

Lorna's Story

'GOOD NEWS!...You can take your husband home!' Words we longed to hear...words I was terrified to hear. Toward the end of a seven week stay in hospital, my husband had come home for only one day trip and then one overnight trial before this announcement was made. Powerful emotions swirled through my mind. Panic lead the field. How was I going to cope with the 24 hour care of an invalid husband? How would we get into and out of the house if an emergency arose? Who would look after him when I had to leave the house? Was our house wheelchair friendly? What about my job? Nobody had ever asked me if I had a life beyond this new caregiver designation. I was not ready. I was bewildered and scared to death.

Our ordeal began when my husband underwent simple nasal surgery to correct a deviated septum. Three days post op' we knew there was something very wrong. He began to spike a high fever and experience severe back pain between his shoulders. Neither his surgeon nor the family GP took this very seriously, simply giving him Tylenol 3's for relief. A few more days went by with the pain becoming nearly unbearable. Still we were given the brush-off from the surgeon, whose receptionist told us very tersely that the doctor was unavailable and, besides, he wouldn't see my husband until six weeks after surgery. (This same surgeon later swore he never knew there had been a problem.) We were not referred to another specialist for assistance. In a panic we went to the family doctor who sent us to have tests to rule out heart complications. The next day my husband collapsed, totally paralyzed from the neck down. He was rushed to emergency where it was found that he had contracted a Staph infection during surgery and it had settled on his cervical and upper thoracic spine. After four days of life and death struggle, my husband finally won the fight, but the real battle was just beginning. Incomplete quadriplegia from a nose operation. Devastation! Disbelief!

My new life as a caregiver began by spending twelve days and nights at the hospital. The first four days were in intensive care and the next eight days I spent with my husband in the acute care department. I helped every way I was able to, to try and make him as comfortable as possible. The nursing staff were so overwhelmed with critical patients at that particular time, that they were unable to come immediately when any of the many machines he was hooked up to started to beep. Everyone's machines were going off constantly. I would alert them at the desk and then eventually someone would arrive. He couldn't have swatted a fly off his face, totally helpless.

Therapy began in full force as soon as he was able to manage without being hooked up to machines that controlled his oxygen levels and medications. He was transferred to the rehab wing of the hospital and the struggle began. Six

weeks of intensive therapy brought us to the "good news" day. So home we came. By this time I had worked out an arrangement with my employer to work half days. This allowed us to fumble through all of the chores getting our day started, and at noon the handi-bus picked up my husband to take him to his rehab sessions. Then I went to work for the afternoon and was home before he returned at five o' clock. I was allowed to do this until my own sick days were used up and then I had to take early retirement. My husband was too severely disabled to spend any time alone and I gladly left work to be there.

During this intensive program my husband had regained some upper body mobility, the use of his left arm and some of the left hand muscles. He is right handed. He could sit up for short periods of time but became easily dizzy and nauseated. He could transfer from wheelchair to easy chair or into bed, using a sliding board. For the first long while I had to assist with his bathroom functions, showers, dressing, and under dressing and a myriad of other personal cares. Slowly, and with dogged and unflagging determination and hard work on his part, things began to show minute improvement. We graduated from rehab at the hospital to an advanced program of rehab and the University of Calgary gym. Twice a week I heaved a bulky wheelchair into and out of the back of the vehicle, loaded him in, and attended the classes with him as his assistant and coach. This was actually an excellent experience for both of us. It was while we attended these classes that we realized, that as rough a time as we were experiencing, we were actually better off than 90% of the people there. They were all dealing with degenerative or permanent conditions and we were lucky enough to be able to celebrate bits of recovery as time went by.

The most amazing thing about being with these wonderful people and the cheerful young people who ran the program, was their constant support and their enthusiasm for us when they noticed that my husband had regained some more movement or was able to walk a little further in the bars or around the track. It was an opportunity for us to be thankful. We also attended a rehab swimming class in a large, heated pool. This was marvelous for my husband, because it gave him such buoyancy and the feeling that his body was free again. He always described the feeling of his paralysis as being 'enclosed in cement'. After two years in the regimen, we decided to transfer to a gym closer to home for our rehab. This was a very disappointing and expensive experience. A great program was planned and promised, but never materialized. The young and beautiful were the ones that were catered to. So we bought a treadmill and a cross trainer ourselves and pursued our activities at home.

By now, my husband had regained full use of his arms and eventually, the use of his right hand. He was becoming a lot more self sufficient. As a matter of

fact, I had become so used to doing most things for him that he asked one day to "please don't take away all my jobs". It was time to back off. This was a very fearful time for me. As my husband became more independent, He began attempting things that scared me silly... like climbing a ladder when he didn't know where his feet were without checking. He also wanted to be able to dress himself independently and there were many humorous incidents during these attempts. He'd lean his forehead against the window frame in our bedroom, steady himself and then try to get his trousers pulled up or button his shirt. Often, he had to grab to save himself from tipping. Our kids threatened to attach a Velcro band around his head and install the sticky parts on the window sills around the house. He'd sit on the end of the bed and try to get his socks on, slowly slip off the bed and end up on his backside on the floor, where he finished putting the socks and then heaved himself back up. I had been attending counseling sessions for families dealing with spinal cord injuries and when I expressed my fears, I received probably the best advice I can remember..." if what he's trying to do scares you...don't look!" It took a while to realize that he was so determined to get his life back, that he would do these things whether I was there to nag, or not. He just waited until I wasn't looking. If he had an accident, or fell, which he often did, and still does, he wouldn't tell me until many days later, unless I noticed him having pain. The consequences are now his, but the nagging worry is still mine.

One special blessing for both of us was my husband being able to start driving again. He's always been a nervous passenger when I drive, so this was really huge. Because he couldn't flex his right ankle muscles, he had to use a removable left foot pedal adaptor which was really exciting to begin with. I was pretty much on kissing terms with the dashboard in the Jeep for a while, but he mastered that in the same fine form as he did everything else.

We had been told by the neurologist that any nerve regeneration we could expect would probably be maxed out after about 2 years. But they didn't know my husband. He let that prognosis go in one ear and out the other. He has never put a cap on his efforts to improve. We are into this new life of ours now for over twelve years and continue to celebrate small, but significant advances. His right leg is still profoundly paralyzed and he wears a drop foot brace to assist in walking. His left leg is about half normal strength. He walks with great difficulty using two canes. He has zero balance. His midsection and back are weak but his shoulders and arms are strong. Over time he regained the use of the fine muscles in his hands. He feels pressure on his feet, but cannot distinguish between hot and cold. His entire body up to his armpits is a patchwork quilt of varying degrees and types of sensations. There is no bowel and bladder function and, barring a miracle, there never will be. There is constant pain.

A time came when the assistance from the medical field became indifferent and mostly non-existent. Sadly, the help and concern of former friends slowly disappeared as well. Everyone moves on with their own lives. All too often the presence of a disabled person becomes a hindrance and even an embarrassment. Many times one has the impression that people view a person with physical disabilities as being mentally challenged as well. They speak as they would to a child, speak extra slowly and loudly, or actually talk about the person to the caregiver who is with them, as if they're not even there. This includes people in the medical professions, who should definitely know better.

Over the years we have developed our own coping methods for my husband's many limitations and problems. Bladder infections were a constant problem. We found that by rinsing and boiling the catheters has brought that problem down drastically. (His last bladder infection was a full two and a half years ago!) Also, a mega-dose (1000 mg) of cranberry extract seems to have been very effective. He takes this in tablet form to avoid the sugar content of the juice. We discovered that in areas of painful skin sensitivity, using a light spray of Solarcaine (with Lidocaine) on the area before bed improved the quality of sleep. We bought adjustable beds which greatly assisted in comfortable positioning and easier breathing. We added 4" foamies on top of the mattresses to absorb pressure from sore spots. The bed has a massage feature which is great for circulation and a feeling of well-being. Regular therapeutic massage has also been very beneficial.

We also needed to be aware of what community support we could call upon. We 'missed' (were not informed of) the staff conference in which we were supposed to be included before leaving the hospital, where pertinent information about agencies and services were to be outlined for us. We never did get and information and didn't know where to begin. So, it was a huge learning curve for us, which we assumed was something everyone in our position was responsible for. Actually, there wasn't much help. After a certain time we realized that we were pretty much on our own. We did get bars installed in the bathroom and a Handi-bus provided transportation to rehab until I started doing the driving myself. My husband was spending upwards of three or more very uncomfortable hours a day sitting on the bus.

This whole mending process was, and still is, a two person and, many times, a family operation. Time seems to evaporate before our eyes. The whole tragic episode was legally investigated which was a waste of time and money on our part. The verdict was (surprise, surprise!) "no fault". The lawyers sent us a copy of the investigative report with a notation at the end..."hoping this helps you get on with your lives". I struggled for a long time with terrible anger and the need to lay blame somewhere. Such an unspeakable injustice! Surely 'someone' should take responsibility.

With the passing of time and the realization that this attitude was self destructive and counter-productive I was able to slowly move it to the back burner. It still simmers sometimes, but it doesn't boil over anymore. My husband has never wasted time on anger and self pity. He had too huge a job to do to waste his energy on negativity. It was too obvious that we had to 'get on' with our lives. My husband spends many happy hours in his greenhouse, growing beautiful tomatoes and bedding out plants. He struggles around mowing and trimming the lawn, and waging a constant battle against dandelions. Grandchildren have begun helping us with that. We have superb family support. He can still do many of the small maintenance jobs around the house and garage. We travel a little and camp a little. We will never be able to ballroom dance or climb a mountain, but that was never on our bucket list anyway.

Even now though, after all these years, I sometimes wish we could turn back the clock and have my husband whole and health again. When I watch him struggle and struggle to accomplish what used to be so simple, I get a sad longing to be able to enjoy our golden years in the way we thought we'd earned after raising five children. But, as the saying goes, 'there is no greater waste of time than wishing your past was different.' With that in mind, we've gotten used to what is now our 'normal' life. We live with the limitations and maneuver around them. Life has changed but it's still good. For that reason every effort has been made to do the best with what we've got and celebrate and be thankful at every opportunity.

The words of Nat King Cole's song, "Smile" are a credo for caregivers. "Smile, though your heart is breaking..." We are blessed with our own and an extended family that can appreciate the ridiculous, find humor in every corner and can laugh at life's left curves. There has been a lot of tragedy within our ranks and it's the gift of laughter that has buoyed us up through the years and helped us heal. And prayer. Always prayer.