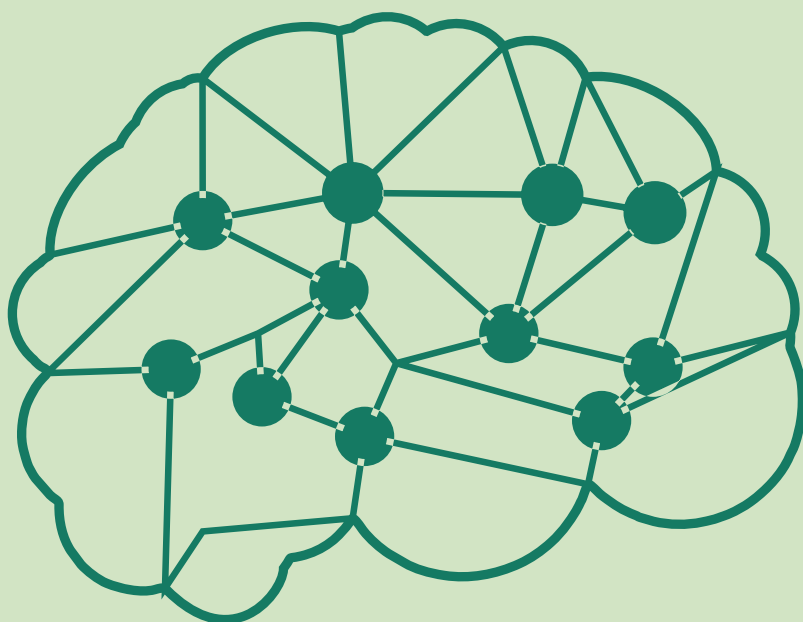


University of Vermont Medical Center's

# STROKE STORIES



**Stories and Resources for Stroke Survivors  
and their Families**

Compiled By

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## INTRODUCTION

Every 40 seconds someone in the United States has a stroke. This leads to more than 795,000 people a year being affected by stroke. The effects of a stroke vary from person to person based on the location and size of the area of damage in the brain. The effects can range from weakness in an arm or leg on one side of the body, balance issues and speech and swallowing difficulties, which lead to difficulty with completing normal daily activities such as walking, talking, dressing, and eating.

Just as the effects of a stroke vary from person to person, stroke recovery also will vary. It is hard to predict how many abilities a person will recover as well as how soon that will happen. Successful stroke rehabilitation depends on a variety of factors:

Physical factors: Severity of your stroke

Emotional factors: Motivation, mood and your ability to consistently complete rehabilitation activities outside of therapy sessions

Social factors: Available support from family and friends

Therapeutic factors: Starting your rehabilitation program early and having a skilled rehabilitation team

While the rate of recovery is generally the fastest in the first few weeks and months after stroke, there is evidence that function can continue to improve even 12-18+ months after a stroke. The journey of recovery from a stroke can be frustrating and feel long at times. Your continued dedication and willingness to try activities in new ways will help you to gain the most benefit.

We have put together this booklet to share the journeys of some local stroke survivors to provide you with some insight about what your journey may look like. We also want you to be inspired with hope and encouragement to never give up on finding ways to do the things in life that give you joy and purpose. This is a new world that has opened for you, and you are not alone.

## **Tom - “The central part of me is intact.”**

Tom was a project supervisor for a building company. In 2013, as he was eating lunch with a coworker, he noticed his vision was changing, but didn't think too much of it. Five minutes later, he said, he was reaching up for a piece of staging and fell down to the ground with an ischemic stroke in his left carotid artery by his left ear. He was rushed by ambulance to UVM where he received TPA.



Around 10pm that night, he had another stroke and he ended up spending time in the ICU and Neurology floors. He was comatose for a while as “lots of drugs were coursing through his days and nights.” Finally he was moved to Fanny Allen for inpatient rehab where Tom received Speech and Occupational therapies. He recalls, “the oddest thing for me was waking up in the morning looking out the window and having no thoughts.” He spent about a month at rehab.

After coming home with aphasia, he felt angry and “it felt so strange, baffling, and different.” He kept working at therapy, both at Fanny Allen and at several programs that specialize in aphasia. He went to the Ann Arbor Aphasia Clinic, Northwestern University, and also a month of therapy in St. Petersburg, Florida.

Eight and a half years later, he is normalizing his speech pattern and has no paralysis. He uses speech to text features and has been able to use AutoCAD again (the knowledge of which left him after the strokes). He wants people to know that there is a network of stroke survivors out there to connect with and share resources with. His wife, Heather, says don't accept no from insurance companies. Keep fighting for the care you need and ask for help from doctors to write letters expressing why whatever you need is important.

Finally, Tom says, “Throughout my recovery, I am changing a little bit at a time. I have aphasia to deal with from here on out, but the central part of me is intact.” He believes it's going to get better and better. He finishes with, “Life goes on, man!”

## **J - “Reading Dr. Seuss books to the children aloud was valuable extra speech therapy!”**

On a fall Saturday morning in 2017, J noticed that he was unusually tired. The previous evening, the back of his head throbbed with a severe headache, but it seemed to have cleared up overnight. Shortly before noon, however, J became groggy and felt heavy. He took a short nap, but, when he tried to get up from his bed, he slid down to the floor. For most of the rest of the day, he slipped in and out of consciousness. When, that evening, he was discovered and EMTs were called, he understood them clearly and responded directly to their questions.

J was living outside of Vermont then, and was taken to a local hospital. He was diagnosed with a hemorrhagic stroke that dissected the right carotid artery and that affected especially the right side of the motor cortex.

J spent a week in an ICU, and two weeks in a shared room under close observation, before he was transferred, “to an in-patient rehabilitation center,” where, he says, “the long, slow, comprehensive recovery really began.” “I was a wreck,” he adds. He spent nearly three months at the center, before coming home and undertaking daily hygiene, cooking, and moving safely about in familiar spaces. Unexpectedly, he discovered that reading Dr. Seuss stories to his children was valuable speech therapy!

Today, he's glad to independently take care of his bathroom and hygiene needs, and he enjoys preparing, sharing, and savoring meals. He gets outside safely (when conditions permit) to grocery shop and do other errands and to get light exercise. And he closely follows (and encourages) his children's progress at school.

J didn't know that stroke survivors are at risk of epilepsy--which he also discovered unexpectedly--and manages through medication.

He is greatly inspired by, “people who recover heroically from a stroke or who, despite a different catastrophic health setback, manage to accomplish significant feats.” These include Sharon Stone, who--after a massive stroke--continues to raise her children and has acted professionally again; triathlete Matt Long, who after a devastating accident, completed another triathlon, wrote a book (*The Long Run*), and married; and Christian Streiff who wrote a book (*Un homme pressé*) about his struggle to recover, which was adapted into a successful movie. There are so many other inspirational stories, which leads J to say, “After you conclude your therapies, maintain your recovery level while--always—setting and working toward new goals. (Doesn't matter how modest or ambitious they are.)”

## Rachel McKnight - “Never give up!”

Rachel had just successfully battled leukemia seven months earlier. On a February morning in 2011, she got up as usual and began her day, getting dressed. She was unable to fasten her bra strap, but after assistance from her husband, Ted, she went about her day. Around 3pm, she was sitting on the couch, feeling fine, and Ted went out shopping. At some point between then and when Ted returned at 5pm, Rachel fell to the floor from where she had been at the computer. She tried to crawl to the phone in the next room, but made it as far as the hall when Ted found her.

Rachel had a hemorrhagic stroke in the sagittal vein which bled into the left side of the brain. She remained in the ICU, intubated and on a breathing machine, at UVM Medical Center for 21 days, followed by an additional 7 in the regular hospital before the doctors decided she was strong enough and ready for inpatient rehab.

She spent 5 weeks at Fanny Allen for acute rehab. “I could do nothing on my own while in the ICU. At Fanny Allen, at first, I could not talk, could not get in or out of bed or walk. I had to get from bed to wheelchair using a lift,” Rachel remembers. She received Physical Therapy, Occupational Therapy, and Speech Language Therapy which she continued over the years. She also found specialized aphasia programs which she has participated in, including at the University of Michigan.



When Rachel first came home, “it felt good to be home,” but there were many changes that had to happen. They built a ramp from the garage into the house as well as moved the bedroom downstairs for the first 18 months. But she has remained active and finds fulfillment “being alive and being a mother, a grandmother, and being active biking, skiing and kayaking.”

Rachel realized early on that she was going to be okay with this new normal, even if she couldn’t use her right arm and leg. She says, “Never give up hope. Never stop looking for the next thing that might improve your condition of life. Never give up!”

**Ted - “There is always hope for a brighter day ahead.” (A Caregivers Perspective)**

When the stroke happened and the severity of the situation was sinking in I decided to do whatever it took to take care of Rachel, my wife, and make her life as normal and comfortable as I could. I dedicated my life to her wellbeing and care. After three weeks intubated in the ICU, I first advocated for her to go to Acute rehab vs. subacute and that turned out to be a great choice. Cannot say enough for the PTs, OTs and SLPs at Fanny Allen acute rehab. That lasted five weeks. Meanwhile at home I built a ramp to get into the house from the garage. Moved the bedroom down stairs where we lived for 18 months after she came home in a wheelchair. During that time, we added two railings to the stairway and modified the upstairs bathroom to include a bench and shower controls that she can adjust from the seat. Once home she continued outpatient OT, PT, and SLP. We found aqua PT at the Rehab GYM to be the best fit for her needs. She continues to do PT today as an outpatient at Momentum PT.



My goal, and hers, was to get back to doing things she did before the stroke. With the help of a fellow quilter, she learned how to quilt again using only her left hand. She also taught herself to write with her left hand. She was right-handed. As a skier she wanted to return to the slopes.



We found Vermont Adaptive Sports at Sugarbush to be the answer. As a bike rider we then found Anja, at Rad Innovations, who introduced us to the Hase Pino tandem bike. A tandem that we could ride together. While at the Rehab Gym we met Cathy Webster, PT, who was exploring adaptive Kayaking. As a result, I modified Rachel’s own kayak and made that a big part of our summer activities along with the biking. The skiing, biking and kayaking have let Rachel enjoy some of the activities she did before the stroke. Maybe more importantly, these activities allowed her to join social groups as before the stroke.

I have continued to do whatever is necessary to make all these activities happen and try to make Rachel’s life as productive and successful despite the effects of the stroke. We both have the belief that anything is possible. You have to have faith and hope that the new life is as successful and worthwhile as possible. Rachel is the mother of two daughters and grandmother of five grandchildren. We connect with them as much as possible and that provides a great motivation for both of us to keep going. We are always looking for the next opportunity for a challenge. There is always hope for a brighter day ahead. Keep your eyes open for options and opportunities.

Personally, I take time for exercise and sports that I am interested in. I feel that it is vital to stay physically strong and well in order to provide the support and care for my wife. NEVER GIVE UP!!!

### **Chris - “Time to medical attention is crucial.”**

In January of 1996, Chris was sitting on his bed. As he fell off, his wife, Tammy, ran in and called 911. Chris was brought to Porter and then transferred to UVM Medical Center where he was diagnosed with a stroke from a blood clot in the carotid artery. He could not receive TPA due to an inherited disease that causes malformations in the blood vessels.

Chris spent a long time in the hospital and was then transferred to inpatient rehab. He found Physical Therapy to be particularly helpful. He struggled when he realized how bad things had been for him and that he had almost died. As he moved out of inpatient rehab, he “was really gaining after the first stroke when I had a second stroke in 2017.” But he continues to “get up and around” and attends Project Independence during the day which helps him be active.

Chris emphasizes that the amount of time before a stroke victim receives medical attention is crucial. He also found the book, *One Handed in a Two Handed World*, to be particularly helpful during his recovery. He says, “The gains are never fast enough. They feel very slow. I don’t have a lot of patience.” But he keeps on going!

### **Bob - “Sense of humor”**

Bob’s stroke was in 2000. When they first called the doctor when something wasn’t quite right, they said to hold off on coming in, because he had a history of migraines. Instead it was a stroke, and he spent 3 weeks in the ICU followed by an additional week at UVM Medical Center.

After that he spent 3 months at Fanny Allen for inpatient acute rehab as well as an additional 4 months at Riverview in Cambridge. Bob continues therapy through his VA benefits at Fanny Allen.

Today, Bob will remember working with tools and want to use them again, so his wife, Dianna, will hide them. He uses a 3 wheel bike as well as takes part in the adaptive kayaking program and takes walks on the road.

Both Bob and Dianna say a sense of humor is so important and to make sure to advocate for yourself with doctors and for things you need.

**Marigrace Manz - “And I can do a lot.”** (story told in her own words)

If you are a stroke patient at UVM Medical Center you are very fortunate. This is where you belong. You are getting excellent medical care, and almost as important, you will be cared for by kind and caring people.

Sunday, August 15, 2021, I suddenly developed a sharp headache, nausea and pain behind my right eye. I’ve had headaches but nothing like this. Luckily, I was only a mile from the UVM Medical Center in Burlington and was rushed there as it became apparent something very different and scary was happening. I had no idea blood vessels in my brain had ruptured.

A long journey was just beginning.

I have almost no memories from my 3 week stay in the hospital. Initially I had the mental and physical abilities of a newborn baby. I couldn’t recognize my family, speak, or respond to commands.

Typically, the bleeding is treated, the rupture heals, and recovery begins. My bleeding was too severe, so none of the treatments could control it until my body healed the rupture. As a last resort, for the doctors and my family, the decision was made to remove the part of my skull near the bleeding to relieve the pressure.

The day after the surgery, I began my recovery. Every day I made progress. I could recognize my family, speak a little, still bedridden but so much better than before the surgery.

After about a week, I was approved to begin acute rehab at Fanny Allen. “Where the magic happens”. Everyday, every therapist challenged me. How much could I do? Could I do more than yesterday? The simplest tasks were almost impossible. I felt like such a loser. If the easiest skills were so hard my old life would never come back. What was the point? Just let me go back home and live out the rest of my life in peace, please!!

I had given up on myself. For some reason the doctors and therapists didn’t give up on me. I didn’t know why. Everyone kept on pushing me until one day it dawned on me that I was making progress, and crucially, I was much better than I was when I started at Fanny Allen. Maybe I could get back more of my old life than I thought. I began to appreciate the progress I achieved since the stroke.

After about a month of therapy, I was ready to leave Fanny Allen but very sad to leave my new friends who had helped me so much.



For the next six weeks I received outpatient therapy from Fanny Allen. Progress was accelerating now. Therapy continued to be satisfying. It was clear now that my new life could be quite rewarding although there would always be some limitations. My focus now is on how much I can do, not on what the stroke took away, and I can do a lot.

The transition to life at home seemed natural. Therapy had taught me what I could and couldn't do but also how to face challenges, not to give up, and when to ask for help. It's still surprising to me how much of my old life has come back and how everyone has adjusted to the changes in my life.

At home, I can do almost everything I did before the stroke - cooking, household chores, daily exercising on my stationary bicycle for 70 minutes and 2 mile walks around the neighborhood although at a slower pace. We started traveling again - two weeks driving around Texas and New Mexico, two weeks in Las Vegas and Arizona, flying up north to visit grandchildren and staycations here in Florida.

## **Steve - "I'm not worthless."**

Steve worked 50 hour weeks in construction, ate healthy foods, didn't have high blood pressure, or any of the other indicators for stroke. There were a few times when he felt dizzy or "heavy" or had some tingling and numbness, but hours later, he would be fine, and his doctors were not concerned. He didn't know these were TIAs and a sign of what was to come.

In 2019, a week after moving to North Carolina to begin semi-retirement, Steve's left side became numb. It took him two days to admit to himself that something was wrong because he says, "it never occurred to me that I wasn't going to be able to be that guy." Doctors couldn't find anything, so he was sent home. A few days later, he awoke from a nap on the couch and "the room was spinning. I couldn't get up and I crawled to the bathroom to throw up." In the hospital, he found that every day there was a new doctor that he would have to repeat his story to, and they couldn't find where a possible stroke might have occurred. Finally a neurologist ordered an MRI with contrast which showed a stroke in the medulla oblongata. Steve was left not being able to hold a pencil or walk without a walker.

Steve was sent home to continue outpatient rehab. When he became more independent and could walk around his house using the counters, his partner packed his bags and told him to leave because she couldn't handle the stress. He drove to Florida to his sister (and acknowledges that he probably shouldn't have been driving but nobody had told him otherwise). She eventually made him leave too when she lost her job. As Steve headed north for his six month check up, not knowing where he was going afterward, a friend called him from Vermont and asked if he could house sit for a few months. He stayed and re-made Vermont his home.

Steve is very passionate that doctors need to sit down with stroke survivors and families and "lay it all out." He was not prepared for life after his stroke and didn't realize, for example, that the constant exhaustion he still feels is normal. He forces himself to stay up until 9pm.

He says, "Expect the unexpected. You're going to cry." He points out that not knowing what to expect due to lack of information from doctors opens the door to anxiety, panic attacks, and depression. He has experienced that first hand as he tries to find purpose in his solitary life. "So now I sit, alone, and watch the sun rise in the east and set in the west every day. I water my plants, feed my goldfish and think...a lot." He tries to stay busy restoring old frames, laying them with gold leaf. It allows him to be creative and delve into something new. "It occupies my mind in a productive fashion and it's occupational therapy." He is still figuring out ways to stay positive and connected to others.

Steve focuses on Stephen Hawking's message (and the subsequent song by David Gillmore of Pink Floyd) of "keep talking." Talking to doctors, friends, family, support groups, therapists... "Keep talking."

In spite of the sadness, difficulty, and loss that Steve has experienced since his strokes, he finishes with, "I may not be able to drywall your ceiling, but I'm not worthless."

### **Pablo - "Stand up, exercise your legs!"**

9 years ago, Pablo was jogging and noticed his leg was dragging. He went to sleep, and the next morning, couldn't raise his arm. When he was at Porter Hospital, they noticed his lip was drooping, and he was then sent to UVM Medical Center. He was diagnosed with a stroke.

Pablo spent two months between the hospital and inpatient rehabilitation. He had multiple therapies each day including physical and speech therapy. He fell many times because of his leg, so he would go "to the conveyor to make his leg work." When he first came home, he continued with Home Health, but no longer has formal therapy.

For Pablo, he has learned that he has to stay motivated to move and continue his therapy exercises on his own. He attends Project Independence in Middlebury "to stay strong." He says, "be patient, be careful, but self advocate. You have to stand up, exercise your legs."

### **Don - "Listen to your therapist."**

Don had recently moved to Tennessee with his wife after a long career in Vermont. He doesn't have any memory of his stroke, but he was already in the hospital after a surgery when it happened so he received medical help immediately. He couldn't walk and lost his voice.

He spent 2 months in an inpatient rehab facility. Trying to walk was so difficult, but after inpatient therapy, 6 months of home physical therapy, and outpatient therapy four times a week for six months, Don is proud to say that he "can walk now, but I have dizzy spells."

Don encourages everyone to go to therapy, and most importantly, to "listen to your therapist."

## **Bob - “You are never alone!”**

Bob was a builder and a softball and hockey coach. On November 23, 2008, four days before his 60th birthday, Bob had a stroke. He still cannot remember anything about that day, but his wife, Jennifer, recalls that Bob was in the bathroom getting ready to go to brunch. “I knocked on the door to tell him we needed to go and found him on the floor.” Jennifer immediately called 911, and Jericho EMT arrived within 5 minutes of the call.

Bob was rushed to the UVM Medical Center, where he received TPA. He spent four days intubated in the ICU, and another week in the Step-Down unit. Bob has no memory of his first four days in the hospital. Jennifer recalls that it was confusing to sit by Bob in the ICU listening to doctors, nurses, social workers, and people of faith asking questions and providing information. She remembers, “One of the ICU nurses told me this was going to be a life-long recovery and that realistically he might not have full use of the right side of his body, which I really needed to hear and it became very real.” In December of 2008, Bob was transferred to Fanny Allen Rehab where he received Occupational, Physical, and Speech therapies.

Coming home, Bob and Jennifer recall that “everything was a challenge.” They made many changes in the house to make it more accessible, including temporarily moving the bed from upstairs and taking off the molding around the bathroom door so a wheelchair could fit through. Bob continued outpatient Occupational, Physical, and Speech therapies, but only 30 sessions were covered by the insurance. This was not enough, so they hired a Physical Therapy intern to see if any more progress could be made in the use of his right hand/arm. After living in their new normal for a while, Bob and Jennifer say that “everything felt a little easier.”

14 years later, Bob finds joy in his community around him. His career as a builder and a coach created many connections throughout his community, in which he is still an active member! Jennifer recalls that, “We were incredibly fortunate to have such support from our community including meals, people driving him places, over-the-top donations to fund-raisers and much more. Since he was self-employed, we could not have made ends meet financially without this support. I hope that anyone in this situation seeks help unabashedly if they feel financially insecure.”

Finally, Bob continues to be involved in UVM Medical Center support groups and the Aphasia Choir. Jennifer states that “the best support he has gotten has been through the UVM Post Stroke Communication Group. These members and UVM professors have become lifelong friends and feel like family to us.” Bob and Jennifer encourage other stroke survivors to lean on their community through recovery. You are never alone!

## **Dale - “I am proud of what I have accomplished”**

Dale was working at Mount Ascutney Nursing Home in October 1997, when she had a stroke. She does not remember anything from the day, but she was told that she was training a new nurse at the nursing home when she suddenly collapsed. Dale received immediate medical attention, but did not receive TPA because she had a ruptured aneurysm/bleeding in her brain.

Dale was initially at Mount Ascutney Hospital but was transferred to Dartmouth Hospital right away. She spent three weeks in the ICU in a coma, and another week in the step down unit. Dale recalls, “Because I was in a coma for several weeks, when I woke up I was pretty disoriented, but I really have no memory of events for several months. My family kept a journal and that tells me what was happening.” After her time in the step down unit, Dale was transferred to a skilled nursing facility for rehab. She was in rehab for 9 weeks before she went home, one week before Christmas 1997.

In the immediate time after her stroke, Dale had many challenges to overcome. When she came home, she needed 24 hour supervision and needed to relearn everything, including how to read and do math. She was treated for depression, but then was re-diagnosed with Post Traumatic Stress Disorder. She is now taking medicine for PTSD.

In the 28 years since her stroke, Dale has worked hard to be where she is today. She enjoys her time attending Project Independence, an adult day center in Middlebury, as well as cross stitching and spending time with her sons and grandchildren. Finally, Dale recounts, “my friends helped me through this and my own determination to get better. I established goals and worked hard to become independent. I went through a GED program to relearn math and reading. I started to volunteer and pushed myself to get out and re-engage. I am proud of what I have accomplished.”

## Trent Campbell - "Advocate"

On an October day in 2018, Trent was out in the field photographing a college sporting event. On his way back to the car, he couldn't walk straight, veering in one direction. Later that day, he vomited but then felt all right again. During the night he woke up to use the bathroom and had a hard time walking there. The next morning, Trent and his wife, Nikki, went to the ER at Porter Hospital where they found evidence on a CT scan of a prior stroke. He was transferred to UVM quickly where they were waiting for him for an MRI which confirmed a cerebellar stroke.



Trent spent a month at Fanny Allen for inpatient acute rehab. When he came home, he was nervous but continued therapy, first with PT and OT through Addison County Home Health and then as an outpatient. By March, Trent had made so much progress that he was using a cane more and more instead of his walker.

On a Tuesday morning as Trent started to get ready for the day, he reached for his cane to stand up, and fell right back down on the bed. He made it to the bathroom using the walker and then went to the ER at Porter. He was admitted for observation overnight, and by morning, could not sit up without leaning to one side. He was transferred to UVM again, and after many more tests, it was confirmed to be another stroke, this time in his brain stem.

Over the next month, Trent was back and forth from Fanny Allen to the hospital 3 times. It was discovered that one of his vocal chords was paralyzed and he could not swallow safely. He developed aspiration pneumonia and was given a PEG tube to get his nutrition. Finally after an additional two months at Fanny Allen, Trent was discharged without the feeding tube!

Over the last several years since the stroke, Trent has continued therapy but also deals with severe peripheral neuropathy which has made progress challenging. He started attending Project Independence, an adult day center, and has become an integral part of that community. In 2021, he went through thousands of his photos and curated an exhibit of his work at the Henry Sheldon Museum.





Trent said he wishes he had known “how hard it was going to be to do the work (of recovery) at home.” As he continued moving forward, in March of 2022, he had another stroke. While small, he was initially discharged from Porter where it became very clear that he needed further intensive therapy. Through the work of his wife and team of doctors and therapists, he was admitted to Fanny Allen again for a two week stay.

Through all of this, Trent and Nikki have both learned how important it is to advocate for the patient and to take notes and keep track of nurses, therapists, doctors, etc. who have helped in the past because they could be the key to getting help in the future.

Trent’s doctors can’t guarantee another stroke won’t happen, but he and Nikki believe that they can still have a meaningful life and can do anything with planning, determination, humor, and hope.

**Nikki Juvan - “I found a strength I never knew I had.” (A Caregiver’s Perspective)**

At this writing, it has been almost exactly four year since our lives changed, when my husband had his first diagnosed stroke. Since that time, we (and I use this term intentionally) have survived two more strokes and embarked upon a difficult road full of ups and downs. It is one we never could have imagined being our reality after only seven short years of marriage. I have learned so much; how inpatient rehab works, the intricacies of the healthcare system, how to deal with the insurance struggles, and handicapped “accessibility” in different locations. I have also mastered enough medical terminology that a few doctors have mistaken me as a medical professional. In many ways, I feel like a different person since that day.

Being a caregiver is hard. Being a caregiver *to your husband* brings with it a new dimension. I have rejoiced that he made it through the strokes and also grieved that our marriage will never be the same. Truthfully, there are days when I don’t handle it well - I am short with him or grumpy about having to get him yet another meal or drink. But we keep going - taking it one day at a time and trying to find the joy in the little things and also the big, disgusting, or meaningful things.

When you are in the hospital, doctors and nurses are always changing, so I am the constant in all this. I am always there by his side, collecting the information, asking the questions, reminding the nurses of the details of his case. I am the one who carries the memories. I remember when a particularly negative doctor told us that he wouldn’t get much better and that he’s going to get aspiration pneumonia again. I’m happy to say that he hasn’t since that day almost four years ago, and yet I remember that conversation like it was yesterday - that lack of hope and the grim picture that was being painted for us.



I’ve come to know that I can’t live that way. I have to stay hopeful and find the strength that we both need to have to carry us through the inevitable difficulties. I have to fight the insurance company to give him more physical therapy sessions even though I know we probably won’t get them. I have to research ways for us to travel to New York City, one of our favorite places pre-stroke, and maneuver the streets without launching him out of the wheelchair on an unexpected bump. I see the world through different eyes now, and I know that to collect these stories

of stroke survivors, I may just be able to give us all hope.



But it is not easy. In encouraging me to take care of myself, countless people have used the saying, “you have to put your own oxygen mask on first.” I’m trying. I started taking medication for depression when the grieving became too much. Though it is not something I had wanted, it is allowing me to navigate life better for both of us. I am part of a Facebook group for stroke caregiving wives, and I cherish the new community that we have found in our support groups and adult day center “family”. But asking for help is something with which I struggle, and I feel guilty when I just want to be by myself. As a way of finding new balance, my husband stays longer at the adult day center a couple of days each week so that I might also focus on the other professional and personal responsibilities that ordinarily come with living life. It is hard.



Through all of this, I have found a strength that I never knew I had. I know I am a good advocate for him. I joke that his doctor goes running when he sees we are on the appointment list because I always come with a long list of questions. When he had his third stroke in March of 2022, I was the one who noticed the slightest droop in his face and asked for an MRI to be done. The doctors kept saying there was no reason to believe it was another stroke. Even though we had to wait through the weekend for the MRI and I know they really did it to appease me, I insisted because I knew something was wrong. I didn’t want to be right, but I was. Thankfully the doctor valued my input and listened because not all of them appreciate the spouse’s perspective. Afterward I used all of our resources and connections with doctors, nurses, therapists, to get him admitted to inpatient rehab after he was initially discharged.

I am proud of what we have overcome and accomplished, but it is never ending, sometimes overwhelming, and exhausting. My advice to other spouses of stroke survivors is to take notes, reach out to community organizations for assistance, keep track of the medical professionals that you really like and trust, and stay in touch with them. Ask questions over and over until you understand the terminology and the process. Ask for help (I need to take this advice). Try to find the good in this journey and be grateful for the little successes. Pray.

I have to believe that there is good that can come from this new life, and amidst the difficulties, there has been. As I have collected these stories from stroke survivors, I have been inspired by them and truly hope you find that hope and inspiration too.

## Resources

### National Organizations/Programs:

**American Stroke Association-** this site offers many educational resources regarding stroke.

[www.stroke.org](http://www.stroke.org)

**Centers for Disease Control and Prevention-** this site offers information regarding the signs and symptoms of stroke, stroke prevention, treatment of stroke and many resources.

[https://www.cdc.gov/stroke/signs\\_symptoms.htm](https://www.cdc.gov/stroke/signs_symptoms.htm)

**Stroke Onward-** Debra Meyerson and her husband Steve Zuckerman share information about stroke and rediscovering your identity post stroke.

[www.strokeonward.org](http://www.strokeonward.org)

Stroke Across America – Deb, her husband and a few others biked from ocean to ocean in 100 days completing 4,300 miles.

<https://strokeonward.org/stroke-across-america-saam/>

**The Stroke Foundation-** this site offers information regarding neuroplasticity and stroke recovery, in addition to many resources for stroke survivors and caregivers.

<https://thestrokefoundation.org/neuroplasticity-and-stroke-recovery/>

**World Stroke Association-** This site offers information regarding stroke education and World Stroke Day (October 29<sup>th</sup>) which is an opportunity to raise awareness of stroke.

<https://www.world-stroke.org/world-stroke-day-campaign/world-stroke-day>

**BEFAST-** this site offers information regarding the signs and symptom of stroke

<https://befast.org/>

**Stroke Educator, Inc. -** Tom Broussard shares his experience with aphasia post stroke. He has written multiple books regarding his story and to educate others regarding aphasia.

[www.strokeeducator.com](http://www.strokeeducator.com)

**Aphasia Recovery Connection (ARC) -** Non-profit organization that offers programs and support for patients and carepartners with aphasia.

<https://aphasiarecoveryconnection.org/>

**University of Michigan Aphasia Program (UMAP) -** The University of Michigan offers an intensive speech-language program. Sessions run 3-5 weeks

with 25 hours of therapy each week. Some of the therapy is individual and other is group based.

[University of Michigan Aphasia Program](#)

**Institute of Neurological Recovery-** The INR provides perispinal etanercept treatment for patient's post stroke to assist with recovery of function. INR is located in Boca Raton, Florida.

<https://www.strokebreakthrough.com/>

**Lingraphica-** this site offers information about aphasia and strategies to improve communication. Also has online groups and resources for people with aphasia.

<https://www.aphasia.com/>

**Katherine Sherwood-** the following links include information regarding how Katherine Sherwood has continued as an artist post-stroke.

Articles on how Katherine has continued to produce award-winning art despite having a stroke that impacted her right hand function and how her stroke changed her art.

<https://www.berkeley.edu/news/media/releases/99legacy/10-13-1999.html>

<https://www.discovermagazine.com/mind/how-a-stroke-changed-katherine-sherwoods-art>

Katherine's website which displays her art and a disability themed art exhibition that she recently participated in

<https://www.katherinesherwood.com/>

<https://www.katherinesherwood.com/news/paloalto>

### **Local Organizations/Programs:**

**UVM Medical Center Stroke Center-**

<https://www.uvmhealth.org/medcenter/conditions-and-treatments/stroke-care>

**UVM Medical Center Stroke Support Group-** meets the first Tuesday of each month from 4-5 pm via Zoom.

Contact Becky Louko for more information at 802-847-0142 or

[Rebecca.louko@uvmhealth.org](mailto:Rebecca.louko@uvmhealth.org)

**Vermont Assistive Technology Program** allows Vermont residents to trial Assistive Technology (creative tools and strategies that help people accomplish tasks at home, school, work and in the community) at an AT Tryout Center or in their home.

<https://atp.vermont.gov/services>

**Vermont Center for Independent Living (VCIL)** supports the rights of individuals with disabilities to live with dignity in their own homes, fully participate in their communities and to make decisions about their own lives.

<https://vcil.org/>

**VocRehab Vermont Employment Services** helps Vermonters with disabilities gain and maintain meaningful employment.

<https://vocrehab.vermont.gov/>

**Age Well** supports provides a wide array of programs to enhance quality of life and improve health outcomes.

<https://www.agewellvt.org/>

**Post- Stroke Communication Group at UVM-** this is a communication group run by student speech language pathologists at UVM for people with aphasia  
Contact Sharon Cote at (802) 656-3861

**Aphasia Choir-** this group of people with aphasia meet in the spring for several weeks to prepare for a singing performance in June.

Contact Karen McFeeters Leary at (802) 864-7223 or [kmcfeeters@aol.com](mailto:kmcfeeters@aol.com)

**Project Independence-** this is an adult day program offered in Middlebury

<https://elderlyservices.org/project-independence/>

**Vermont Health Care Advocate Helpline-** this is a free resource to all Vermonter to assist with problems related to health care. They can be reached at (800) 917-7787 or via their website.

<https://vtlawhelp.org/health>

### **Sports Organizations/Programs:**

**Challenged Athletes Foundation-** help people with disabilities access a variety of sporting activities

<https://www.challengedathletes.org/>

**Green Mountain Adaptive Sports-** help people with disabilities access a variety of sporting activities

<https://greenmtnadaptive.org/>

**Northeast Disabled Athletics Association (NDAA) -** help people with disabilities access a variety of sporting activities

[www.disabledathletics.org](http://www.disabledathletics.org)

**Paradox Sports-** help people with disabilities access a variety of sporting activities

<https://www.paradoxsports.org/>

**RAD Innovations-** They produce adaptive bikes for all abilities.

<https://www.rad-innovations.com/>

**Vermont Adaptive Ski and Sport-** help people with disabilities access a variety of sporting activities

<https://www.vermontadaptive.org/>

**Thank you to:**

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Jenna Wydra and the UVM Medical Center Stroke Center

The doctors, nurses, and therapists who have been on these journeys with us

The stroke survivors who shared their stories

# THE SIGNS OF A STROKE

## Remember BE FAST

