

A family's nightmare with ALS

BY: Kirk Winter

It is safe to say that one of the worst possible things parents can ever experience is to bury one of their own children. Bill and Gwen Denby of Cameron had to do that when their son Paul lost a four year struggle with Amyotrophic Lateral Sclerosis in February 2017. To honour her son's life Gwen agreed to be interviewed about what they went through. She hopes to raise the profile of this rare disease that reduced her strapping 220 pound son, who made his living as a landscaper, to fewer than 100 pounds, unable to do even the most basic self-care chores for himself.

Paul Denby was born in 1984 and was a healthy child who developed into a sturdy young man. He was a strong guy who loved to work outdoors and build with his hands. He attended Fleming College, graduating as a heavy equipment operator. He loved his work as a landscaper and enjoyed the company of a large and boisterous peer group on the weekends.

In 2009, Paul began to complain about hand weakness to his parents. That hand weakness soon extended into his arms and then his back. Initially the symptoms were ignored and thought to be the by-product of years of punishing labour on the job site.

Paul continued to go to work, but found the job increasingly more difficult to do. His hand and arm weakness grew worse and soon he began to drop things. Paul's frustration with his declining health spiralled into a deep depression when his long time girl friend and mother of his young daughter ended their relationship at this time.

Gwen Denby noticed a considerable worsening of her son's condition after the breakup and insisted that Paul see a doctor for a diagnosis. What followed was an eight month odyssey of testing and more testing that took the Denbys from Lindsay to Peterborough to Toronto. Paul ended up at Sunnybrooke because the doctors he saw first could not identify with specificity what was ailing Paul.

In June of 2013, Gwen accompanied her son on that specialist trip to Toronto, and it was there that the doctors confirmed that Paul had ALS. The specialists continued by saying that Paul had 2-5 years to live and that if the home where he was living didn't have wheelchair access it soon would need it.

Gwen Denby remembers knowing nothing about the illness her only son had just been diagnosed with, and focused only on the greatly reduced life expectancy shared by the doctors. She remembers crying all the way home from Toronto to Cameron that day.

According to the Mayo Clinic, amyotrophic lateral sclerosis is a progressive nervous system disorder that affects the nerve cells in the brain and the spinal cord, causing loss of muscle control.

ALS is often called Lou Gehrig's disease after the legendary New York Yankees baseball star who contracted the disease during the 1930s and died soon after. Doctors usually don't know why ALS occurs. ALS often begins with muscle twitching and weakness in a limb, or slurred speech. Eventually ALS affects control of the muscles needed to move, speak, eat and breathe. There is no cure for this fatal disease.

After the diagnosis, Paul insisted that he wanted to continue living on his own rather than move in with his mom and dad. Gwen said that lasted from June to October of 2013 when Paul was convinced that for accessibility and nutritional needs it was better for him to move back in with his parents.

His new partner at the time, perhaps realizing what was about to happen, ended her relationship with Paul, leaving all primary care with Gwen and Bill.

As Paul's body began to wither from the ALS he progressed from leg braces to a cane, to a walker and then eventually a wheelchair.

As Paul began to grow weaker he told his mom it felt like bricks were holding him down and all movement was difficult.

For the next four years Gwen and Bill were primarily responsible for all Paul's self care. Gwen was up with Paul every two hours around the clock as sleep came

fitfully to him. The Denbys installed a baby monitor in Paul's room so they could hear him at all times. Gwen introduced Paul to a much healthier diet and to aid in chewing and digestion most foods ended up in some kind of smoothie.

Gwen said Paul did remarkably well mentally and emotionally considering the lot he had been dealt. He enjoyed watching movies and television and one close friend dropped by occasionally to spend time with him. Gwen was deeply disappointed that most of Paul's long-time friends slowly drifted away, likely not comfortable with the physical decline that he was going through. Gwen shared that the only time Paul cried was when his mom and dad had to help him with the shower and toilet. Paul didn't want to be helpless, but as the ALS progressed there was less and less he could do for himself.

Bill and Gwen realized that with Paul's passing all but assured, while he was well enough to travel they would do as much as they could as a family. They took Paul and his daughter on an 18 day trip throughout the United States where memories were made particularly between Paul and his daughter.

The Denbys bought a little Jack Russell terrier for Paul when he was home ill with ALS. The dog proved to be a wonderful companion for Paul and made Paul laugh time and time again with its antics.

Bill borrowed \$30,000 to take Paul to Mexico, where he had read that stem cell treatments were helping some with ALS. With the help of his brother-in-law, Bill got his wheel chair bound son to Mexico where Paul received two rounds of stem cell treatments. Unfortunately, it was to no avail as Paul's condition continued to worsen.

As the illness progressed, all the muscles in Paul's body began to fail him including his tongue, which made eating and speaking very problematic. Near the end Paul generally only communicated by shaking his head for "yes" and blinking his eyes for "no."

Gwen Denby was thankful for PSW support two hours a week to assist with Paul's physical therapy, taking a bit of the load off she and her husband.

Paul's staggering loss of weight had the Denbys concerned. A decision was made to have a feeding tube surgically implanted at the Peterborough Regional Health Centre.

The night before Paul was to be transported to the hospital for surgery he told his mom, "Mom you are awesome. I couldn't have a better Mom."

Gwen wondered if the end was near, feeding tube or no feeding tube, because for a month before the planned surgery Paul had to sleep with his head on his knees so he wouldn't choke to death.

Paul was transported via ambulance to Peterborough, and Gwen was not surprised when the doctors informed her that despite all her efforts Paul was doing very poorly. Gwen was very concerned that the surgery, necessary or not, might kill Paul considering the frail condition he was in.

Late one evening while awaiting surgery, Paul Denby went into cardiac arrest and was pronounced brain dead soon after. Gwen said his liver and his kidneys were donated to three separate donors so that those people might benefit from Paul's misfortune.

Paul Denby died on February 11, 2017 at the age of 32, leaving behind his mom and dad, a sister and his daughter Summer who was six at the time.

May has been designated ALS month by the government of Canada. I asked Gwen what advice she would have for other parents dealing with children who have terminal illnesses like ALS.

Paul's mom began, "ALS is like nothing you have ever seen. It is the worst possible way to die. When Paul died he weighed 96 pounds. He couldn't swallow and could speak only with considerable difficulty."

Gwen added, "You will need lots and lots of patience to deal with ALS. You will need to make them as comfortable as you can. You, as a parent, are so frustrated at your inability to make things better. You have to understand the frustrations that your child is dealing with too. I would do it all over again having Paul at home. It was the best possible place for him to be till the very end. It was tough,

but my son never had a bedsore. The nurses in Lindsay remarked how well cared for he had been. A memorial service was held to honour Paul's life. Over 200 friends and family attended to celebrate the person that Paul had been. Paul was loved to the very end."