep and when he woke up. As the weeks passed Justin needed more and more pain medication, he had a drug going into his port-a-cath that had been used for chemotherapy, along with four other pumps over his body to deliver a constant source of various pain meds – morphine, lidocaine, propofol, etc. With all this pain medication he still endured tremendous pain, I could see the cancer growing under his skin over his ribs, within a short time he complained that he felt like his arm was being pushed off. The tumour had reached his armpit and was actually separating his arm from his shoulder.

His palliative care was the best you can get and it was wonderful to have the opportunity for him to say goodbye to family and friends with some level of pain management. One day he had a visit from about 10 of his friends from his school and during that visit he asked his friends not to forget him. As a symbol of their commitment not to forget him, they had bracelets made with his name and the school's name on them, which I still wear today.

But he would wake up in the morning, feeling stressed and disappointed that he had not died during the night. While he said he was starting to feel lonely and that he would miss us, he also wanted the pain to end.

He asked to speak to a priest and talk to him about being angry at God for the cancer, the year of pain endured in bed and the pain of dying. He felt more prepared to die after his conversation with the priest and after having received his last rites.

Justin was unable to eat when we went to Roger's House, he drank sips of Gatorade or water throughout the day which were his only source of nutrition. The first few weeks of palliative care were manageable. But then Justin started to decline and his pain level increased, such that he no longer wanted to have any more visitors. He was suffering physically and mentally. I am not sure at what point I started to pray for Justin to die, but it was clear to me that he was done and needed to move on. It was extremely painful to pray for my child to die, but that was my only option to help him to be released from the pain caused by rapidly growing cancer in his body. We could not hug him and our only physical contact was through holding hands or placing our hand on the top of his head. Even kissing his forehead the night before he died irritated him.

With a Catholic background, was I to pray for a miracle that would leave him cured or pray for him to die? He had prayers said for him for all the years of his illness and a miracle was not to be! I wanted to help him to die. His pain medications could not be increased, because they were at their maximum dosage and we were told any increases could cause convulsions. He had requested a do not resuscitate order and to be put into a drug induced coma. Unfortunately, the way his body responded to the drugs he could not be put into a coma.

He had a full understanding and appreciation of everything that was happening, which I think most agree is the definition of competence. As an indication of his level of competence and understanding of what was happening to him – we discussed what he wanted done with his belongings, he indicated that he preferred to be buried rather than be cremated and that he wanted one of his favourite songs “Fireflies” to be played at his funeral.

The night before he died he started to get a build-up of fluid in his lungs – I sat with him for a few hours during the night and then in the morning he needed more drugs to manage the issue. When things settled down, I closed my eyes and slept for a while and when I awoke and looked over at him, I could see his chest was no longer going up and down. My first thought was one of relief. His dying process was over and his pain and suffering had ended.

What if there had been another option to just waiting for one of his organs to fail and having to pray that it would happen quickly, with no fear and no pain. I believe that it would have been easier to hold Justin’s hand, tell him that I love him, say good-bye, and wish him well on his journey. Then have him go to sleep from an injection and the dying process would be over.

Justin spent five weeks in palliative care at Roger’s House.

Thank you,

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cc. David McGuinty, M.P., Ottawa South