

## Living Life With Joel, An ABI Survivor

By Marg Willemse

June 6, 1980 and July 11, 2004 are two very significant dates in my life and especially in the life of my son Joel. June 6, 1980 was the day I gave birth to Joel Boudewyn Willemse, our third son. July 11, 2004 was the day Joel's life and the lives of his immediate family changed in a way we could never have predicted.

It would be difficult to talk about what it is like to live with a son with ABI (acquired brain injury) without starting from the beginning and explaining what our lives were like prior to Joel's injury. Joel has two older brothers, Keith and Adam, and a younger sister, Aprille. Visiting Specialists was not foreign to me or to my husband due to the fact that both of Joel's brothers had been born with clefts which required numerous trips to London for doctor appointments and hospital stays.

When Joel was nine years old he had his first epileptic seizure. It was hoped that as he grew older he would out grow them. Unfortunately, that was not the case. Joel has always been on anti-seizure medication of one kind or another since he was nine. He was never able to go an entire year without having a seizure. Naturally, by the time Joel reached his sixteenth birthday, his friends were all getting their driver's license which of course Joel was not able to do. It was a tough blow at such an important time in a teenager's life. Aprille, who is two years younger than Joel, had her first epileptic seizure at the age of thirteen. When our son Adam was fifteen, he was diagnosed with Type 1 diabetes. As you can imagine our lives were busy, yet amazingly under control. At one point our son Keith said it looked like he was the only "normal" kid we had. I imagine that all the surgeries he had gone through seemed minor compared to what his brothers and sister were dealing with.

After a year of trying different anti-seizure medications, Aprille's seizures were under control, but Joel's were not. Nothing seemed to work for him and it took a toll on Joel's life, especially his self esteem. Yet, Joel managed to get through elementary and high school and went on to college. It wasn't smooth sailing, but it was manageable. After a number of years Joel decided he had had enough of school and wanted to start working. He had been in a Law & Security course and made the decision to move to London, Ontario where he moved in with a couple of friends. Shortly after, he was hired by a London security company and was to begin his new job the following week. In the mean time he was working part-time as a bouncer at a local club. On Saturday, July 10, 2004 after his friends had left to go out for the evening, Joel was preparing for his shift at the club which would have been around 9:30 P.M... It was 2 A.M. when one of his roommates returned and found Joel seizing in his room. This particular roommate was an old childhood friend of Joel's and had been with Joel more than once when he was having a seizure. As a parent you always dread that phone call that tells you something terrible has happened to your son or daughter. This time, when Cory called me, I could tell by his voice he was really scared and then he told me he had never seen Joel quite this bad before. He was blue, still seizing and had been vomiting. I could hear Joel in the background and asked Cory if he had called 911, which he had. We were instructed to meet them at University Hospital.

Upon our arrival we were allowed to see Joel before he was moved to the ICU. He was not responding and had been given a large dose of medication to stop the seizing. Needless to say it was a long night and we were not getting a lot of answers. Joel had only had one seizure when he was younger that required a hospital visit to stop it. Otherwise, they always stopped on their own, until this time. The doctor's told us that Joel had seized for approximately 4 - 5 hours and due to the vomiting he may have asphyxiated. If so, this may also have cut off the oxygen to his brain, possibly causing brain damage. There were no definite answers and no explanation as to why it happened in the first place.

All we could do was wait. During the first day, we were getting a lot of information coming at us from all directions; he had a temperature of 102, there was an infection in his body they could not explain, he was dehydrated, his brain was swollen, his heart rate was too high, his blood was too thin, and he was also on a respirator. They thought he might have meningitis, so we had to wear gowns, gloves and masks when we went in to see him. The doctors had actually given Joel a drug to paralyze him; it was the only way to stop the seizing. With all this information coming at us, I decided to start keeping a daily log. It was total overload for all of us. When the doctors decided to bring Joel out of the induced paralysis it took 5-6 attempts because he would start to seize each time. On the second day they were able to get him off the medication. They also stopped sedating him, in hopes he would wake up, which he did not. We were told Joel was in a coma. By the end of third day the doctors told us that they had done everything they could, but that Joel's liver and kidneys were failing. He was "very critically ill". Basically, if he did not "turn that corner" soon, it did not look like he would make it.

I have always been strong in my faith, but I can honestly say that I have never prayed as hard or more desperately in my entire life. Fortunately, my husband and I are both from large families and we immediately had their support, love and prayers. Family members and friends sat vigil with us waiting for some good news. My mother, who was 82 at the time, was and still is a huge comfort and support to me and my family. The hospital staff were wonderful in that, they would let his Dad and I, Joel's brothers and sister and any extended family or friends who wanted to spend time with him, go in to see Joel any time day or night. It was not until some time later that we realized they did this because they did not expect Joel to survive. He was steadily going downhill. At one point, when the doctors were basically saying there was nothing else they could do, a wonderful neurologist by the name of Dr. Young went in to see Joel a number of times and he was able to discover why Joel was not improving. With a change in medication, came a change in Joel's body and he started to respond to the new treatment. Although Joel was still in a coma he was managing to hold on. On the sixth day a MRI was done, but the prognosis was grim. Dr. Young had actually stayed late that Friday night just to be there when the results came in as he knew we were waiting.

Dr. Young sat us down and explained that according to the MRI there was considerable brain damage on the right side of the brain. Joel would still have his speech, but he would not be able to walk, meaning he would have to be in a wheelchair. His eye sight would be affected in a way that he would see everything "flat"; he would not be able to see three-dimensionally. He would not be able to see depth either, using stairs as an example. Dr. Young said he was sorry to have to tell us this. At this point, we were happy that Joel was still alive because we felt we could deal with anything.

As we waited for Joel to come out of his coma, numerous tests were being done on a daily basis and with each day came more problems and little improvement. It was on the tenth day that Joel actually tried to open his eyes. I had just come into the room and the nurse was trying to get a response from him which they would do on a regular basis through the day. She said to him, "Joel, your Mom is here" and his eyelashes began to quiver and his eyelids started to flutter. I just kept talking to him and he kept trying so hard to open his eyes. By the twelfth day they had to do a tracheotomy. It was the next day, when I was holding Joel's hand, that I asked him to squeeze my fingers, which he did three separate times. It seems like such a small thing, yet to us it was huge. He was responding to voice commands. Then he started to yawn to us and as he stopped, he opened his eyes! It only lasted a couple minutes, but he gave us more joy and hope in those few minutes then we had had in almost two weeks.

Over the next few days he continued to give us small signs that he was starting to come out of his coma. Then on the sixteenth day we were told Joel had blood clots in his left leg. The doctors administered Heparin in an effort to dissolve them. The next day Joel's bilirubin was up and he had a yellow color. His liver and kidneys were not working properly. His temperature went as high as 106 degrees F. The doctors continued to run tests such as a MRI, x-rays, blood cultures, and an EEC. They also kept him sedated all day with a sedative that causes amnesia. The doctors told us that this would keep Joel from having any memory of all the terrible things he had endured over the past few weeks while in hospital. The following day they did not administer a sedative at all and Joel opened his eyes and followed the nurse with his eyes as the nurse moved around the room. He then gave nurse Fernando the "thumbs up" and opened and closed his eyes on command.

It was on this day (day 18) that they started to take Joel off the ventilator for short periods of time and allowed him to breath on his own. His temperature was still too high and his hemoglobin was too low so they gave him a unit of blood. The doctors decided to call the Department of Infectious Diseases to have a look at Joel. They concluded that Joel was free of any disease, which made us happy, but still left us with out an answer as to why his temperature was so high. By the twentieth day Joel was no longer receiving sedatives of any kind and was starting to move around and was becoming more alert. When I went into see him, Joel opened his eyes and when I started to talk to him he looked at me and then smiled, twice! Then, as his Dad began speaking, Joel turned his head towards his Dad. We like to think it was because he recognized our voices. By the end of the third week Joel was able to stay awake for a good part of the day. He then started having problems with his blood pressure and heart rate. They were both too high. For a number of days now they had tried to get Joel's temperature to drop by literally packing him in ice. He was lying on a mat that actually had ice in it and they would put ice under his armpits. It was discovered that he had an infected sore on the back of his head from lying down so long, so an antibiotic was administered. The doctors said that the infection might have been the cause for the high temperature, but they could not be one-hundred percent certain. Two days later Joel was moved up to the seventh floor because he was staying awake and holding his own even though he still had a high temp which was somewhat manageable. He was put into the Intensive Observation Unit on the seventh floor and would be there until it was safe for him to go into a private room.

On the twenty-sixth day, August 5, Joel woke up and said "Hi" to his Dad and me. It was the first word he had spoken since July 11. I asked him how he was feeling and he said, "Like crap", which was not hard to believe at all, considering everything he had been through. Once he was awake the doctors felt it was important to get him moving. He could barely stand on his own. Physio therapy began with Joel just lying in the bed and the therapist helping Joel move his arms and legs.

He also seemed to be having a problem with being able to tell the difference between reality and the dreams he was having. He was actually calling his dad "Optimus Prime" although he knew everyone else by name. He had been dreaming about the Transformers, an animated TV show he loved to watch when he was young.

There was a Picc line in his arm which he found really irritating and he kept asking anyone and everyone that walked by if they would take it out. The nurses had tied him down to the bed because he kept trying to get up even though he could barely stand on his own. He even offered his brother Keith \$20 to untie him. After a couple days the Picc line was removed and he had managed to pull out his own feeding tube. It was decided by the doctors not to replace it and they began to feed him soft foods. He could not seem to get enough water and was constantly asking for it because he was so dehydrated.

When I asked him if he knew why he was in the hospital he said "no". So I went on to explain to him that he had had a really bad seizure, but that he was getting better.

It had become my habit to call the hospital first thing every morning to see how Joel had fared through the night and on this particular morning the nurse told me the doctors had decided to remove Joel's tracheotomy. He was able to swallow on his own. It was at this point that Joel starting complaining about pain in his shoulder.

On day thirty, Joel was moved to a semi-private room where he had COM care watching him 24/7. Test results for his liver were coming back and the doctors were telling us Joel's liver was still not right. They were still working on it. A couple days later Joel was moved into a private room and still complaining about the pain in his shoulder, which they eventually found to be a shoulder dislocation.

Five weeks after his admission Joel's Dad and I went to Parkwood Hospital in London to look into the arrangements that had been made for Joel's rehabilitation. Four days later Joel was moved to Parkwood where they gave him a couple days just to get used to his new surroundings before starting therapy which included physio, occupational and recreational. By this time it was September and I had returned to my job as a Secondary school librarian. Needless to say it was a very stressful and difficult to concentrate on my job. By the end of the third week I decided I needed to take a leave-of-absence from my job and try to get a firmer grip on all that was happening in our lives. It was about ten days before Joel's initial seizure in July, when we had just started the construction of our new home. We were doing all the contracting ourselves. It was a project that I was really looking forward to and knew I would really enjoy. I had already done most of the footwork as far as getting numerous estimates for the various jobs that needed to be done. It just added to the already full plate that we had. During the first week after Joel was admitted to the hospital I didn't even want to talk about the house and it was basically put on hold. We were living in a four level-split at the time and when we were told Joel may very well be in a wheelchair we knew we had to continue with the new house which was going to be a one-floor plan. Our lives basically revolved around Joel and we did our best to work on the house and be there for our other three children.

I would have to say the first six months were the most challenging as far as adjusting to all the changes in our lives. I can still remember driving home one day and thinking about how much our lives had changed. I did not even recognize my own life anymore. We were no longer living in the home we had loved for the past sixteen years. It was no longer just the two of us. Our daughter had moved back home after graduating from university and when Joel was discharged from Parkwood Hospital he naturally moved back in with us. My husband and I were so involved with Joel's life, work, and the finishing of the new house that we had very little time for each other. It seemed we had entered into this long dark tunnel and were so busy trying to deal with the "new" Joel, and all that entailed. We both were doing all we could just to hang on to our own sanity, let alone be there for each other.

Joel spent five weeks at Parkwood and progressed well enough to come home. When Joel first arrived home he was very moody and had a very short temper. There were many outbursts when he was with his immediate family. Yet, he seemed to know that same behavior was not acceptable when his extended family members were present. He spent most of his mornings sleeping and in the afternoon he would watch television and spend a considerable amount of time on the computer. Originally, we were concerned by the amount of time Joel was spending on the computer, but over time we came to realize that it was actually helping with his reading skills. He also seemed to be able to retain a fair amount of the information he was reading.

We also noticed that Joel was very sensitive to noise and light. During the day he would close all the drapes in the house because he could not tolerate the light. He also had a lot of headaches and migraines which made him even more irritable. Most nights he would be in bed by 7 P.M. He would come into the living room just before turning in for the night and turn the television and all the lights off and leave the rest of us sitting in the dark, literally. When we would tell him that we were watching the television he would tell us that we should be going to bed too. He didn't like the noise. We would have to try to keep our sense of humor during this time or we probably would have gotten into even more disagreements with him. Eventually Joel was able to stay up later into the evening. We also noticed that whenever anyone came over to visit, he would say hello, but then disappear to his room or the computer room.

Approximately three days a week a support worker from the Outreach program would come to the house to help Joel work on relearning his life skills. It wasn't long before Joel was complaining and telling us that he didn't need help. There was a tension in the house that was present for a long time and we would feel it the moment we came through the door.

There were a couple of incidents where Joel became totally out of control. The first time he was upset because he was not able to use the computer because his sister was using it. Aprille had been hired to work in Japan and was busy making arrangements. Joel, being upset with his sister, actually started to hurt her hand and when she got upset their older brother Adam stepped in to protect his sister, telling Joel to leave her alone. This upset Joel even more and he got into an altercation with his brother. Due to the weakened condition that he was in, it did not take much for Adam to subdue his brother. It was so sad to have to see Aprille and Adam have to deal with Joel in this way. By Spring of that year to Aprille left for her job in Japan. It was easy to see that the situation with Joel was taking its toll on her. When Aprille had been gone about 2-3 months, I asked Joel if he missed his sister and he replied "No". Six months later I asked him again and that time he said "Yes, I do". For Aprille it was probably the best thing she could have done.

In May, which was approximately ten months after Joel had been admitted to hospital, we noticed that Joel was becoming depressed and even more irritable. One Saturday morning we were preparing for the wedding of one of our God-daughters. Joel came into the room, where I was ironing his shirt, at which time I told him he needed to take a shower and get ready for the wedding. He told me he didn't want to take a shower and when I repeated that he had to take one, he grabbed the ironing board I was working at and threw it across the room. I picked it up and put it back in place. Then I tried to calmly explain to Joel that he had to get cleaned up and it was going to go to the wedding. Again he grabbed the board and threw it. At that point his Dad entered the room to see what the commotion was about. When his Dad told him his behavior was unacceptable he got into a physical altercation with his Dad. Again, in his weakened state he was not a match for his Dad. As he made a quick exit out of the room he grabbed a candlestick holder off the fireplace mantel, turned and hit his father in the forehead with it. He then tried to grab a heavy dish off the coffee table and was about the throw it at the big window in the room when his Dad stopped him just in time. He had to literally pin Joel down on the floor in an effort to get him under control. After a few minutes he asked Joel if he was ready to behave. Joel told him that he was not going to the wedding and that he would destroy the house while we were gone. He continued to struggle with his Dad. It was at this point that my husband told me to call the police. Joel was out of control.

It was the hardest thing I have ever had to do as a mother, but I knew I had no choice; there was no way of knowing what he was going to do next. He was out of control. After calling the police, I called our son Adam. Joel has always listened to Adam even when no one else could get through to him. After the arrival of the police and Adam, Joel seemed to calm down, but was claiming that his father had thrown him across the room. The police could see the blood on his father's forehead and tried to talk with Joel, but he was in a very agitated state. One of the officers' told me that he was worse then they originally thought and were going to remove him from the house. They then wanted to warn me that they were going to have to put him in handcuffs. I can't even express how terrible it felt to see him that way. They then put him in the back seat of a cruiser and they spoke with him there. The officers agreed that his brother Adam would take him over to their brother Keith's house and he would stay there for the next day or two. It was an absolutely heartbreaking time. The following Monday we took Joel in to see our family doctor and explained to the doctor what was going on. After talking to Joel he decided to put him on an antidepressant. Joel was already on eleven different types of medications since being discharged from hospital so this added another one to the list. After a few weeks we started to notice Joel's mood started to improve; the medication was making a difference.

During the time Joel was living at home with us, I had a difficult time finding some type of support as far as rehabilitation for Joel was concerned. When he was discharged from Parkwood, we were told we would be able to find services in our own country. The best we could do was the Outreach program. There were no specialized programs for anyone with an acquired brain injury in Lambton County. It was through doing some research of my own that I discovered the Dale Brain Injury Services in London, Ontario. Their objective is to work with their participants to help them maximize their potential for independence and reintegrate them into their community. This was the goal that Joel had set for himself. There was a waiting list, but by March of 2007 Joel was accepted into the program. Four months later it was felt that Joel was ready to live independently. Joel was happy to have achieved his goal is such a short amount of time. He moved into a house in London and lived with some students from the University. He continued to receive visits from a support worker from the Outreach Program in London.

Over the next year and a half both of Joel's older brothers got married and his sister Aprille was still working and living in Japan. They went on with their lives and it was probably the best thing for them. Although one of the toughest things for Joel has been watching his family and friends go on with their lives and all his plans had come to a grinding halt.

Watching our other three children move ahead has been good for both of us, but as Joel's parents, our hearts break for him. Joel may have a brain injury, but he knows exactly everything he has lost. As his parents, all we wanted to do and still want to do, is make everything right for him. We could not have dealt with all that has happened to Joel if it were not for his brothers, sister, extended family, and friends. You try to pull from an inner strength, that we all have during some of the toughest times in our lives, but sometimes that's not enough and that's when it helps to have others to talk to; especially other parents who are dealing with the same type of situation. I work as a Secondary school librarian and I will never forget having a teacher, that I had once worked with at a previous school, stop in to see me. Her own son had been in a car accident and was also an ABI survivor. I knew she had a good idea what it was I was dealing with. Naturally, when she asked me how I was doing, I smiled and gave her the same answer I gave everyone, "Joel was really coming along." She looked at me and smiled saying, "I know what you're doing." When I asked her what she meant, she said, "You slap that smile on your face and tell everyone everything is fine, I did it myself all the time". I have to admit she was right, but for me it was the easiest thing to do. You really don't think people want to hear about everything your dealing with and sometimes it was just easier to fool myself and everyone else into believing that everything is fine.

Life was a struggle for all of us, but where to go from here? We were living day to day and dealing as best we could. For me a turning point came when my younger sister Pat invited me to go on a trip with her. Basically, my brother-in-law Pete was giving me his ticket to go on an Alaskan cruise. It is one of the nicest things anyone has ever done for me. The idea of going away on a holiday was not even anywhere on the radar for me. It did not even occur to me that a trip, and getting away for a while, was just what I needed. We were only gone for ten days, but it was a turning point for me and my husband. The trip gave me the time and space I needed to get refocused on my life and my marriage. My husband and I had become so focused on Joel and everything that was going on that we lost sight of each other, even after 29 years of having a truly, happy marriage. It is very much like when a loved one dies; everyone deals with it in their own way. We were both mourning the loss of the son we had lost and were trying to get to know and love the new personality that had come into our lives so unexpectedly.

July 11, 2008 will mark four years since Joel acquired his brain injury. Joel is not the same person he was four years ago, but over the past four years we do see more and more of the old Joel. He will never be the same exact person that he was, but interestingly enough there are things about Joel that we actually enjoy more now then ever. Changes include a greater appreciation for his family and a greater appreciation for his grandmother, aunts, uncles and cousins too. They have all been so good to Joel and his immediate family and he recognizes that fact and shows his appreciation on a regular basis. The other day he called his Dad and asked him, "Do you know what an awesome brother you have?" His Uncle John, who is a fishing enthusiast, had given Joel an "Ugly stick" which apparently is some type of awesome fishing pole. His uncle and aunt live nearby and invite him over for dinner every now and then. They are always there for Joel whenever he needs their help, just as all his aunts, uncles and cousins are. Things that may seem minor to others, such as his cousins inviting him to watch wrestling with them on TV or asking him to be the goalie for family hockey games at the local arena, mean more to Joel and his immediate family then they could ever know. When Joel is happy, he reflects that happiness onto everyone he loves, including his own immediate family. They are all instrumental in helping us cope with the situation and the majority of the time they have no idea how much.

About a year ago, Joel also became a member of the Cornerstone Clubhouse in London Ontario. Cornerstone is a community-based day program for people living with the effects of an acquired brain injury. He has taken up wood burning at the Clubhouse and puts a lot of thought into different projects that he has produced for his Grandmother and various aunts and uncles. He has also made a true effort to get his life back on track by applying to a security company. He was tested and hired by the company to work as an occasional employee. Though he has only worked a few shifts up to this point, it has helped Joel in a huge way when it comes to his self esteem.

There is also a financial stress that comes along with being disabled and unfortunately the monthly amount that the disabled receive from ODSP (Ontario Disability Support Program) is not enough to cover rent, utilities, food, transportation, and other financial commitments Joel had previous to becoming an ABI survivor, like his student loan. Joel worries that he will never be able to get ahead in life and that he will never be able to afford a home of his own. Naturally, we do as much as we can, which in turn puts a financial strain on us and of course more stress. Yet, when we stop and think about the doctor's original prognosis for Joel, we can't help but be thankful for all the things that have gone right for Joel. Life is a daily challenge for him and his family, but that is the keyword "family". Joel is grateful for his and we, his family, are grateful every day to still have Joel with us.