

My Stroke Journey²

From Stroke Sufferer to Stroke Survivor
(The Things I Learned that Helped Me Along the Way)



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MY STROKE JOURNEY AND MY NEW LIFE

Contents

- Reasons for Writing this Second Article 5
- My Story 6
 - Stroke Number 1..... 7
 - Aphasia – My Experience 7
 - Stroke Number 2..... 8
 - Anxiety 9
 - Stroke Number 3..... 10
 - Stroke Number 4..... 10
 - Depression 11
- Did you know? 13
- Stroke 101 13
- Physical and Mental Effects of a Stroke..... 14
 - List of Physical and Mental Effects of a Stroke 15
 - List of Physical Effects (including Sensory and Perceptual Effects) 16
 - List of Mental Effects 16
- 6 Steps of Stroke Rehabilitation 17
- “Mistakes” Stroke Survivors Make 18
- Things not to Say to a Stroke Survivor and Why 19
- Things You Can Do to Support a Stroke Survivor 20
- Ways the VON (Victorian Order of Nurses) Supported Me and other Stroke Survivors..... 20
- Reality Check..... 21
 - Grieving..... 22
 - Letting Go..... 22
 - The Importance of Setting Boundaries 24
 - Setting Goals and Priorities..... 25
 - Adaptability Quotient (AQ)..... 26
- Stroke Survivor vs. Stroke Sufferer 27

MY STROKE JOURNEY AND MY NEW LIFE

Wound versus Scar 28

Rehabilitation Choices 29

Interprofessional Stroke Rehabilitation Team 29

Things a Survivor Would Like You to Know 31

Circle of Friends 31

Things I have Learned Along the Way..... 32

Final Thoughts..... 32

Acknowledgements..... 33

How can you Support..... 34

References 35

Reasons for Writing this Second Article

The reason I wrote my initial article was because of the way I felt after my first stroke. I was completely lost and had no idea what or why I was feeling the way I did. I remember desperately looking for something that I could read to help better understand what just happened to me and what I could possibly expect next. I needed something written in a straightforward manner by a fellow stroke survivor. Something that I could relate to. I wasn't looking for a guide, more of an example, to show me what they did to start and get through or out of the hell I was in. Equally important, to let me know that I was not alone and I could get through this. My hope was that such an article would ground, educate, support, and inspire me to move forward. Honestly, I struggled to find these types of articles or any personal stories from fellow stroke survivors. As a result, I put pen to paper, and I wrote an article about my personal struggles. At that time, my hope was to provide other stroke survivors with the kind of information that I was so desperately looking for. The article turned into a helpful guide for family, friends and caregivers of stroke survivors as well.

After writing my first article, "MY STROKE JOURNEY" in November 2024, I unexpectedly had another stroke the next month, followed by a series of TIA's (Transient Ischemic Attacks). The latest stroke offered up a whole new set of issues and challenges, both mental and physical. Considering the positive feedback that I received from my first article, I felt compelled to open up about my latest struggles. Even though I touched on some of the mental challenges in my first article, you will notice more of an emphasis on the importance of mental health in this article.

As with the first article, my hope is to give the reader, e.g., fellow stroke survivors, family members, caregivers, friends, and the public, a first-person account of some of the experiences and challenges a stroke survivor could face every day.

I have had four strokes. While some of my physical and mental limitations and various associated challenges are unique to my strokes, most of the issues I experienced are universal, which many of my fellow stroke survivors had and must deal with daily. The things I would like the various readers to know:

- For the stroke survivor, I hope this article
 1. Inspires you to move past the trauma and the limitations associated with your stroke and focus on your future,
 2. Motivates you to make any necessary lifestyle changes that will aid in lowering your risks of stroke. Remember, 80% of strokes are preventable (Centers for Disease Control and Prevention, 2017). I made the mistake of

MY STROKE JOURNEY AND MY NEW LIFE

thinking that I would never have a stroke. Please do not make the same mistake that I made, and

3. Makes you realize or remember that you are not alone.
- For family members, caregivers, friends, and the public, I hope this article:
 1. Provides you with some insight, education, and personal tools to better understand and support all stroke survivors you meet in your lives.
 2. Inspires you to become an advocate by informing and explaining the realities and some of the physical and mental challenges a stroke survivor faces every day, and
 3. Makes you realize or remember that everyone's stroke is different.

Chances are, you know someone who is living with a stroke or will know someone in the future. The more we all understand how to prevent or manage strokes, the better it will be for everyone.

It is also my goal to provide all readers with a forum in which to start a discussion about strokes. Mainly, stroke awareness, prevention, education, and the resources available to stroke survivors and their families. In addition, and this is the tough one, an opportunity to have open and honest discussions between the stroke survivor and the people in their lives. More specifically, to be able to discuss the effects of the stroke, your feelings, your physical and mental challenges, and your future.

Shockingly, it is estimated that in Canada, a stroke happens every 5 minutes (Holodinsky et al., 2022).

My Story

My hope is that by writing my story, my fellow stroke survivors can relate to some of the physical and mental challenges that I have faced along my journeys. More importantly, how I tried to overcome those challenges, and learned to accept the new me. For everyone else, I hope this section provides some insight into the life of a stroke survivor and the many challenges, both mentally and physically, they may face.

My name is Dan; I am a four-time stroke survivor. My stroke journey started in 2017. Let me back up a bit, I was born with a deformed tricuspid valve in my heart. To make a long story short, a typical tricuspid valve should look like a Mercedes Benz symbol, while mine looked more like a Hyundai symbol. So, in early 2018 my valve was successfully repaired by Dr. Hamilton and his team at the Kingston General Hospital, KGH. Unfortunately, after the surgery, I developed an irregular heartbeat, called Arrhythmia, which is one of the major causes of

MY STROKE JOURNEY AND MY NEW LIFE

strokes. Did I know it was a risk factor? Yes. Did I take it seriously and change my lifestyle? Regrettably no!

Stroke Number 1

In March of 2021, it was a typical spring day, I was in my garage repairing an old vehicle and at the blink of an eye my entire world changed. The next thing I remember was being strapped to a gurney and being loaded into an ambulance. I had no idea what just happened, but I did know that I was going to the hospital and the trip was not on my to-do list. In hindsight, this first stroke was a result of living a less than perfect lifestyle, combined with a pre-existing heart condition and an attitude that it couldn't happen to me.

For the next seven months, through extremely hard work and determination, and with the assistance of an army of therapists, and the support of my family, I learned to walk and talk again. Not perfectly, but good enough to look forward to the start of my new life. For the next two years I changed my lifestyle, exercised, ate healthier, lost weight, and reduced my alcohol intake. I was doing everything I could, but I still had arrhythmia and some lingering physical limitations, including aphasia.

Aphasia – My Experience

“Aphasia is an **acquired language difficulty**. It happens when the language areas of the brain are damaged.” Australian Aphasia Association (2025).

Briefly, this is how aphasia affected me:

- reduced my ability to verbally communicate, slurred speech,
- restricted my ability to quickly understand written words, and
- limited my ability to verbally express myself.

I developed aphasia after my first stroke and it became more prominent after my forth stroke. It affected my ability to understand, read, write and speak. More specifically:

- **Reading** is now one of frustration. Mentally, it is exhausting, overwhelming and confusing, and brings on feelings of frustration, anxiety, helplessness and sadness. Now, whenever I am reading a simple paragraph of instructions; for example, reading the label of a cleaning bottle, by the time I have read, identified, and understood the fifth word in the sentence, the first word, unfortunately, turns to dust and has gone from my memory. In other words, I retain about four words. When I read a paragraph, unless there are associated diagrams beside the words, I have little chance of understanding what they were trying to explain. That is the same with everything I read. To counter act this issue I have developed a strategy where I review the entire paragraph and identify and highlight the nouns and verbs in the sentences to give me some sense of what the topic is about. If I don't do that before I read a paragraph, it is very hard for me to

MY STROKE JOURNEY AND MY NEW LIFE

recognize the meaning of the paragraph. The words would effortlessly blend into the next word and as a result, nothing would make sense.

- **Writing** is my sanctuary. Strangely enough, I cannot read my own handwriting, and when I do write something down, it is elementary. However, place me in front of a keyboard and I can hear myself again.
- When I am **speaking**, I usually know exactly what I want to say, but by the time my thoughts reach my mouth, your guess is as good as mine as to what I will actually say. For example, I will think of the word 'Hello' yet by the time it reaches my mouth and my lips move, it might sound like a mumbled hello or just a studder followed by a look of frustration.

What I found helped me with my aphasia:

1. Protecting my energy, stay rested. The more rested I am, the stronger I am, and the better able I am to handle my emotions and the associated frustration of aphasia.
2. Talking out loud, to myself, every chance I get.
 - a. It gave me a chance to learn how to talk again and get comfortable with the sound of my new voice.
 - b. It gave me an opportunity to learn how to synchronize the new way I talk with my different swallowing and breathing pattern.
 - c. More importantly, it gave me a chance to recognize the words I was having trouble with and needed to work on.

As a result of my strokes, writing has become my primary and most efficient and comfortable outlet to communicate with the world.

Stroke Number 2

In January 2024, I had my second stroke. This time my stroke happened at work. Fortunately, I was surrounded by several co-workers that knew the signs of a stroke. They placed me in a safe position and immediately called 911. Within an hour, I was in the hospital on an operating table, having a blood clot removed. Amazing!

For that reason, it's important that we all know the signs of a stroke, **FAST**, it could save a life.

FAST, stands for:

F - Face. Is it drooping?

A - Arms. Can you raise both?

S - Speech. Is it slurred or jumbled?

MY STROKE JOURNEY AND MY NEW LIFE

T - Time to call 911.

(Heart and Stroke Foundation of Canada, 2024)

Note: Stroke symptoms could also include loss of balance, trouble walking and trouble seeing out of one or both eyes.

It is important to also know that in Ontario a surgeon cannot remove a clot from your brain without your permission. Fortunately, I was able to talk (enough) to give the medical team permission to proceed. So please make sure you have in place a preset means in which to express your wishes. Strokes happen more often than most people think.

My procedure was successful. They were able to remove the clot; however, the clot did damage a part of my brain, and I developed an anxiety disorder.

Anxiety

While the effects of this stroke were hidden from the public, the personal changes and challenges related to my anxiety disorder were very clear and real to me. Again, through extremely hard work, determination, and the help of several mental health specialists, I learned about the warning signs related to my anxiety disorder and several techniques to manage my anxiety.

I must confess, I read and tried many online techniques to try to manage my anxiety. While I found some of the physical anxiety techniques helpful, these techniques were not always practical or easy to remember when needed. Strangely enough the technique that helped me the most was suggested by one of my speech therapists. While she was teaching me various ways to improve my swallowing and speaking, I had an anxiety attack. She noticed, and stopped the session and we started to talk about anxiety. Below is the technique that my speech therapist suggested that I try. It draws on your sense of smell to help refocus and reset the brain and thereby manage the anxiety. Here's how it works:

I used three Ziploc bags, one bag contained coffee grounds, one contained lemon juice and the third contained peanut butter. Three strong distinct smells. When I had an anxiety attack, I opened one bag, closed my eyes, and inhaled while concentrating on the smell. I repeated the same process for each bag. When I finished, I noticed that the three different smells allowed me to reset and refocus my thoughts. I even forgot what I was anxious about.

Having the physical bags easily accessible made it easy for me to remember this technique when I became anxious and couldn't focus on my recovery. Believe me, the hardest part was the looks and explaining to a perfect stranger why I was sticking my nose into these bags. To me, the benefits of performing this technique far outweighed any awkwardness of the

MY STROKE JOURNEY AND MY NEW LIFE

situation. For me, the real challenge, was making sure I closed the bags correctly or worse; making sure I didn't sit on or puncture the bags, throughout the day.

While my symptoms are now relatively minor, I am still technically a work in progress. Importantly, the lessons I learned were to recognize and accept the fact that mentally, I was in trouble and more importantly, I was not afraid to reach out to mental health professionals for help. Looking back, reaching out was one of the best decisions I ever made. It also reaffirmed the fact that mental wellness is every bit as important, if not more important, than physical wellness.

Stroke Number 3

In April 2024, I had my third stroke. This stroke I had in my sleep, which made my nightly trip to the washroom one to remember. I will spare you the transportation logistics, but what is important to know is that I did make it to the hospital. For two days, I laid in the hospital bed, unable to move the left side of my body. All I could think of was, why me? Lying there in a hospital bed for hours on end, not being able to move one side of my body and thinking of my future, I was scared. I did my best to stay positive. I kept remembering the stroke survivors I met since my first stroke. Their positive attitude and determination and how they accepted their limitations, setting new life goals and moving forward, were my inspiration. I told myself, "If they can do it, so can I!" I knew at that point, no matter what life had in store for me, I was going to be different, but more importantly, I was going to live.

On the third morning, as usual, the nurse asked me to move my left leg. It moved! I had never been so surprised in my life! I even teared up a bit typing out that line. A few days later I was walking around the hospital halls. It was not pretty but it did not matter. After another week, most of the effects from this stroke were gone. However, I was left with a new case of drop foot and I was unable to physically control the left side of my throat. I later learned that I was paralyzed from the Adam's apple up. The medical term for this is called Dysphasia. Again, With the support of a speech-language Pathologist, I was taught new swallowing and speech techniques, and again through hard work and determination, I was able to swallow and talk again. Swallowing is still a challenge and will be for some time. Talking, though not perfectly, is gradually improving.

Stroke Number 4

In December 2024, one month after I wrote my first Article, I had my fourth and hopefully, my final stroke. This stroke happened when I was driving. Without warning, my left hand released the steering wheel and dropped into my lap. Unlike my previous strokes, I was aware of my surroundings and was still physically and mentally alert. I knew that I was not in any immediate danger, but I needed to get to the hospital as soon as possible in order to reduce any further damage to my brain.

MY STROKE JOURNEY AND MY NEW LIFE

On my trip to the hospital, I did a quick assessment of my condition and realized that I could not move or feel my left leg and arm. I was also having trouble swallowing and speaking, similar to my previous stroke, but the physical effects of this stroke were not as severe. Although, unbeknownst to me, the most serious effects of this stroke were yet to come.

Once at the hospital emergency department, I was quickly assessed and admitted. My worries were confirmed; I did have another stroke. I spent the next few days at KGH, Kingston General Hospital for observation. Then, I was discharged and admitted to PCH, Providence Care Hospital, as an out-patient, for rehabilitation. Once at PCH, I was enrolled in several therapy programs, which were geared to my specific needs. For example:

- Physical therapy: through precise personalized physical exercises, I learned to retrain my brain to control my limbs, in order to move my left arm and leg again
- Speech therapy: through various mouth and throat exercises and techniques, I learned to swallow and speak again. Not perfect, but good enough to still be heard.
- Occupational therapist: to evaluate and treat any physical and cognitive challenges I was experiencing and prepare me for my new daily lifestyle.

Depression

Initially, I thought that the effects of my fourth stroke were only physical but quickly learned that the most serious impact was yet to come. During my time at PCH, I started to notice my thoughts were changing and I was having trouble concentrating. I was becoming increasingly unhappy. My mental changes were noticed and I was referred to and met with the resident psychologist to assess my mental health. At first, I was diagnosed with mild depression. Over the next few weeks, my depression became severe. It was no longer a momentary negative thought or feeling. My negative feelings became more intense and constant. I simply didn't care about anything. Looking back, there were several factors that contributed to my depression:

1. I was experiencing multiple TIAs and felt that another stroke was inevitable.
2. I was undergoing another series of medical tests to determine the reasons why I continued to have strokes, which was very stressful.
3. My father (my hero) was dying, and
4. A bit of a double-edged sword but through my ongoing medical tests, it was discovered that I had an irregular heart wall that required surgery. Within a month of my father's passing, I was on my way to, Saint Michaels Hospital, in Toronto to have a 'watchman' device placed, which would smooth the surface of my heart wall; thus reducing, not eliminating, my chances of having another stroke.

MY STROKE JOURNEY AND MY NEW LIFE

During this time, all I could remember was feeling like my world was spinning out of control. My thoughts and feelings were getting darker. I tried to pretend that I was doing okay so that those around me wouldn't worry about me. As much as I tried, my depression was noticeable.

Fortunately, during my darkest days, a psychologist was available to meet with me. She was very professional and reassuring, which put me at ease. She began by asking questions regarding my feelings, medical history, recent changes in my environment, and future goals. I spilled my guts out. It felt so good. Once the severity of my depression was determined, we met again. I am not an expert, but I think it was called "talk therapy." I began to talk about my negative thoughts; she identified my underlying issues and provided me with coping skills to manage those dark thoughts and feelings. Just knowing I could get out of the dark place I was in was the most important thing to me.

When I was feeling better, the things that bothered me the most were how dark my life got and how the depression came on so quickly. I didn't recognize or know how to control the feelings that were taking over my life. The following is a list of some of the things to look out for when **you** or those around you suspect that you might be suffering from depression:

Mental changes, lasting for two weeks or more (Berry, 2025):

- Not caring (trait: caring about nothing)
- No interest in usual activities
- Change in appetite
- Feeling sad or worthless
- Usually tired
- Negative feelings, and
- Difficulty focusing

Note: Saying they are "OK" when they display any of the above-mentioned characteristics is a red flag. **Don't be misled.**

Please don't make the same mistake as I did. I was fortunate enough to have mental health professionals around me to help. Know the signs of depression, so you can identify and seek help for a stroke survivor you care about in your life.

After my third and fourth stroke, I learned a very important lesson in life; the life you have in front of you is so much more important than the life you lived. Please do not waste your time looking back.

Did you know?

Did you know, according to the World Health Organization, 2022, “1 in 4 people will have a stroke in their lifetime?” While in Canada, the number is roughly 1 in 6 people (Heart and Stroke Foundation of Canada, 2024).

The stroke risk factors are many: diabetes, high blood pressure, high cholesterol, smoking, excessive alcohol intake, heart disease, obesity, family history, age, lack of exercise and so on (Heart and Stroke Foundation of Canada, 2024). What is important to remember is, while some of the above-mentioned factors are out of your control, a lot of these factors you can control. Please do not overlook them, like I did.

For those stroke survivors reading this article, remember you are now at a higher risk of having another stroke. According to Johns Hopkins Medicine, 2024, in North America, 17% of the population (over 50 years old) will have a stroke. Of that 17%, 23% will have a second stroke (or 4% of the total population). Of that 23%, 25% will have a third stroke (or 1% of the total population).

Stroke 101

Stroke 101: A stroke happens when there is an issue with blood flow to a part of the brain. According to the Heart and Stroke Foundation of Canada (2024), strokes can occur in three ways:

1- Ischemic Stroke

When blood vessels become blocked by a clot, this is known as an Ischemic Stroke. Approximately 80% of all strokes are Ischemic Strokes (Lu, 2011).

2- Hemorrhagic Stroke

When a blood vessel bursts and causes bleeding in the brain, this is known as a Hemorrhagic Stroke. Both Ischemic and Hemorrhagic strokes restrict or stop blood flow to that area of the brain. Thus, without a steady supply of blood and oxygen, that area of the brain starts to die. The results can lead to permanent brain damage, long-term disability, or death. The longer the length of time the brain is without a steady supply of blood and oxygen, the greater the severity of the damage. This is why understanding the signs of a stroke and quick medical treatment is so important.

3- Transient Ischemic Attack, or TIA

When blood vessels become briefly or temporarily blocked, this is known as a Transient Ischemic Attack, or TIA. A TIA has stroke-like symptoms, but unlike the Ischemic and

MY STROKE JOURNEY AND MY NEW LIFE

Hemorrhagic strokes the TIA does not damage brain cells or cause permanent disabilities.

In addition to understanding the different types of strokes, it is important to know which part of the brain has been affected by the stroke. To the medical professionals, knowing the size and location of the damage to the brain provides the doctor with valuable information as to what body function will possibly be affected and to what extent. This information will provide the medical professionals with a better understanding of what they are dealing with and be able to provide the best care possible to stabilize the patient and stop and/or minimize any damage to the brain.

While this section provides a high-level overview of the different types of strokes, it is important to remember that everyone's stroke is different.

Physical and Mental Effects of a Stroke

Please re-read the line above. Now, think about the fact that:

- Physically,
 - you adjusted your head to look at the page,
 - you directed your eyes and focused them on the letters,
 - your hand(s) were holding the page steady to view the sentence. While at the same time,
- Mentally,
 - you were processing and recognizing the letters in the sentence,
 - recognizing and formulating words to form a sentence, and
 - processing and interpreting the meaning of the sentence and the lines that followed.

Now take another minute and imagine not being able to do one or more of the above functions, physical or mental, and then imagine re-reading the sentence. Welcome to the world that many stroke survivors live in.

I wrote that analogue to give you some perspective as to what it is like for someone to live with the effects of a stroke. Too often, family members and friends don't see or don't want to see the effects of the stroke on someone they know and care about, it's human nature. Sometimes stroke survivors just want to minimize, ignore the changes or believe all we need is time and things will be back to normal, me included. It's less painful.

MY STROKE JOURNEY AND MY NEW LIFE

Believe me, the better informed everyone is, the better able everyone is to recognize and understand specific ways that someone is affected by their stroke. At that point, everyone can focus their energies on providing more meaningful, helpful and productive actions to support the stroke sufferer through their recovery. It is equally important to provide positive encouragement and support, with the peace of mind of knowing you are doing everything you can to help. I certainly knew when someone around me had done their homework.

List of Physical and Mental Effects of a Stroke

Below are lists and brief descriptions of some of the possible physical and mental effects on a person that survived a stroke. If you still need more information or advice, don't be afraid to ask your health professionals and providers questions. This is not the time to trust your instincts or the people you know for answers.

While there are many effects from stroke, some of the more common ones have been listed below (FlintRehab, 2024). For the record there are many great lists out there, from countries all over the world, including Canada. The reason I decided to cite the FlintRehab article was because of the way the author separated the effects of a stroke into distinct categories, Physical and Mental, with brief and clear descriptions of the associated effects. Of particular importance, was the way they further defined the Mental effects into two distinct categories, Cognitive Effects and Emotional and Behavioral Effects.

As you read through the lists, please keep in mind,

- After a person suffers a stroke, they are instantly on the road to recovery. On a journey from the old person to becoming a new person.
- Defining and describing the physical and mental effects of a stroke gives everyone a better understanding of the many ways a person can be affected by a stroke. To put it simply, it provides a road map of their journey. The real value of the road map is to:
 - Locate the sufferer's starting point (where their recovery begins), and more importantly determine the survivor's destination point (their goal/target).
 - Identify all the various routes between the starting and destination points to help visualize their goal(s).
 - Realize that the routes/roads are hilly, bumpy, under construction, filled with potholes and detours everywhere These represent some of the challenges faced along their journey to recovery.
 - The last factor, this is the tough one, the changes they have experienced from the stroke. In other words, the mode of transport they use to begin their journey, i.e., existing abilities, both mental and physical.

MY STROKE JOURNEY AND MY NEW LIFE

Before you start your journey, many of these challenges and changes will be explained and support provided to you by various therapists and medical professionals to help you do your best. Three things these professionals cannot tell you or do for you:

1. The Map does not come with a scale bar, no distances shown, so no one knows how long their journey will take.
2. The Map does not accurately describe or define your 'No Exit' roads, but they do exist.
3. The Map does not come with a gauge of your willingness to start and do your very best to reach your destination.

Your journey is not a race; it takes a long time to recover. The road to your recovery goals is dedication and consistency, not perfection. When you are having trouble don't be afraid to reach out for help.

List of Physical Effects (including Sensory and Perceptual Effects)

- **Weakness or Paralysis:** A stroke can cause weakness or paralysis, usually on one side of the body, depending on the location and severity of the stroke.
- **Speech and Swallowing Problems:** Strokes can affect the muscles in the mouth and throat, leading to difficulty speaking or swallowing.
- **Sensory Changes:** Stroke can cause changes in sensation, including numbness, tingling, or pain on the affected side of the body.
- **Vision Problems:** Stroke can lead to vision problems, such as loss of vision in one eye, or problems with depth perception or coordination.
- **Balance and Coordination Problems:** Strokes can affect the brain's ability to control balance and coordination, leading to difficulty walking or performing everyday tasks.
- **Fatigue:** Many people experience fatigue after a stroke, which can persist even after recovery.
- **Foot Drop:** Difficulty lifting the front part of the foot, which can cause dragging of the toes while walking.
- **Spasticity and Contractures:** Muscle stiffness and tightness.
- **Changes in Sensation:** Changes in feeling contact, pain, heat or cold on the side of **your body affected by stroke.**
- **Swallowing Problems (Dysphagia):** Difficulty swallowing, which can lead to choking or aspiration.

(Flint Rehab, 2024)

List of Mental Effects

(1) Cognitive Effects:

- **Memory Problems:** Strokes can cause problems with memory, including difficulty remembering recent events or facts.
- **Difficulty Thinking and Problem-Solving:** Strokes can affect the brain's ability to think clearly, make decisions, and solve problems.

MY STROKE JOURNEY AND MY NEW LIFE

- **Attention and Concentration Problems:** Strokes can make it difficult to focus, concentrate, or pay attention.
- **Learning Difficulties:** Strokes can impair the ability to learn new information or skills.

(2) Emotional and Behavioral Effects:

- **Depression:** Unable to feel positive. A constant feeling of sadness and loss of interest.
- **Anxiety:** Excessive and irrational worries and concerns.
- **Emotional Lability:** Strokes can cause mood swings or difficulty controlling emotions.
- **Changes in Personality:** Strokes can sometimes lead to changes in personality or behavior, for example anger or aggression.
- **Random or Inappropriate Outbursts:** Re: Laughing out place
- **Disinhibition**

(Flint Rehab, 2024)

6 Steps of Stroke Rehabilitation

From my experience, I genuinely believe that there are **6 steps** to successfully manage a stroke: **Trust, Listening, Learning, Practicing, Courage, and Acceptance.**

- **Trust-** As a stroke survivor you are lying on a hospital bed, dazed, confused, scared and vulnerable. This is when you must put all your trust in the medical professionals. The doctors and nurses are working around you, ordering various tests and scans, all to better understand the type, extent and location of the stroke that occurred in your brain and the probable effects: physically, mentally, or both. Remember you are the only person in the room that should not be there.
- **Listening-** You have been diagnosed, stabilized, and told how the stroke has affected you. Next, you are introduced to the various stroke associates: doctors, therapists and other healthcare professionals that specialize in stroke health. These various professionals talk to you about your stroke and the range of rehabilitation services available and tailored to your needs to optimize your chances for the best possible recovery. Your rehabilitation in hospital services could range from occupational, community and speech therapists to psychologists, physicians, and social professionals, and as you improve, a transition to home care. As the survivor progresses, the therapists will be constantly evaluating the patient's progress and providing dynamic rehabilitation strategies, plans, exercises, tests, and words of encouragement to aid in your recovering. So, this is a good time to listen, it worked for me.
- **Learning-** Now it is time to learn and understand the benefits of the various rehabilitation strategies, plans, exercises, and tests so you can achieve your best results.
- **Practicing-** This is where things get hard. Only with the instructions and guidance of the various therapists and your hard work can you become the best version of the new you.

MY STROKE JOURNEY AND MY NEW LIFE

Treat this stage of your recovery as the most important thing you can do to improve your quality of life, because it is. It is important to note, results do not happen overnight, your brain is healing and rewiring, fatigue is common, do not get discouraged. Recovery is not measured in hours or days but weeks, months, and years. Recovering from a stroke is a long process, there are no quick fixes. **Remember, if you get tired, learn to rest, not quit!**

- **Courage-** This is where you find the courage to look beyond your limitations. As a survivor you have done everything you could possibly do to recover from the stroke. Unfortunately, due to your stroke you may not be able to resume your previous lifestyle.
- **Acceptance-** This is where a survivor is courageous enough to let go of the old person they were (the pre-stroke version of themselves) and accept and embrace the new person they are (the post-stroke version of themselves). This stage does not come without grief. I will be talking about grief and learning to let go later in this article. When I was younger, I was told by one of my grade school coaches, “No one ever won a race looking backwards.” The same can be said for surviving and managing a stroke. The life still ahead of you is much more important than the life behind you.

“Mistakes” Stroke Survivors Make

- Telling people, you are okay when you are not.
- Not managing your energy.
- Ignoring signs of Post Traumatic Stress Disorder after your stroke.
- Not working through communication problems, such as Aphasia.
- Not thinking about prevention.
- Not thinking about lifestyle changes.
- Over training.
- Not exercising.
- Not eating right or knowing the importance of good nutrition.
- Not learning how to manage and control environmental and personal stress.
- Not getting enough sleep.
- Overcompensating with your unaffected arm or leg, thereby minimizing or ignoring rehabilitation on the effected limb.
- Losing your drive to recover through the tough times.
- Not practicing rehabilitation techniques on a regular basis.
- Rehabilitation training based on emotions, not strategy.
- Quitting or losing motivation.

MY STROKE JOURNEY AND MY NEW LIFE

- Not setting recovery goals.
- Not setting realistic goals.
- Waking up without a plan.
- Ignoring or minimizing Mental health issues.
- Thinking you are alone and no one can help.
- Not reaching out for help when needed.

Things not to Say to a Stroke Survivor and Why

- **You are too young to have a stroke.** Some people think strokes only happen to an older person. According to the Public Health Agency of Canada (2022), approximately 25% of strokes occur in people under 65 years of age. Another sobering statistic is that approximately “four out of every 100 strokes happen in people ages 18 to 45” (Campbell et al., 2015).
- **You do not look like you had a stroke.** Some people think that strokes only cause visible effects to the person. A stroke can occur in any part of the brain. In other words, since the brain controls every facets of the body’s functions, both physically and mentally, the effects of a stroke can be visible or invisible or both.
- **You work hard enough you will get better.** Some people think a stroke is like a broken bone or stitches. That understanding could not be further from the truth.
- **Better Now?** Again, a stroke (brain injury) is not like a broken bone or stitches. While a minority of stroke survivors recover to their pre-stroke selves, most stroke survivors must adapt and manage their post-stroke selves for the rest of their lives.
- **I know what you are going through, I get headaches and get tired too.** I am sure that person has the best intentions and is trying to relate to the stroke survivor, but trust me when I say, “Stop while you are behind!”
- **I know someone who had a stroke, and they are fine now.** Those are great feel-good stories, and I am happy for the survivor. However, those stories, to most survivors, are not that helpful. Total recovery from a stroke is rare. In fact, as a general breakdown, only 10% of stroke patients will recover almost completely (Williams, 2025).
- **Your stroke could have been worse.** Comments like that fall within the range, from inappropriate to insulting. Regardless of the extent of the individual’s limitations from a stroke, the stroke is usually traumatic and a life-changing experience. The effect on an individual is not just semantics.
- **It is too bad you had a stroke. I really could have used you for ...** Putting your needs and feelings before the survivor’s is never a good starting point in any conversation.

Things You Can Do to Support a Stroke Survivor

- Get the details of their stroke so that you have a better understanding of its effects and what the stroke sufferer is dealing with.
- Offer emotional support.
- Encourage self-sufficiency whenever possible.
- Help with the rehabilitation whenever possible.
- Stay connected.
- Be upbeat and positive.
- Do not be afraid to offer help.
- Learn the best ways to communicate with the sufferer and survivor.
- Be aware of their medications and the possible side effects.
- Listen.
- Understand and accept the changes to the stroke survivor in your life.
- Be patient and kind no matter where the stroke survivor is on their journey.

Ways the VON (Victorian Order of Nurses) Supported Me and other Stroke Survivors

This topic was hard to write about. I did not know where to start. To say that the VON (Victoria Order of Nurses) has done so much for me through the various stages of my recovery does not do it justice. With that said, here I go.

The VON and their excellent people, such as Emilia (Stroke Coordinator in Kingston, Ontario), provide in-person and online educational and support programs for stroke survivors and their caregivers, which covers a full range of stroke related subjects. Their lectures are prepared and presented by the VON and other stroke professionals, such as doctors, nurses, and a wide range of therapists, and cover all facets of stroke rehabilitation and wellness.

During my rehabilitation sessions at the Providence Care Hospital and at home, several care workers told me about the various programs the VON offered. A year after my first stroke, I attended my first in-person meeting at the VON office. Surprisingly, I was the guy that just sat quietly in the corner, not really knowing what to say or what to ask. After two years of attending meetings, I learned more about strokes and more importantly how to live with a stroke.

From that first meeting, I realized I needed to be there. The stroke related educational and support discussions and presentations helped me understand the physical and mental changes I was experiencing. In addition, it provided me with the support and confidence I needed to

MY STROKE JOURNEY AND MY NEW LIFE

better manage the effects of my strokes. Another very important aspect of attending the meeting was meeting my fellow stroke survivors. At that point I realized, I was not alone.

Today, I really enjoy the discussions I have with my fellow survivors. One of the benefits that the group offers is open and honest conversations. Usually someone in the group has faced a common challenge in their life and their advice and ingenuity as to how they dealt with that particular issue is invaluable to us all. Another take away from our discussions, besides bad jokes, is the support and encouragement we give each other. Priceless.

Over the years, I have met several stroke survivors from other support groups, from Brockville to Belleville, and their coordinator's, which I respectfully call them our coaches and supporters. Everyone, no matter what their story is or where they come from, has so much to offer.

Lastly the VON support services provide stroke survivors, like me, a non-judgmental place and forum in which to discuss our issues, heal, rebuild, and help find our new selves. Thank You!

To pay it forward, I became a VON volunteer. I can only speak for myself, but I really enjoy helping stroke survivors in any way I can and making new friends along the way.

Reality Check

At this point of your stroke recovery journey, you have been educated about the different types of strokes. You now know how your stroke has affected you. You have participated or are still participating in every physical and mental rehabilitation program available. You have done everything you could possibly do to recover. Now, your recovery, through no fault of your own, has slowed down or stopped. You did not reach the personal plateau you were working towards or hoping for. Now reality strikes.

This is by far the hardest moment in a stroke survivor's life. My thoughts turned to what used to be, what I am now and what I will be. I was scared, confused, hurt, and sad, just to name a few. Then I realized, **I will never be the same again.**

At this point, a survivor has two options:

1. Hold on to your past, or
2. Imagine your future.

I learned years ago that you can't look forward to your future, if your eyes are looking at the past. Another inspiring quote that I recently read is:

"If you focus on your past, you will continue to suffer. If you focus on your future, you will continue to grow." (Unknown).

For the record, I picked the second option and decided to let the past go and start looking towards the future.

MY STROKE JOURNEY AND MY NEW LIFE

Grieving

In order to look forward to your future, you must accept the new you. That means letting go of the old you. This is where the grieving begins.

I had to let go of the old me, that person that was able to do all those things before my strokes, so that I could accept the new me. I quickly realized I could not accept or enjoy my post-stroke life, if everything the new Dan did, or was going to do, was going to be compared to what the old Dan would have or could have done. Letting go of the old Dan was like a death in the family. I grieved.

For two weeks, I mourned, I cried, I got mad, I missed the old Dan. After two weeks of crying, I had no more tears left. When I opened my eyes, I realized I had grieved and all that was left was an empty box of Kleenex and the new Dan. It was very hard, but I knew I could not start my new life by comparing myself to the legend of the old Dan, in my mind.

To move forward with your new life, it is essential that a stroke survivor makes every effort to make peace with the old you and move forward as the new you. I can safely say, there is life after surviving a stroke. But like everyone's stroke is different, the same can be said for your future life. **Same world, new you.**

Letting Go

Writing about my journey to 'letting go' helped me so much. Having said that, this was by far the hardest section to write. Letting go involved a certain measure of grief and sadness, and grief is never easy to talk about, especially when it involves yourself.

I discovered that looking back at the previous version of myself only added to the grief and sadness and slowed down my recovery. Like they say, you **can't** change your past, but you **can** change your future.

Grieving and letting go of something you lost, is a part of healing. Healing does not have a timeline, so be kind to yourself. The healing enables you to move on. As you read this section, you may have the impression that it was not that hard for me to let go of my past. All I can say is, it was very hard to let go and it didn't happen overnight. After my first stroke, it probably took me a year and a half to let go. That was a long period of wishing for the past. In hindsight I don't know what I was looking or hoping for. Letting go of something you love is hard. It is healthy to remember your past experiences; honour your past, but don't dwell on it. Use those memories as an educational tool and move on. Dwelling on all the things you were able to do in the past, and can no longer do, is hard. It's like death by a thousand paper cuts. You have a choice on which road to take; cry, grieve, let go of the past, accept the changes, and look forward to the future or continue to look back, don't accept the changes, hold on to the past, and not look towards the future.

MY STROKE JOURNEY AND MY NEW LIFE

The benefits of letting go:

- The first and biggest one for me was, when you start your recovery journey, it takes a long time, and your primary rehabilitation goals should be; **you just have to be better than you were yesterday**. This goal is realistic, achievable and measurable. Seeing the progress that you make each day benefits the new you. If you don't let go of the pre-stroke version of yourself, there is a very real chance that you will compare your rehabilitation progress to the old you, which is not a fair **comparison** and does not benefit anyone, especially you.

The earlier you are able to accept that your stroke may have changed you, the sooner you can focus on looking ahead. In other words, it gives you more time to prepare yourself, to face and deal with any challenges head on as opposed to looking back at what your previous life was like.

- Secondly, letting go of the old you allows you to start fresh; a new beginning and a new you. You eliminate comparisons and reduce the pressure to compare the new you to the person you used to be. Just focus on becoming the best version of the new you.

The minute I came out of my brain fog and realized my stroke had physically and mentally affected me, I knew my life was going to be different. I thought of it this way, the original Dan still existed. I had to learn how to do things again, develop new abilities and utilize different tools to work with.

- Thirdly, by starting over, I got the chance to find out who the new me really is. What you are truly capable of doing and finding out how mentally strong and resilient you really are.

The reality is that no matter how hard you work towards your recovery goals, there are no guarantees that you will be successful. I am not saying that accepting the concept is easy, I've had to accept the concept four times. Trust me, it's essential to your progress, mental health, and your future. I see some of my fellow stroke survivors, years later, still having trouble accepting their physical and/or mental changes, post-stroke.

- My final reason is that I am just glad to be alive. Approximately 8 to 15 % of people that suffered an ischemic stroke, died within one year of their stroke (Brooksville Healthcare Center, 2023). I look at it this way, I survived, I was given a second chance in life and what someone does with their second chance is their decision. If you decide to move forward, please do not waste your time looking back at what was and will likely never be the same. For me, my new life is not perfect, but my strokes gave me a chance to look around and see the people and things that were and are still

MY STROKE JOURNEY AND MY NEW LIFE

important to me. Also, it gave me an opportunity to live in the present and truly appreciate what I have.

As a side note, I will never forget, during a stroke survivors group session, one of the participants asked the group to describe themselves using one word. I sat back in my chair and thought, what a great question. My honest and unfiltered reply was, 'student.' After I said that, I quickly began to analyze why I chose that word. The reason came fast. Since my first stroke I realized that all I have been doing over the past four years is learning how to redo things. It didn't hurt that I always enjoyed learning as well. That doesn't mean that I was a good student, but I was a student. You can learn a lot about a stroke survivor from that one answer.

The Importance of Setting Boundaries

Once you look forward, you quickly realize that the world is the same, you are different. This reality can be overwhelming so don't be afraid to tell people around you what you're feeling and the challenges you're facing. Remember you don't have to take this journey alone. Your family and true friends will be happy to help. I made the mistake where I thought I could merge the new me, seamlessly, into my previous environment (lifestyle). It takes time, it's not a race so move forward at your own speed. Those that care will understand. The toughest lesson I learned when it came to friends and help is that you don't lose true friends.

Some thoughts to keep in mind as you face the world as the new you:

- Your life comes with new limits and boundaries.
- Know your new physical and mental limits and don't push pass them; the new you recovers differently.
- Recovery takes energy, your energy is the most important commodity you have in your recovery. So, protect your energy at all costs. If that means putting yourself first, so be it! It doesn't mean you are selfish; it just means that you know how important your energy is to your recovery.
- Don't be afraid to set boundaries with family members and friends to protect your energy and your recovery. The people in your life that care will understand and help. Sadly, I don't remember all the people that helped me recover, but I do remember the ones that didn't.

Recovery takes time and energy. Value your time and protect your energy at all costs, your future depends on it.

Setting Goals and Priorities

This is an excellent time to reflect on who you are now, a stroke sufferer, and set some realistic goals for your future, to become a stroke survivor. These are the ground rules that I set for myself, which helped me to succeed.

1. **Why me?** - Knowing the reasons you had a stroke will give you an opportunity to ask the medical professionals for further information, advice and suggestions regarding possible lifestyle changes, which help in reducing your chances of having another stroke. This is an excellent time to listen.
2. **Acknowledge and Understand** - Acknowledging the fact that you suffered a stroke and understanding how you were affected, will go a long way in mapping out your recovery. It's a confusing time. Everyone's stroke is different. Not wanting to know or being too afraid to ask what the existing and possible future effects of your stroke are, does not help your situation. Not accepting the fact that you suffered a stroke is worse. Don't be afraid to ask health professionals for advice and guidance.
3. **Me First** - Develop a 'me first' attitude. This is not to be selfish, but to prioritize your recovery and self-protect yourself (your energy and peace of mind). The right people around you will understand and support you.
4. **Focus on your recovery** - First and foremost, your initial goal, aim, need, want, and desire must be to recover. I know that sounds like an obvious point, but trust me, after a stroke, it's easy to get overwhelmed by the various internal and external changes you are experiencing. Thus, making it hard to focus on your primary goals and recovery. Focus; think things through. It's a process, it is worth your time and effort. If you are having trouble with this goal, please don't be afraid to reach out to professionals for help. I know they helped me.
5. **Share** - Let the people in your life know how the stroke affected you, physically and/or mentally. These changes and the challenges are real, and not all of the effects are visible. The more the people in your life know and understand the ways your stroke has affected you, the better it is for everyone's peace of mind during your recovery. When you inform and educate someone about your stroke, it also re-defines the dynamics of your relationship. Once someone (who cares) sees and understands the post stroke you, you begin to clearly see their compassion and empathy for you. These people quickly become your biggest supporters and fans. In addition, putting your information out there saves you a lot of time in re-explaining things to everyone individually.
6. **Do your very best** - Develop a 'do your very best' mindset. Sure, during your recovery, you are going to have good days and bad days. That's normal. The fact is, you will never

MY STROKE JOURNEY AND MY NEW LIFE

know what ultimate level of functionality you can achieve, if you don't do everything you can, physically and mentally, to improve.

7. **Don't compare** - Do not compare your stroke or recovery to other stroke sufferers or survivors. Everyone's stroke and recovery journey will be different. To put things in perspective, to meet someone with the exact same stroke effects as you, chances are, you are looking in a mirror.
8. **Realistic Goals** - Your recovery goals should be based on consistency and dedication, NOT perfection.

The above list became the foundation and formed the ground rules for my recovery. The key, element, putting yourself first.

Adaptability Quotient (AQ)

When recovering or living your new life, your IQ (Intelligence Quotient) is helpful, but your Adaptability Quotient (AQ) is much more valuable.

"The Adaptability Quotient (AQ) is a measure of an individual's or organization's ability to adapt to change, learn from failures, and thrive in uncertain environments." (Askarov, 2024).

The ability to adapt your new (post-stroke) physical and mental abilities to complete everyday tasks is vital. As well, adapting or learning new ways to take on challenges that were once routine often involves creative problem solving.

When you think about it, many of the tasks you used to do, you can still do today. I am not saying you can do the tasks the same way, but they can be done. It may take more time or money, additional equipment or the assistance of other people, but the original task can be completed. It may not be done the way you originally were able to do it, but it can be done. Unfortunately, that is the new reality of a stroke survivor, recognizing and accepting the fact that a task can be completed, just by a different you. This is a huge stage in your journey of understanding, grief, letting go, setting boundaries, acceptance, and finally adapting to your new reality.

I try to look at all the things I can no longer do as a challenge. Being a student, I am always on social media sites looking at unrelated life-hacks and trying to figure out how I can incorporate these hacks into my life. For example, I have very little sensations or dexterity in my fingers, so threading a small nut on a bolt is a monumental challenge. My solution was to cut up one of my old fridge magnets and set a small piece of the magnet into the fingertip of my rubber glove. I am now able to pick up the nut and secure it on my finger while threading the bolt. Task completed. This simple adjustment allowed me to continue to enjoy those things that I did

MY STROKE JOURNEY AND MY NEW LIFE

before, like fixing up old vehicles. What is important to remember is not to give up on those things that you used to love to do. Try to find a workaround, if possible.

Stroke Survivor vs. Stroke Sufferer

Stroke survivor, those two words do not describe the physical and mental pain a person who had a stroke may experience and even more so, it does not infer that their stroke or journey is complete.

However, for most people that have suffered a stroke, the reality is different. They are suffering the loss of a person they remembered and loved, themselves.

I believe that when we describe a person that has suffered a stroke, we don't use the term stroke sufferer enough. The use of the word 'sufferer' describes the physical and/or mental pain someone is experiencing. Many times, when we talk to, talk with, or talk about a person that suffered a stroke we usually refer to them as and/or think of them as a stroke survivor. We hardly ever think of that person that suffered a stroke as a stroke sufferer. That needs to change. It's that important.

Knowing the difference; means everything to the person that had a stroke. The minute you recognize and understand if the person you are dealing with is a sufferer or a survivor, everything will change for the better.

The number one factor or word that differentiates a stroke sufferer from a stroke survivor is 'acceptance.' I don't mean quitting. I mean, letting go of the old you (pre-stroke) and accepting the new you (post-stroke). As they say, you can't look forward to the future, if your head is turned looking at the past. It's not easy but it is necessary that you do.

Trust me, there is a huge difference between a stroke sufferer and a stroke survivor. I've been a sufferer and stroke survivor a number of times. I've been asked on a few occasions what the difference between a stroke sufferer and a stroke survivor is. As I wrote this article, I was trying my best to put into words the difference. Relying on my own transformation from stroke sufferer to stroke survivor, I realized that there was a huge difference between Dan the 'stroke sufferer' and Dan the 'stroke survivor.'

First, there was no way that Dan the 'stroke sufferer' could have ever written this article. That version of me was suffering, hurting, enduring, rebuilding, healing, and more importantly, not surviving.

We hear it a lot where a person who was physically and/or mentally impacted by their stroke is called a survivor. In other words, you survived the stroke, you lived. But trust me, a better description is 'stroke sufferer.' To make that leap to stroke survivor, without acknowledging the suffering, feels like the hard road to recovery is not recognized and appreciated enough.

MY STROKE JOURNEY AND MY NEW LIFE

To truly understand a 'stroke survivor,' you must first know and understand the difference between a stroke sufferer and stroke survivor. This is the way I would describe and define the differences:

Stroke sufferer: A person who suffered brain damage, a stroke. The stroke affects the individual physically and/or mentally. The person is left with a new set and level of abilities and disabilities after their stroke. The sufferer is usually hurt and confused and realizes the changes to them. They begin their recovery journey, rehabilitation, and/or therapy. The sufferer will face the post stroke challenges in their lives as a new person. But no matter how much they recovered and rebuilt themselves, physically and mentally, including all the challenges they faced and overcame, they do not accept the new person they have become.

Stroke survivor: The same definition as a stroke sufferer except for the last line. A stroke survivor accepts the new person, post stroke. They have moved on and look forward to the future, as a new person.

The importance of recognizing and the difference between a stroke sufferer and a stroke survivor is huge for everyone involved. When I began my first recovery, it was told to me, and over time it became clearer to me, that people will be around to educate and support you through your recovery. However, your recovery successes begin and end with you and no one else. Other people can help and support your efforts, but they can't do the hard work required, only you can.

Wound versus Scar

In my previous article, I wrote about the wound versus the scar. The wound is very similar to the 'sufferer', and the scar is more like the 'survivor' described in the previous section. For some, the wound versus scar might feel more relatable and therefore, I felt that it was worth repeating in this article.

You can learn a lot about where someone is in their stroke recovery journey by simply listening to them and the way they talk about their stroke(s). My following assessment was derived from listening and talking to survivors about their life experiences, the way I expressed myself through the stages of my strokes and lastly reactions and feedback I received from my fellow stroke survivors. As a result, I deduced that stroke survivors fall under two categories: the Healing Stage and the Healed Stage.

Healing Stage: Usually when you listen to a person talk about their stroke in the present tense, you notice they are talking about their stroke as an open **wound**. These survivors are usually also looking for advice on how to do something that may help them to improve their recovery. At this stage, the survivor is rebuilding or functioning from their

MY STROKE JOURNEY AND MY NEW LIFE

stroke. They are looking to get back to the person they used to be. In other words, they are still healing.

Healed Stage: When you listen to a person talk about their stroke in the past tense, you notice they are talking about their stroke as a *scar*. These survivors, when asked for advice, they provide sound information on ways and techniques that improved their recovery. At this stage, the survivor has healed and accepted their stroke and has moved on. They are looking to the future as a new person. In other words, they are in the healed stage. It is worth noting as well that these people have so much to offer new survivors that are still in the healing stage.

Note: The information included within this topic was based on my personal experiences and observations, not on scientific data. However, I felt so strongly about describing the difference between these two stages because it helped me so much to understand my surroundings and myself along my journey.

Rehabilitation Choices

Most stroke survivors have basically two choices to make and one very important question to answer when it comes to their rehabilitation. Your choices, no to rehabilitation or yes to rehabilitation. No matter which choice you make, you should first answer the question, 'Why?'

Believe me, I've been down this road four times. Each time I had to ask myself, do I want to stop or go. Fortunately for me, each time I have chosen to go, and proceed with rehabilitation. My 'why' was always because I felt like I had more to do and live for.

If you choose to stop, you should still answer the question 'Why?' My hope is that once you logically, realistically, and carefully assess your reason(s), you will change your mind.

Rehabilitation programs are based on scientific research and proven physical and mental healing techniques and procedures designed to improve your functional abilities. Based on my medical test results, the team developed a customized rehabilitation program designed to optimize my recovery and stop or reduce further damage to my brain. I was also evaluated, on a continual basis, to ensure I was progressing well. When necessary, my rehabilitation program was revised and if other issues were discovered, new courses and recovery programs were introduced. I truly can't remember if my initial recovery programs had to be revised, but if they were, credit to the Stroke Rehabilitation Team because the changes were seamless.

Interprofessional Stroke Rehabilitation Team

Now is a good time to introduce the Team that is available to you. In Ontario, interprofessional stroke rehabilitation teams include a range of healthcare professionals working together to

MY STROKE JOURNEY AND MY NEW LIFE

help individuals recover from a stroke. These teams typically include nurses, physiotherapists, occupational therapists, speech-language pathologists, social workers, and may also include physicians (like physiatrists or neurologists), dietitians, pharmacists, and others depending on the specific needs of the patient. They collaborate to provide comprehensive care, focusing on restoring function, improving independence, and facilitating community re-integration.

For your reference, the following is a list of some of the key professionals that make up an interprofessional stroke rehabilitation team and a brief description of their duties and responsibilities:

Core Team:

Physicians: Cardiologist or neurologists with stroke expertise, and potentially other physicians involved in the patient's care.

Nurses: Registered nurses with specialized stroke care training.

Physiotherapists: Experts in movement, mobility, and physical function.

Occupational Therapists: Focus on activities of daily living, improving independence in tasks like dressing, eating, and bathing.

Speech-Language Pathologists: Address communication and swallowing difficulties that may arise from a stroke.

Social Workers: Provide psychosocial support, assist with discharge planning, and connect patients with community resources.

Additional Team Members (as needed):

Spiritual Health Practitioner: Offers individual support on key personal matters such as; spiritual, emotional and existential wellbeing and provides, one-on-one, forum in which to discuss an individual's present and future activities, values, expectations and leisure pursuits. In order to prepare the stroke survivor for the Journey ahead. *Important to note; this service does not represent a specific religion or faith group.*

Rehabilitation Assistants/Aides: Support regulated professionals in delivering therapy under supervision.

Dietitians: Provide nutritional guidance, especially important for stroke recovery and management.

Pharmacists: Help with medication management and reconciliation, especially important during transitions in care.

Stroke Care Coordinator/Navigator: Acts as a central point of contact, guiding patients and families through the rehabilitation process and connecting them with appropriate services.

MY STROKE JOURNEY AND MY NEW LIFE

Other Specialists: Depending on individual needs, teams may include specialists in areas like spasticity management, seating and mobility, or spiritual care practitioner.

(Heart and Stroke Foundation of Canada, 2025)

Things a Survivor Would Like You to Know

- **Talk to me.** I might be disabled, but I am not stupid.
- **Make eye contact with me.** I am still here.
- **Listen to how I was affected.** The stroke affected some of my abilities, not my IQ.
- **Understand me.** Get to know what I am going through.
- **Do not minimize or trivialize my stroke.** It is life changing.
- **Make sure I understand you.** Ask if I understood a simple yes or no. My ability to listen and understand you may have been affected.
- **Make sure you understood me.** Be aware of the possibility that my tone, speed, and the method in which I now communicate may have changed.
- **Be patient with me.** I am healing.
- **Encourage me.** It does not have to be very much, just positive.
- **Support me.** I still have present and future goals.
- **Accept the new me.** If you cannot accept the survivor, leave. You are not helping anyone.
- **Feel free to offer help when you can.** It helps more than you think. Could be anything.
- **Be patient with me at gatherings.** They can be overwhelming. Boundaries may need to be set, do not take it personally.
- **Be honest with me.** Lies still hurt.
- **Tell me when I miss something important.** I can't correct my unsafe and unhealthy practices until I'm not aware of them. Show your concern, start the conversation.
- **Respect me.** I would hate to have to say goodbye.
- **LASTLY,** the more you know about strokes (my stroke) and their effects, the more it will help us both recover.

Circle of Friends

The fact is, after a stroke people leave your circle of friends. Why? There is no shortage of reasons for two people to drift apart. No matter what the reason is, it still hurts. The important thing to remember is that you never lose true friends. They will still see you and you now (really) see them. These friendships are priceless.

MY STROKE JOURNEY AND MY NEW LIFE

I can recall a personal experience and lesson that happened to me. I was having a good post stroke day. A very good friend and I were talking about our old school days. I did not remember a lot of the details of the story, so I just nodded and smiled and pretended that I remembered. At that point, my best friend looked at me and said, “you’re back!” I realized at that moment that I screwed up. Trust me, unless you are actually back, do everyone a favour and explain your mistake and apologize immediately.

In hindsight, I realized that I was just trying to cover up the memories that I had lost from the stroke. Instantly, the way I felt when I heard that comment, “you’re back,” I knew that I deceived a good friend. I put my pride before my friendship. Something I told myself never to do again. So far, I have held myself up to that promise.

Lesson learned: not everyone understands what you are going through and the challenges you still must face. Be honest with the people around you, a true friend will understand and help.

Things I have Learned Along the Way

- **Just because you think you can do it, does not make it so.** Know your limits.
- **Do not be afraid to ask for help.** It is okay.
- **Do not be afraid to tell people how you feel.** Without using the F word.
- **Do not mask your disabilities.** Be proud that you survived.
- **Ignore what negative things people say.** Their opinion and \$1.50 will get you a cup of coffee.
- **Educate people about strokes.** You both benefit.
- **You win when your mind is stronger than your emotions.** It is a work in progress.
- **Do not ignore any negative feelings you may have.** Feel free to get help.
- **Be positive.** If necessary, adjust your state of mind.
- **Accept recovery advice from others.** Especially from people who are where you want to be.
- **Okay, I am ready for my next mistake.** New adventures await.

Final Thoughts

If you were, like me, looking for more information to help you move past the initial trauma of your stroke and inspire you to move forward, my hope is that this article was of some help. In addition, I hope this article motivates you to make any necessary lifestyle changes that will aid in lowering your risks of stroke. Remember, 80% of strokes are preventable (Centers for Disease Control and Prevention, 2017). I made the mistake of thinking that I would never have a stroke. Please do not make the same mistake that I made.

MY STROKE JOURNEY AND MY NEW LIFE

To family, friends and caregivers of stroke survivors, I hope this article provided you with valuable insight into the challenges and issues faced by a stroke sufferer and survivor. Remember it's important to know the difference between the two, in order to, better understand and help those people you love and care for.

To my fellow stroke survivors, if you have the chance and the interest in writing your own story, I fully encourage you to do so. You will not regret it. I found that revisiting and writing about my own journey was very therapeutic. As hard as it was to revisit the events of my strokes, it personally gave me a chance to (re)assess the trauma. It allowed me to process the events and my actions and reactions as well as the results associated with my strokes. Having to look at all the past events gave me a chance to finally put closure on the effects of my strokes. I was able to take a critical look at the decisions I made and how I could do things better moving forward. I can only speak for myself when I say, again the benefits of writing your own story far outweigh the mental difficulties and mental fatigue of revisiting past traumatic events. If you have the chance and opportunity to write about your journey, I encourage you to do it. I look forward to reading about your journey and strength.

Now for some parting words to new survivors, which has helped me through my journey from sufferer to survivor. Look for and focus on those things that inspire you. They will become a great source of strength.

I wish you all the best on your journey.

Sincerely,

The New Dan

Acknowledgements

To the army of doctors, nurses, therapists, caregivers and administrators at the Kingston General Hospital (Emergency, Surgery & Kidd 7 departments), Providence Care Hospital (Stroke Rehabilitation Unit), and Home Care Services, thank you for your professionalism, dedication, and compassion that enabled this stroke sufferer to become a stroke survivor.

To my friends, thank you for putting up with and accepting my transition from the old to the new Dan. While my friends did not always know what I was going through (truth be known, at the time, neither did I), you were always just a call away and gave me the space and time to heal. I cannot thank you enough.

To my new VON friends (caregivers, supporters, educators, and fellow survivors) thank you for letting your guard down and letting me be part of your supportive stroke community. I would like you all to know that everyone at the VON played an important part in helping me. You

MY STROKE JOURNEY AND MY NEW LIFE

provided the support and tools I needed to process my stroke experience and to move forward with my life.

To my family, thanks for listening and talking with me, like you always did. Our conversations let me know I was still here and that you still see me. I cannot tell you how much that meant. Thank You!

To my wife, Rose, and my son, Ross, thank you for all your support and understanding and being so strong in front of me when I was not. I could not have done this journey without you.

How can you Support

If you found this article helpful in better understanding strokes or gave you a chance to start a conversation with someone you know that was affected by a stroke, I would be honoured and appreciative if you would consider making a donation to your local stroke support group, such as your local regional stroke network, in Ontario, or the Heart and Stroke Foundation. Your donation will be greatly appreciated by everyone affected by stroke.

Also, feel free to pass on this article to anyone you feel would benefit from it.

Thank you for your interest in my article. I look forward to the day when the word 'STROKE' is a short reference in a medical history book. This is the new Dan signing off.

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MY STROKE JOURNEY AND MY NEW LIFE

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