



Finding Our Way

Hello, my name is Larry Varcoe and I am a caregiver for my wife Sandie. I've been a caregiver now for the past 35 years. Being a caregiver was not something I planned or expected to happen, but it did. So how do I manage and how do I deal with this change in my life and what do I recommend to help all caregivers?

Firstly, I'll share with you some of my story and how I became a caregiver then I will tell you what works for me to be the best caregiver that I can be and what I believe caregivers need most.

My wife like a lot of others had a stroke. Hers was a result of a ruptured artery and they did not believe she would survive the night. They were unable to do much for her because at the same time she was dealing with 5 brain aneurysms. But by some miracle she did survive and is still with us today 35 years later. The stroke was so severe it took her right back to being a child. She had weakness on her right side, loss of speech with global aphasia and after clipping her aneurysms she was left with double vision in her left eye. She nearly spent a total of 14 months in the hospital to get to the point where she could go home full time. She still has weakness on her right side, has limited speech and global aphasia, still has double vision but except for about 6 months she has regained her memory and relearned to be the person that she is today.

The journey to finding out new normal of life was going to be long and challenging but day by day and step by step we got to where we are today. My wife still has challenges, but she has never complained, never got down on herself and her situation and is one of the happiest people I know of. I know everyone we know will agree with that.

One thing I found is that when a family member has a stroke the entire family experiences it and is affected almost like they had that stroke along with them. I also found out that we became more alone. People that we thought we knew and hoped to lean on disappeared. We truly were for the most part alone. I have since noticed this to be a pattern for a lot of survivors and caregivers. Loneliness can be devastating for a lot of people and needs to be addressed.

Now I'll share with you some of the things that I have learned over the years that helped me to be the best caregiver that I can be for my wife and how to maintain my own sanity if you will. I believe this

information will help others today as well. Like most people everything was going along like normal then bang one day everything was turned upside down. With fear and shock that was absolutely devastating I was wondering what was next, how am I going to manage everything, who can I talk to for advice and direction? Unlike today, there was very little help or support back then. The future looked bleak at best. At the time I was still working and had an 11- and 15-year-old that also needed my time.

So, this is what I did and for the most part it worked. There was a couple of hiccups along the way, but we dealt with them the best we could and kept moving forward. Knowing there wasn't a lot of help and support for caregivers I leaned towards my family doctor who I knew well and the psychologist that I worked for. They gave me similar advice that turned out to be exactly what I needed at that time and this advice I believe is still valuable today. They told me first and foremost let my wife know that you are there for her and you are not going anywhere and together you will both get through this. Remember she is very scared and needs to know she is not alone. Although at the beginning she couldn't fully understand with words I could tell by being there and with the way I spoke to her it brought comfort that was much needed. It would also help motivate her to fight on the best she could.

I also sat down with my kids and explained to them their mother's condition and the journey ahead of her. I also told them I was going to need their help and support. In a way they now became caregivers as well even at a young age. Their life was going to change also even though they should be just doing what kids do. They each took on a little more responsibility around the house which helped a lot. We can't forget them or think they are only along for the ride. Keep them informed.

The second thing they told me was to make sure that I took care of myself. I was not going to be of much help if I became ill or run down. Make sure you get plenty of rest, eat well, exercise and above all and this is crucial - take some time for yourself, relax, and re-energize yourself as often as you can. Remember you are going to be a caregiver not a servant on call 24-7. You need time to relax so that you don't wear yourself out. Find some time each day to do your thing. By staying healthy and energized you will be better able to look after your wife. I've never forgotten those words of advice and learned how valuable they were.

I have, considering the circumstances lived a fairly normal and healthy life. I feel very fortunate to have been given that advice at the time and can assure you it does work. After all these years and speaking to many caregivers I've noticed most receive very little support or guidance. They've never received any training to be a caregiver and were not in many cases ready to take on this challenge put upon us. Some

may have physical challenges of their own.

After our survivor comes home, we are suddenly supposed to be caregivers, homemakers, cooks, maids, taxi drivers and so on. Most of us try to do it because we care for the person, we are helping but the emotional and physical stress put upon us can sometimes be overwhelming.

After my wife's time in the hospital, she regained strength and understanding, and we knew of her abilities and disabilities. We arranged the house and made everything accessible for her. Once home my wife and I talked about how she can contribute with the daily functions of the home. She was at first able to help me by explaining how to cook, do the laundry, cleaning etc. Although I did learn before she got home that didn't matter. The point was it made her feel wanted and useful. A lot of this was part of her recovery. Also important to her learning daily activities was that I still had to go to work, and the kids had to go to school. There were times she would be alone. I did make a career change that allowed me more time to be with her during the day until our kids got home. We did everything necessary to move forward.

Looking back, I feel lucky that we figured it out, through trial and error and with the advice I received. I have met a lot of caregivers that weren't so lucky. Back then, the support available was limited and so was the know-how for caregivers and survivors once they went home. Today there are support groups, lots of help and information from very knowledgeable and caring people, but they need to be aware of them. When Sandie and I moved into this region the first thing we did was search out a support group. We found the Community Care Group for South Hastings. They have put together a tremendous support group program for survivors and caregivers. I recommend them very highly. There you will receive a lot of information and guidance to help you move ahead. You will receive a lot of support and most of all meet people who are going through the same things you are. Being able to meet and talk to people who are experiencing the same challenges as you is a huge benefit.

With time it did get easier for my wife and I, we developed a schedule and system that works for us, and we are now not along with the support group. My wife and I work together and support each other. She also knew I was learning to be a caregiver and knew I needed time to relax and re-energize, it wasn't always about her but about us. Yes, that advice I received worked for us and will work for you also. It was invaluable. My wife and I supporting each other was also invaluable.

In conclusion, most if not all the people put in the position of becoming a caregiver do not have that support or advice. But they need to be recognized for what they are about to take on and given all the support and guidance necessary to succeed. If everyone took a look at themselves and saw what it would be like to suddenly be confronted with such a challenge and then visualize what they would require for support, you would realize the overwhelming challenge it would have on your life. Remember no one is immune to having this thrown upon them and it can as you know happen at any time.

As caregivers, we know that today with the COVID 19 virus it is not easy for anyone. As healthcare workers I tip my hat to you all and feel for you.

But it will one day pass but as caregivers it is here for the long term, and we do need your support and understanding. One thing I would suggest is that every survivor and caregiver be given a name and number of a support group to call upon leaving your care. They are definitely going to need it.

Thanks.