

This is my story of how the computer and being on-line has made a difference to me. Being on-line has helped me keep my sanity at times and is probably the single most reason I keep myself active, brain active, that is. On-line service is more important to disabled people who can access it more than able-bodied people will ever know. I've met hundreds of super, disabled people on-line. The Internet allows us to meet, from all over the country, and sometimes the world. Many of us would not be able to make this trip without this cyber travel. E-mail, message boards and Internet chat groups have become a way of life for me now. I turn on my computer each day and have a routine where I check each and communicate back accordingly.

Stroke affects many people's cognitive skills but I was lucky this was not the case for me. I am quadriplegic but I sometimes think that having my cognitive skills intact has made it a worthwhile trade off. I don't mean to imply that other stroke survivors can't think for themselves but I don't have to deal with some of the cognitive problems that others may have. I will try to explain how my life has changed and how I have found a way to continue to feel productive.

My stroke occurred on June 20, 1994 while I was in France on a business trip. I spent two weeks in acute care in France and then four more at a hospital in Washington D.C. I was then moved to one in Baltimore for rehabilitation. I spent two months there. My doctors tried to prepare me for the worst condition of recovery. I had quadriplegia, couldn't speak, and had to receive liquids through a stomach tube. I also had many other symptoms associated with quadriplegia. I couldn't believe that my once promising career was being replaced with this life style.

Four days before I left the rehabilitation hospital, very minor movement started returning. I was still discharged on time so I continued therapies as an out-patient. I continued to make progress but it was extremely slow. At home, in my leisure time, I was starting to use the computer. I had regained enough movement in my left arm and hand that I would slide the mouse around and click when I wanted. I was rigged up with a Plexiglas lapboard which rests on the arms of my wheelchair. The mouse pad is placed on the lapboard in front of me and my hand is then positioned on the mouse. I could move the cursor to wherever I need to go on the screen.

I type using an on-screen keyboard. My on-screen keyboard has "word prediction" so that I only have to type the first letters of the word. My keyboard displays a list of words that begin with those

letters. I then click on my word. This software speeds up my typing significantly. I usually type fast enough that I can go on-line and keep up with chat groups without being noticeably slow. My on-line playing games became a way to supplement my therapy life. When I wasn't at therapy you could almost always find me on the computer, often on-line.

Sometime in early 1995, I discovered a message board for stroke survivors so I made a couple of posts there. Pretty soon I was contacted about joining an on-line stroke support group. The members would write each other letters of support and meet every two weeks in a chat room on the Internet. I really wasn't interested at first.

After receiving these emails for several weeks, I decided to look into what this group was about. I found out that many of the members knew little about how to use the computer. My computer skills were relatively good so I offered my technical help. I would answer questions about how to use the computer. Sometimes, I wrote about how to use the Internet. I must have written 30 or 40 plans. I would mass e-mail one per day. They were very well received and appreciated. This motivated me to want to be more involved. Several members of our small on-line stroke support group eventually began discussions that we needed to have our own "web page." There was a lot of e-mail being circulated about this issue within our small discussion group and it soon became painfully apparent that no one knew how to make a web page.

Finally, I said that I would try (I had no idea of what or how I would do it). I did pretty extensive research using the Internet as a reference. Soon, I had learned enough that I made one web page. I visualized many ways for expanding it into a larger website. Our support group started actively corresponding with each other by e-mail with links to other websites with information about stroke.

We soon realized that the links were growing and someone would have to organize them. I felt obligated to do this because I was making the website. I had the basic structure of the website mapped out all in my head. The website started to grow. Ten, 20, 30, 40 and finally 50+ pages. This of course didn't happen overnight. It took about six months. I'd like to say that as the "webmaster" for that site it kept me extremely busy. There were updates to do almost daily. Adding a new link that someone found. We were all proud of our web page. It reflected what many of us collaborated on.

I also learned that making your website known on the Internet is very important. It must be advertised so people will know it exists. Well, I set out to do this too. I advertised it as much as I could on all of the major search engines. The Stroke Network was listed by US & World Report as one of the top 5 websites for information about stroke! We have stroke survivors and stroke caregivers registering with us from all over the world.

Our web page has recorded well over 100,000+ hits, or visits, on its counter since May, 1996. To date, it has been visited by over 100 countries. Our tiny on-line stroke support group was incorporated in 2000 and became a 501(c)3 non-profit charity organization in 2001. We are known as The Stroke Network.

Our website is located at <http://www.strokenetwork.org/>. It was actually the very first on-line stroke support website on the Internet. I am the Founder, President and CEO. We have about 40 volunteers on staff. At last count, we had over 12,500 registered members. We add over 1000 newly registered members each year. The Stroke Network grows in numbers every day.

I hope you can see that there is life after disability. The computer is certainly one way this can be done. Don't ever give up on yourself. My disability is from stroke. This is just one disability of many. Where there is a will there is a way. Almost 20 years ago I would have never believed I'd be doing what I'm doing now but I love it. You couldn't pry me away from my computer no matter what. I even don't mind being disabled. That may seem hard to believe but I have my reasons. Spending time on the computer, on-line, has helped make living with my disability more manageable.

If you get the chance to use the computer, I recommend it.

*Well, that's about it. I feel very productive doing these things. **One thing is for sure...I may be disabled...but on the computer I'm practically able bodied again.***

Footnote: Around 1997, I had to change my method of typing because I was doing so much of it! It was not uncommon to see me on the computer 12 – 14 hours per day, 7 days per week. I found that other, much easier methods of making the cursor move than sliding my arm around on top of my lapboard were available. I began using an infrared head pointer instead.

This was 100 times easier and lightning speeds faster! I just had to move my head and wherever I looked on the computer screen the cursor automatically moved. Gone were the days of my arm getting totally worn out from me constantly pushing it. My shoulder muscles do not work so all of my arm movement was caused by my arm's bicep and triceps

muscles. My determination and willpower kept me typing but it was becoming more and more difficult to type for long periods of time every day.

I also wanted to mention, how much my faith in God has played such an important role in me being able to accomplish what I have. Due to health issues, I lost all ability to move my limbs. Basically, the only real movement I retained was my head control, which allowed me to move the cursor and one finger, which allowed me to click the mouse. These two movements are all that is necessary for me to be able to use the computer and type whatever I want.

I have been using this method for over 15 years! I am so thankful for what I CAN do! It is not much but is just enough that I can still work at my non-profit organization and on our website. My point is that God definitely had a plan for me. *I feel that all my work has been inspired by God! God is awesome!*