

End of life: from chronic rhinosinusitis to a late diagnosis to intensive care

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About a decade ago, Barb presented to the emergency department because of a decreased level of consciousness 2 days after her first chemotherapy treatment for an esthesioneuroblastoma, a rare cancer arising from her nasal cavity.

Barb, a 52-year-old mom, had been married to Pete for 28 years, and they had 3 children. They lived in Calgary.

A year previously, Barb had presented to the emergency department with a nosebleed and a 2-month history of nasal congestion. For the next 10 months, she was treated for rhinosinusitis by complementary health care providers, and in the tenth month for depression by her family doctor, who had referred Barb to an ear, nose and throat surgeon. During this time, her condition deteriorated.

About a month before she last visited the emergency department, a computed tomography (CT) scan, taken while in emergency, had shown a large tumour in Barb's sinuses, extending to the frontal lobes of her brain. She was admitted to hospital and, after a biopsy, received a diagnosis of esthesioneuroblastoma.

On this presentation, Barb was intubated, treated with mannitol and dexamethasone, and transferred to the intensive care unit (ICU) in the hope that she would improve enough to be able to receive a second round of chemotherapy.

Unfortunately, during her 6-day ICU stay, Barb's neurologic status deteriorated and she never regained consciousness. After a meeting between Barb's family and health care team, a decision was made to refocus her care so as to ensure her comfort and dignity at the end of her life, leveraging The White Rose Program.¹ Barb died 3 hours after being extubated, with her family by her side.

Husband's perspective

Throughout my wife's challenging health journey, I tried to make sense of what was happening and understand my role.²

Unfortunately, during 10 months, no one took her symptoms seriously enough. Frustrated that things weren't improving, we visited the emergency department, where a CT scan revealed a large intracranial mass, 1 month before she died.³

Remembering her 6 days in the ICU is like watching a slow-motion movie.

Before we entered the ICU, one of the social workers shared, "In the ICU, families don't fix things. You're about to experience

the biggest roller coaster of your life." That helped, because the ICU was foreign to me. Asked during rounds to please summarize things, Dr. Stelfox, the ICU doctor, said, "We're supporting Barb — giving her a chance to wake up."

During clinical examinations, her nurses would repeat loudly in her ear, "Barbara, Barbara, open your eyes." Sometimes Barb would respond, sometimes not. I'll never forget her name always being used, and my emotional roller coaster based on her responses. Tanya, her nurse, supported her by playing music during the last 2 days Barb was alive; her heart rate dropped by 25%, and I sensed she was comforted.

I continued hoping that Barb's health would improve. I didn't realize the seriousness of her condition until the meeting between our family and the health care team, where her oncologist said, "I'm sorry."

Everyone had tears. We discussed the high probability of brain damage and decided to remove life support.

As I moved from hoping her health would improve to suddenly realizing she was going to die, my role changed: from trying to make sense of things to being there for my family.

With end of life expected, we appreciated Sheri bringing our children and chaplain (also a friend) to the hospital for our family meeting, where I shared that their mom was going to die. We experienced compassionate care during the end of Barb's life.

I often reflect on Barb's health experience and how her tumour masqueraded as sinusitis, resulting in a late diagnosis, poor prognosis and end of life. Much earlier symptom recognition and medical referral involving a CT scan might have helped.³

While Barb was in the ICU, I was subconsciously coming to grips with the possibility that she might actually die. I'm unsure if I would have benefited from earlier, more candid conversations about her illness with her ICU team. Intensive care, including end of life, was immensely meaningful for everyone because it was so compassionate. That care has unexpectedly helped me discover my passion: serving those in distress, in the worlds of ICU, grief, cancer and crisis. — Peter R. Oxland

Social worker's perspective

Over time, I have learned there is a delicate balance in meeting a family in crisis and quickly establishing a supportive rapport. I first met Barb's husband, Pete, shortly after Barb's

admission to the ICU. I could sense his worry and his need to have questions answered. To mitigate his distress, I began with simple information to help him navigate the ICU. I learned about his family and the importance of spirituality in their lives, which informed my approach on how best to provide support.

As I moved from hoping Barb's health would improve to suddenly realizing she was going to die, my role changed. — Peter R. Oxland

Barb's family had only a short period of time to absorb a devastating cancer diagnosis before facing the difficult decision to transition to end-of-life care. The gift of time, which presumably would have included vital conversations between Barb and her family, was denied them. The potential for her family to suffer complications of grief was very real, and their experience in the ICU could have had lasting implications. I wanted to ensure they felt supported and included in Barb's care.

Because of timing, Barb's children could not be present at the initial meeting where Pete and his mother-in-law learned of Barb's devastating prognosis. Pete was able to give Barb a voice. To honour her wishes, the decision was made to begin to move to comfort measures.

Transitioning from maintaining hope to accepting the reality that Barb was going to die was incredibly overwhelming. After the meeting, Pete's priority became his children. He sought my guidance on how to tell them, when to tell them, and with whom present. I recommended transparent communication in a supported setting, once his children had arrived at the hospital. Because spiritual and familial support was important, I suggested that Pete's pastor and mother-in-law also be present. I contacted Pete's friends to assist with his children's transportation to the hospital.

It was very important that the time the family had left with Barb was meaningful and in accordance with her wishes and theirs. The ICU staff ensured that Barb's final moments were surrounded by the love and comfort of her family while her favourite music filled the air. Having witnessed the incredible bond between Barb's family and their community connections, I was reassured that her family would be well supported on their journey after the ICU. — Sheri L. Barnes

Registered nurse's perspective

I have looked after many patients in the 15 years of my nursing career, but my experience with Barb and her family definitely stands out.

The experience was so memorable because of the peacefulness of Barb's passing. As devastating as her death would be, it was as ideal as it could have been. I remember the yoga music playing in the background, Barb surrounded by the ones she loved the most: Pete, her devoted husband; their 3 children; her mother; the chaplain.

Before the decision to transition to end-of-life care, I supported Pete by listening to the devastating news he was receiving — reviewing the CT scans, the statements that this woman, his wife and life partner, would never wake again.

I always wish that as a medical team, we could do more. That miracles would just happen. It makes me question why awful things can happen to good people at such a young age. It sometimes just doesn't make sense; it is not fair. Experiences like this made me decide to travel while I was young because I never knew if I would be given the opportunity later in life.

I left that day and went straight to a yoga class. I found myself crying in the middle of class, as I was able to do something that Barb never would again — something I was sure she and her family wished she could.

My experiences with patients like Barb make me more grateful and aware for what I have and can do. At the end of each day in the ICU, my goal is to try to make the best of what is usually one of the worst times in someone's life. It is a privilege to be part of it. — Tanya L. Cottrell

Physician's perspective

I still remember the day I met Pete Oxland. Years later, I reflect on how that meeting changed how I practise medicine and conduct research.

Pete, bright eyed and energetic, was waiting outside his wife's room. Barb had been admitted to the ICU overnight. She was approaching the end of life. Sheri, our social worker, told me about her teenage children. Tanya, her bedside nurse, introduced me to Pete. I knew this was going to be hard.

Pete joined our daily multidisciplinary rounds. He listened, took notes, asked thoughtful questions and expressed hope that Barb would get better. I tried to be candid and kind. I knew Barb was going to die, just not when. Our interactions were like a cautious dance between new partners, each carefully probing, assessing and reacting to the other. We danced around the issue of end of life.

I wonder what I could have done differently. Could I have asked better questions about Barb's wishes? Could I have been more candid about Barb's prognosis? Barb never woke up. I was grateful that her neurosurgeon and oncologist helped our ICU team shift the focus of care to palliation. I remember expressing my condolences to Pete, his children and mother-in-law.

What I did not realize was that this was just the beginning of my journey with Pete. He and I met months later, to review the autopsy results. Pete was frustrated that Barb's diagnosis had come too late for successful treatment. At the end of our meeting, he asked me how he could help improve end-of-life care. I was stunned. Patient- and family-centred care practices were being adopted in ICUs. However,

the concept of citizen engagement in clinical care or research was new — one I had no experience with. Pete was determined to contribute, and a few meetings later, became a health care system adviser.

The subsequent decade has been a blur of learnings. Together we considered and learned what roles patient and family advisers can play in health care and research. How and when they should be engaged. When their work is voluntary and when they should be paid. For me, what began with learning how to better provide compassionate end-of-life care has transformed how I practise medicine and research. I learned the value of listening to lived experiences and how partnering with patient, family and citizen advisers can improve care. Thank you, Barb and Pete. — Henry T. Stelfox

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