

Share Your Story:

Butch's Story

Cystic fibrosis is an awful disease. For families witnessing the suffering of a loved one, there is no relativism, no "I guess it could be worse", no scale of 1-10 on which to rate the horrors of the disease. There is nothing that can yield any real relief from the constant worry, the angst, the terror of living with death... not just as an inconsiderate visitor whose calling card is pain and chaos, not even as a sworn enemy who makes you want to scream at its relentless intrusion but as a full time, ever present, live-in member of the household who is always in the driver's seat.

This is not a happy story. It is not a hopeful story. But it is a hero's story. It is unabashedly and unapologetically Butch's story shared with the writer over the last few months before his death at age 19 in April 2018. It is a story about anger, hurt, kindness and courage. It is about the care of a child, growing determinedly into a man against all the odds. It is about racism, denial, cruelty and injustice. And, finally... it is a true story.

Butch was born in 1998 healthy and of normal weight but an early and dramatic loss of that weight soon made it apparent that something was very wrong. It was only a month later that an Emergency room doctor at the North Bay hospital diagnosed the problem as cystic fibrosis, a fatal, genetic disease affecting the vital organs and respiratory system of the body and, in Butch's case, with no family history of the disease and one, they were told, which was rare among Indigenous populations. The family, reeling from the news, was sent to Sudbury to the CF clinic there for treatment. At seven months, infant Butch was released, and the family returned to North Bay.

But after a couple of months, he was sick again from having to take enzymes orally to aid absorption of nutrients into his body. It caused terrible thrush in his mouth making it impossible for him to eat. This time he was transferred to Sick Kids hospital in Toronto. Through a six week stay, Butch rallied as he would many times to come. The family returned to North Bay but the realities of having a child with cystic fibrosis and the demands it would make on this young family's future were just beginning... a saga of lengthy hospital stays for their young son, endless treatments, hopeful if short-lived respites and small victories overtaken by constant setbacks.

Until he was four, he remained relatively stable going to Sudbury for CF maintenance treatments. But then he contracted a chest infection the family chose to take him to CHEO where he was treated until a move to the General campus of the Ottawa Hospital when he turned 18.

When he was seven years old the family moved to Ottawa for a year but then returned to North Bay because they were homesick for their community, the comfort of their extended family, familiar country and their culture and traditions. Butch still continued treatment at CHEO with his Mom and Grampa driving him back and forth. It soon became apparent, however, that a second, more permanent move to Ottawa for his Mom, Dad and two brothers was required to make Butch's care easier. This time the unexpected discovery of the Wabano Centre for Aboriginal Health and the support the family found there helped make the move and acceptance of their new life in the city less stressful.

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Both Butch and his parents remember their experiences from this time very positively. In 2010, the Ottawa Citizen published an article featuring Butch as a CHEO 'poster child'. Both Butch and his Mom expressed their confidence in and their immense gratitude for CHEO staff and doctors. The article quoted Butch's mom as saying: *"CHEO is awesome. They've made it so he's not kicking and screaming when I take him to hospital. A lot of the people at CHEO are like family. When we were commuting from North Bay, Ronald McDonald House was also a huge help. Butch says he really loves going to CHEO but misses his birds when he's there. At CHEO he gets to do lots of crafts, play board games and video games and read..."*

Butch was a gifted child blessed with a keen mind, quick wit and an unquenchable desire for learning. He was a happy child with a big heart and remarkable sensitivity to the needs of others around him no matter his own pain and circumstance. He laughed easily, was kind and had a smile and personality which would light up a room. He displayed remarkable courage overcoming much adversity in his young life. His close family was the very centre of his universe, his Mom holding the special place of his best friend and caregiver, never spending more than a few hours away from his side while Dad, his buddy, worked hard to care for the family and make ends meet. Butch approached each day with a strength and determination to live life to the fullest in spite of insurmountable challenges in his path.

He was a proud Anishinaabe and celebrated his Algonquin ancestry. He loved spending time with each of his grandparents learning 'the ways' of the land and history of his people from the Antoine and the Algonquins of Pikwakanagan First Nation. Butch had a profound respect for all living creatures, especially animals and birds, and had the ability to coax chickadees into his hand and have hummingbirds land on his shoulder. And creatures, be they his pets or in the wild seemed to know his special gifts. These included his beloved parrots and cockatoo, his dog, guinea pig, pet rats, and even neighbourhood squirrels. He seemed to be a "whisperer" to all creatures. When he was 12, he made sure his family knew that he had firm plans to attend college to study avian veterinary medicine.

For most people, to know this young man was to love him. His specialness, intelligence, gentleness and kindness in the face of his awful suffering makes it even more difficult to comprehend the later years of his hospital care, but does make it possible to understand Butch and his family's anger, hurt, and immense sense of betrayal by the very people and institutions charged with his care.

As Butch grew older the disease took an ever-greater toll. His hospital stays became longer and by age 12 he had undergone more than 20 surgeries. He developed esophageal varices and cirrhosis of the liver and spleen. Around this time, he was sent to the Sick Kids hospital in Toronto to determine whether he should have a liver transplant. There was no immediate consensus on a transplant then, but the family's doctor in North Bay notified them that he had received a letter from Sick Kids asking for a follow-up visit for Butch every six months. For some reason – never explained to Butch or his family – that referral was never acted upon at CHEO, and he was not sent to Toronto again though the possibility of a liver transplant was held out to the family at various times.

By his teen years Butch's knowledge of his disease was encyclopedic. He knew his body and its warning signals, and he knew his medications by name, purpose and amounts, the respective benefits and often difficult side effects of each one. With such knowledge and by now lengthy experience living with CF, Butch expected and had a right to expect that he would have a voice in his own care and treatment path. He was also acutely aware and accepted from early on that he would never have the opportunity to live a long and healthy life, but he was determined to fight for his survival as long as he could and live every day to the fullest.

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At fifteen his pain medication regimen no longer provided him reasonable comfort. An MRI had shown that Butch had two compression fractures in his spine and some bones were malformed resulting in chronic pain in addition to all the other problems as CF wracked his body. He was referred to a pain specialist to explore possible new avenues for relief. Accompanied by his Mom, Butch met with a new physician at the Roger Neilson House, a facility at CHEO “dedicated to loving and skilled palliative care to support children, youth and their families” according to their website.

Butch’s experience with the doctor there was anything but loving.

He had welcomed the meeting hoping for some support to make his days more bearable. Instead, this meeting marked one of the most hurtful experiences in his history with the health care system. Making no effort to get to know Butch, the Doctor opened the meeting by stating that he was unlikely to prescribe new pain medication for him because of addiction... “a condition you would know all about being native and living with addicts and alcoholics every day where you are from.” He continued in this vein for a time until Butch and his Mom walked out, stunned and now emotionally scarred by the doctor’s ugly words and the hateful assumptions upon which they were based.

His long stays at CHEO had their bright spots and as Butch never ceased to express, there were many good people who did their best to make his life bearable. One of those “bright spots” was the amazing, caring, friendship and advocacy of Michèle, who was the Child Life Specialist at CHEO that became very special to him. Michèle took a real interest in Butch and encouraged his love of learning and passion for his birds. She remained his good friend for much of his last years. Upon learning of his passing, she wrote the following in a heartfelt condolence to his family, *“BUTCH and family... The exceptional privilege was for me to accompany and support Butch throughout his journey at CHEO... Brilliant walking encyclopedia, creative dreamer, nature and animal lover, bacon and chocolate milk connoisseur... he taught many of us at CHEO lessons of courage, resilience, optimism, acceptance, caring and loving... Another adventurous journey is starting somewhere else Butch... Thanks for your contributions on CHEO’s Youth Forum and for your unique presence with all of us all these years...”*

There were others involved in his care who made his life a living hell. The treatment of Butch by a very senior nurse in the CF unit at The Ottawa Hospital - General Campus was nothing short of appalling. She waged a relentless campaign with Butch and, when she could, each of his parents, to force the signing of a Do Not Resuscitate order (DNR). When Butch challenged her in any way it became worse. She would lecture him on how much his care cost the hospital, the implication being as a terminal patient he was not worth the investment.

Butch made it clear he understood that he was dying but would fight for as long as he could for the right to treatment involving antibiotics, blood transfusions and other non - invasive measures that would prolong his life. Butch and his Dad took the time to have those very difficult conversations and his decision was to keep going on that basis... but if it was an emergency, he did not want extraordinary measures like the shock paddles, having his chest pounded or the use of other desperate actions used to revive him. When the Grim Reaper, as Butch aptly nicknamed this individual, persisted the family complained of her harassment to the hospital administration. Even Butch’s aunt travelled to Ottawa to help advocate on his behalf. When Butch or members of his family complained, the vindictive nurse threatened and on occasion withheld snacks, TV and telephone privileges which Butch was entitled to. The hospital did nothing to reprimand the nurse but did finally agree to the family’s request to have her taken off his medical team.

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There were other horrific incidents as the challenges of the disease increased. Butch's attacks became more severe and each time he spiralled downwards it seemed that it would be his last. Yet he would rally and challenge his treatment with his Mom advocating passionately on behalf of her very sick son when they knew his fragile body was not responding well. During one of these times, Butch was fed a regimen of strong laxatives for two solid weeks to try and flush his system. Not surprisingly, he lost weight. Hospital personnel said it was not the laxatives and suggested there was a possibility that Butch's Mom was starving him, eating his hospital food and probably had Munchausen syndrome, a mental disorder where the caretaker of a child, often the mother makes up fake symptoms or causes real symptoms to make it look like the child was sick as a desperate ploy for attention.

Another time Butch's Mom was accused of being a drug addict based on absolutely no evidence except as far as the family was concerned, negative assumptions they made because she was rake thin, had some bad teeth and was part of an Indigenous family going through hard times. To fight back, Butch's Mom took a drug test, and when it showed absolutely no evidence to confirm the accusation there was never an apology nor an end to the routine rudeness and disrespect both Butch's parents were subjected to during these many months as they held vigil over their son during his long weeks in hospital.

One can only imagine what the family went through dealing with such madness and absurd judgements raining down because of who they were. The worst part was that all of this misinformation and innuendo, the family believes became permanent entries in Butch's hospital record and charts. Once information went into his records his parents were told it could be redacted but never removed and the Butler family was always discouraged, indeed prevented, from gaining access to his medical records including as a reason, the enormous cost to photocopy the information of a now heavy file. These records in a very real sense 'travelled' with Butch and were the first thing seen by unfamiliar medical personnel every time he landed in the Emergency room. It never took long after a cursory review of his file for initial concern and caring bed side manners to turn into something else.

On Butch's 18th birthday, without any warning, discussion or explanation Butch was moved to the General campus. His charts, of course, followed him. He was told abruptly that from now on he would receive adult care and any consultations with Sick Kids hospital including the possibility of a liver transplant were no longer an option. For Butch and the family, weeks turned into months at the General. The quality of Butch's care did not improve nor did the attitudes towards his family. Palliative care, intended as a pathway to bring some relief and comfort to a dying patient, seemed the opposite to Butch... it was more like a cold and uncaring shortcut to hasten his death. So much so that a few months before he died, he insisted that his family take him home no matter what, where at least he could spend his last days with them and tend to his beloved birds. And so, he came home.

While at home, his bleeds happened more frequently, and vomiting was a daily fact of his existence. Still Butch battled for some time every day to feel, to laugh and to love and be loved by his family and friends dear to him. He had had an IV pick inserted in his arm in order to allow him to have IV medicine at home. There were several trips to the Emergency and on one occasion both he and his Mom fought to prevent the removal of the permanent pick having been advised by his palliative Doctor that given the condition of his veins it was very likely the last one they could give him. In other words, the pick was his remaining life line for transfusions and medicines. Their pleas were not being heeded, so in fear they left the hospital for home. The hospital called the police saying Butch was a danger to himself and others. When the police arrived at the family's home and the situation was explained, they were embarrassed,

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apologetic and angry at such treatment by the hospital and their own part in adding to his misery. Butch did not survive long after that horrible night.

As a postscript, this brave young man fought as long as he could. But his last hours were spent in excruciating pain, a victim of hallway medicine and dreadfully absent palliative care, this time at the Montfort Hospital. Some hospital staff seemed not to care about easing Butch's suffering at the end of his journey or helping a very frightened and grieving family to understand what was happening. Although the Butlers had tried to prepare for this inevitable moment since Butch came into the world, that knowledge did not soothe or make coping with the death of their beloved son the slightest bit easier. Butch passed away at 4:35 am on April 30, 2018 in the arms of his Mom.

A long sought-after meeting with senior hospital personnel was finally granted with Butch's parents almost four months after he died. Apologies were made for what had happened, but it was expected that the family would share the hospital's view that whatever disciplinary measures and corrective actions they had taken (details of which were not shared) as a result of what happened, were adequate and enough to satisfy the family. In addition, the parents were advised that the experience would be useful as a "teaching opportunity" moving forward. For the Butlers, the real truth of their son's last hours however difficult to hear and understand, remains out of reach. They have been denied that face-to-face conversation with the doctor actually responsible for his care that night. For them, not getting to the hard truths of that night no matter how difficult to hear or admit has left them with an unshakeable and profound feeling that even in his final hours, everything and everyone quit on Butch. And in their grief, sometimes that feeling gets misdirected to themselves as parents and they worry they could have done more to protect their son as his best and long-time advocates.

In the time that has passed since Butch's death, enormous love, respect and admiration has flowed from far and wide to this incredible family. There are many, many people who are missing and grieving for this special young man. For his family and for some time to come there is only the indescribable pain of loss, and their broken hearts. As a baby, Butch's Dad wanted him to have a 'strong' name to see him through life. So 'Butch' was added to the wee boy's already chosen handle of Steven Michael Butler. Butch certainly lived up to that name. And for his Mom, Dad, brothers and sister their comfort and ours comes from knowing his spirit is now finally free to soar without pain and suffering like the birds he loved so much.

It was hard for Butch and his family to share their private journey. It was not done for reasons of revenge or recriminations. Butch never allowed himself to wallow in pity or be driven by resentments of the all the things he missed of a normal childhood. He was able to attend school only for short periods, but his learning was deep and unique, and he was wise beyond his years... an old soul. For Butch his sharing was instead a call to action that we must strive to build a more caring world and as human beings never give up on efforts to bring about reconciliation based always on kindness and respect, patience and understanding for each other.

The determined young man wanted his story told and he asked that the world listen, acknowledge and stand up to the ugly realities he and his family endured at the hands of a health care system and too many professional caregivers who could provide not a single credible excuse for such treatment. Butch wanted to know and be convinced that his city and his community will not tolerate this happening to another Indigenous person. Unlike cystic fibrosis, an illness with no known cause or cure, the racist attitudes and

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treatment, disrespect and downright ugliness of too many of his experiences can and must be dealt with, ended and never allowed to regain a foothold to victimize another Indigenous child or family.

This work, the dedication and determination seemingly Olympic in size, is not beyond the citizens of this city. The task to reform and rebuild a health system on a foundation of love, tolerance and kindness with no cracks in the foundation to permit the terrible sickness of hate and prejudice in, will for Butch and his family, finally be an acknowledgement... an acknowledgement of his short time among us and his contribution as a human being. To contemplate anything less as a legacy for this young hero and his incredible struggle, is to ignore our difficult truths and perpetuate them.

Recorded and Written by Melody Morrison

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