

Patient Story

A Stroke Survivor Perspective on the Importance of Team and Never Giving Up

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INTRODUCTION

On Friday, June 25th, 2021, I suffered a "mild" stroke while meeting in my home with Sam, a window specialist from the local home improvement store. I was initially overcome by the inability to control my right hand before slumping over in the dining chair where I was sitting. My mild stroke was characterized by a difficult-to-control right arm, and motionless right leg and foot. After my stroke, I went from lying in bed unable to wiggle my toes to walking short distances with support in just under three months due to perseverance, hard work, and a great medical and rehabilitation team.

I would like to share my account of my stroke from the patient perspective, starting from discovery to treatment and rehabilitation, along with my remarkable recovery. In doing so, I hope to emphasize the importance of a team, acknowledge those that helped me along the way, especially the nursing staff, and convey the need to "never give up" and "never surrender" (words from Sir Winston Churchill, 1940).

THE BLESSING OF A WITNESS

Without a witness, often referred to as a stroke bystander, such as Sam, I would have been in a very dire, perhaps life-threatening, situation. Fortunately, at the time of my stroke, Sam instinctively knew what to do without panic or undue excitement. He immediately held me in the chair while using two cell phones - one to dial 911 (the Emergency Medical Services dispatch number in the United States), and the other to call my wife. This resulted in the paramedics and Emergency Medical Technicians (EMTs) arriving in my kitchen within 10 minutes of notification. I was urgently transported by ambulance and arrived at the Emergency Department (ED) of a Primary Stroke Center, part of the large

Integrated Medical System, within 25 minutes of the onset of my symptoms. Sam was the first of my many blessings in this life-changing event.

THE POWER OF AN ACUTE STROKE RESPONSE TEAM

Upon arrival at the Stroke Center, I was urgently attended to in the hallway near the ambulance entrance by the Emergency Stroke Response Team. This included a head nurse, and an ED Physician at my shoulder, conversing simultaneously with me and the Tele-Neurologist Stroke Specialist on the video monitor at my feet. At first, it was hoped that I had experienced a transient ischemic attack (TIA). But after having a STAT CT scan followed by an immediate MRI, it was determined that I had suffered a “mild” stroke and the decision was made to admit me to the hospital.

My first night was spent in ED, as the hospital was at full capacity due to the COVID-19 pandemic. That evening, I was visited by a middle-aged male clinician who voiced pessimism about my short-term and long-term future because of my stroke. I was immediately depressed and spent a sleepless night alone reflecting on my faint recovery prospects.

JOINING THE RECOVERY TEAM

Early the next morning, I was transferred to my regular hospital room in the Stroke Recovery Unit. There, I was visited by a woman physician, whom I believe was a neurologist, who asked the obligatory question, “How are you doing?” I shared with her my grave disappointment with the predictions from the previous night’s visit. She confidently replied, “I don’t know who this person was but let me tell you what the real prospects are for what could be potentially a full, or at least nearly full, recovery.” My hopes and aspirations were immediately inflated to a full 100%. She carefully explained what would happen almost immediately and who would participate in my initial medical treatment. This began my restorative rehabilitative journey and my further introduction to the Stroke Team approach to treatment and rehabilitation. After she left, I started to have a deep appreciation for and was impressed by the attentive and compassionate attention of my nursing staff. Two more blessings!

On admission, I was reluctant to be tested for COVID-19. The nurses had to be disappointed because they had to completely gown in personal protective equipment each time they entered my room. I quickly recognized that this was a major imposition. So, I asked a very compassionate nurse about the COVID-19 test, and her explanation displaced my fear of having my already injured brain stabbed in the testing process. She assured me that she was “very good at performing the test” and could do so without inflicting more than minimum discomfort on me. After I had the test, the results were negative; staff no longer had to put on an isolation-typespace suit just to refill my water carafe. And most importantly, I felt that I was now a committed member of my Recovery Team.

“TEAM” began to have much more meaning than I could have imagined. I could feel the incredible power of the diverse group of individuals involved in my care, each

with a specific responsibility, working in concert over obvious lines of responsibility. This teamwork was evident through each shift change and specialty visit. I marveled at the sharing of responsibility as doctors, nurses, therapists, and other specialists eagerly assisting one another to make sure I was being cared for properly. I have been around many corporate “teams” and observed the petty jealousies and back-biting that can plague such teams. This behavior was never evidenced by any member of my Stroke and Rehabilitation Teams. This brought me comfort and continued hope.

MY RECOVERY BEGINS

From the first day in the Stroke Recovery Unit, everything and everyone focused on my RECOVERY. Early on, I was being assessed for my potential for Acute Inpatient Rehabilitation. During the acute care hospitalization, I dreaded being shuttled off to a Skilled Nursing Facility to make do with whatever attention I might get. But my entire hospital stroke recovery team recognized my potential to “matriculate” from the Acute Care setting to the Acute Rehabilitation Hospital. The prospect for this special opportunity was spearheaded by the unwavering leadership of my Patient Care Coordinator, a veteran RN. Because My TEAM shared my goal for Inpatient Rehabilitation, they extended my hospital stay by two nights until a bed could be secured. This was a heartfelt relief and only added to my determination to succeed in the Acute Rehabilitation program and make my hospital stroke recovery team proud.

THE TEAM EXPANDS

At the Rehabilitation Hospital, I no longer had a private hospital room, as I was with three other patients in a four-bed room. This was unsettling initially, but I quickly realized the rationale. We all had suffered a stroke and thus shared similar rehabilitation challenges. And it provided much-needed moral support and encouragement to each of us, if only for a few days. Plus, it was obvious that the four-bed proximity made for more efficient nursing. Important, as we were at the height of the COVID pandemic.

Being a rehabilitation patient was extremely rewarding. I was playing on a new Team. The entire staff, from physicians to housekeeping, was on par with the hospital team. Everyone was courteous, caring, and highly professional 100% of the time. Again, I observed no rift between the hospital staff and the several rehabilitation specialists.

Once more, the sense of TEAM prevailed. This was especially true between the therapy disciplines. Each recognized and supported the efforts of the other and could relate to their shared goals and intentions as they related to my recovery. And the therapy team recognized and respected the job being performed by my nurses to “keep me in the game!” This team represented a new set of blessings.

MY TEAM OBLIGATION As a patient, I had to recognize that I must join a TEAM that is already in place - an Acute Rehabilitation TEAM - ready to lead me onto recovery. The TEAM would set the bar based on their assessment. The bar would be raised as I progressed. Often, the bar was high - but I was determined. My mantra became “never

give up” and “never surrender” to the stroke or any negative thoughts. I had to consciously keep up my end of the agreement. I quickly learned that I had to play my position in the team to the best of my ability, starting with cooperation. The rehabilitation hospital had a very tight schedule. There was no sleeping in. I had to take my meals and rest on time. If I was scheduled for a shower, I had to be prepared to take it on time. If I was late, I forfeited the opportunity until the next shower rotation. I learned that passing up any time to eat, rest, or relax would negatively affect my schedule and success on any given day - seven days a week. The choice was mine and mine alone.

Supporting the coordination between nurses and therapists in my daily rotation of medical care and PT, OT, and SP therapy sessions meant that I understood the plays they were calling and how I was to run those plays for my TEAM. Finally, I learned that with my returning capabilities, I couldn't wait for anyone to “get me ready” to go to therapy. I needed to be dressed, have eaten, and assembled everything I needed for my next scheduled session. I had to be ready to “head out”. As I became more mobile and able to dress, I was fully preparing myself to depart on time to therapy. Eventually, I even wheeled myself to and from therapy - what seemed to be half a hospital away. This self-help provided more time for my nurses to assist those not as recovered as I had become; or whose schedules were not the same as mine (Figure 1).



Figure 1.
*Skip Batchelder and Janette,
RN at the Acute Rehabilitation
Hospital*

FACING THE NEGATIVE EMOTIONS

I had the good fortune to deal with my emotions early in my recovery. A patient has very few defense mechanisms while hospitalized. Positive and negative emotions could be expressions or reflexes in response to the things happening around me. Emotions could help or hinder the relationship with my medical care team - especially nurses. This is especially true as nurses have the greatest contact with patients during their hospital stay. There were several emotions I had to deal with as a stroke survivor and hospital patient. Some were obvious. Others were more subtle and even fleeting at times. Here are some raw emotions I felt and my tips for dealing with these thoughts.

Loss of Control

The first emotion was a loss of control. There I was, a self-sustaining male with a Type A personality, used to getting things done quickly and effectively. I had never experienced any deep dissatisfaction with the function of my body or mind. I seemed, most often, to deal successfully with my emotions and, most of the time, those around me. Then my world suddenly and unexpectedly changed. I lost control of nearly everything in my life. Yet, I still had a full deck of emotions. Some emotions, like those keeping me awake in the

ED that first night, had to be suffered alone. Frustration in making a simple shirt button function could be another. Some emotions, like fear and anxiety, could be shared. And only occasionally could they be observed by my medical care team. I had to learn how to deal with things I couldn't control directly. I did this, in part, with the help of my nurses.

Panic and Fear

Retaining my cognitive abilities at the time of my stroke prompted me to immediately be worried about my short and long-term prospects. This is where the ED Team excelled. My greatest fear during the ambulance ride was the prospect of being stacked with the other patients while the clock was ticking. My fear was reduced to near zero by the incredibly rapid and cohesive assembly and actions of the ED staff. The huddle of physicians, nurses, and technicians around me, joining in my examination, was reassuring and settling at a critical juncture. Having truthful but hopeful information also helped to address my initial fears.

Disappointment

As early as my arrival in the ED, my first true feelings were:

“Oh, why me?”

“What did I do to deserve this interruption in my life?”

“ Why do I have to endure this alien setting? I just want to go home and be in my own bed!”

“You mean I won't be better in a few days?”

I found the best way to combat disappointment is to firmly establish what has happened, how it happened, and what can be done to begin charting my unique course to recovery. Learning how my stroke likely came about was the catalyst for understanding that my situation could get better, so long as I was willing to take to heart what changes would have to be made in my patterns and routines to not only achieve recovery but to stay in recovery and hopefully prevent another stroke. This catalyst was fortified with every single shift change of my nurses.

Impatience

On reflection, impatience seemed to be the emotion I experienced most. This was often with me, my situation at the moment, and, unfortunately, those trying to do their part to help me. The professionalism of my medical staff helped me to anticipate when I might develop an impatience that I could control if I was paying attention.

Frustration and Annoyance

Frustration can be the seed of so many other negative emotions. The stroke made the familiar unfamiliar. Frustration with the remnants of a stroke became the seedbed of many annoyances. I found dealing with annoyance to be a constant battle. Most often, I was annoyed with myself, which could quickly be projected onto those around me. “Why don't these people see that such things upset me !” “Why is it taking so long to do?”

Loneliness

I was truly blessed to be surrounded by family, friends, and neighbors from the very beginning. Those finding themselves alone in their recovery will need to be so much more resilient and courageous. Your emotions will likely be more difficult to share and communicate when the opportunity arises. Be inwardly tough and outwardly gracious, and things will be better.

POSITIVE EMOTIONS

Left unattended, negative emotions can get in the way of successful recovery. Positive emotions are equally important and should be celebrated and shared. Fortunately, there are positive emotions that can counterbalance the negative feelings experienced in hospital and home recovery. Positive emotions were the buoys that charted my course to recovery.

Pride

Pride is the emotion that propelled me along my course to recovery. Sometimes, it was small achievements. Sometimes they were huge, like qualifying for Acute Rehabilitation or showing my therapist that I could handle the “tough stuff.” And can you imagine the pride in wiggling your toes or finally being able to button a shirt? Pride in my progress was a great reward and one that was shared by my nursing staff.

Confidence

Confidence may be the strongest emotion of all. Doses of confidence are the building blocks of recovery. Stacked, one on top of the other, you will be able to see over your difficulties and into the next level of potential achievement. My nurses came to recognize my confidence, which made their day stronger, as well as mine.

Gratitude

I have had so many things and persons to be thankful for in my recovery. Gratitude is maybe the most important emotion I experienced in the hospital. It is not solicited; it is given. A gift! It is now my mission to give back. This includes sharing my story so that others can benefit from my experience and my work as a stroke peer navigator and stroke prevention advocate.

SUMMARY

It was an honor and a privilege to have been nursed and cared for by a team of medical professionals that inspired me to BEGIN my journey to recovery with my pledge to stay on that path. My acute hospitalization was filled with fear and apprehension for circumstances I had never faced. However, this period of hospital care was dotted with small islands of hope and encouragement, many of which were delivered by my faithful nurses. Things like a fresh carafe of water, making me more comfortable, being extra

Careful with injections, and ensuring my vitals remained safe, may become so commonplace that you might not think them important to me as a patient. But to me, every small task is extremely important. It's because even as they are routine, you deliver them with consistent compassion and appreciation for what I am and what I will be going through as I struggled to come to grips with a period that was new and uncharted in my life.

This experience taught me that the two most powerful words are “**thank you!**” I came to know that when I sincerely spoke those words to my nurse, med tech, or housekeeper, it was a validation of my respect for the duty and initiative they were delivering to me at that precious moment in their very busy schedule. Eventually, these small islands of compassionate service in my struggle to recover would come together to form the solid ground on which I, and my entire Critical Care Team, would build my stroke recovery.

There seems some reverence among nurses and other members of the healthcare team for the “miracles” that might be achieved when one of your patients is allowed to advance their recovery in Acute Rehabilitation. It's true; what can be achieved is nearly miraculous. But it is also true that patients arrive at Acute Rehabilitation already inspired by and respectful of the power of critical care nurses as they do their part to ensure the potential for these miracles.

My message to the nurses of all Critical Care Patients is “Have faith that among the thousands of acts of seemingly routine nursing, you will very often stand on a Little Island alongside your patient while performing a service whose significance is only recognized and appreciated by that patient . . . even while you modestly, and professionally, perform your compassionate duty.” Thank you for seeing the miracle in me and the many others under your care.



Figure 2.
Skip Batchelder and staff approximately 1 year post-stroke

Author Bios:

Dan "Skip" Batchelder: From his Stroke event and throughout his recovery, Skip has endeavored to find ways for Stroke Survivors to accelerate the several phases of their Stroke Recovery, including the specific knowledge of the recovery process and early filing of benefit applications. Plus, the importance of avoiding fall risks, plus being committed to exercise and proper nutrition - all aimed at avoiding a second stroke. His efforts, aided by his new healthcare colleagues, have resulted in the creation and promotion of StrokeAngel.Org.

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