

# INVISIBLE SCARS

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STROKE SURVIVAL, RECOVERY, AND THE  
UNEXPECTED MENTAL HEALTH FALLOUT

ANGIE READ

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*I dedicate this book to my fellow stroke survivors. Brain injuries of any kind change you. The most noticeable changes are physical—paralysis or loss of motor control in parts of the body. But there are other changes people can't see, which can be just as devastating and debilitating as the physical. We've fought different battles—some far worse than others—but we all know how difficult it is to say goodbye to who you used to be and embrace the new, post-stroke you. Regardless of the gravity of our ordeals, we've all lived through a version of hell and have stories to tell. My story is unique to me, as yours is to you. I can't begin to touch on everything you've experienced in this book, but I've tried to do you justice and shed light on our collective invisible scars. To you, I say this: you are stronger than you think, and help is out there. I hope this book helps you feel seen and heard while inspiring you on your path to recovery.*





## INTRODUCTION

The brain is a beautiful, complicated, powerful gift. However, when a stroke or traumatic brain injury (TBI) damages its nerves and connections, it can turn your life upside down and inside out. There are invisible injuries no one sees or understands, including the person who has them. What do you do when that happens? How do you cope when your life takes a complete 180? How do you accept who you are and let go of who you were? How do you explain the invisible scars you don't fully understand yourself?

On July 25, 2017, at 6:30 a.m., I experienced that 180 turn after a right-side ischemic stroke affected the entire left side of my body. Blocked nerves in my brain caused the left side of my face to droop. My left leg, arm, and hand wouldn't work, and I couldn't get out of

bed. No matter how hard I tried, I couldn't move. I had visited the emergency room days before with a migraine I couldn't control with a high dose of ibuprofen. The doctor ordered a computed tomography (CT) scan that returned normal and an IV cocktail of medicines to reduce the migraine. I returned home with a bearable headache, and a day later felt normal again. On July 24, I went to work with the same drive and intention I had always done. I went to bed that night feeling like my usual self. But I was confused and alarmed when I woke up the following day and couldn't get out of bed. I didn't understand what was happening to me.

I've always been a driven, determined, and disciplined person. I love a challenge and have been successful in most of the exacting tasks I've pursued in my life. This included learning to play the oboe (the most challenging woodwind instrument to master), earning a music scholarship to Arizona State University, and later working myself up through the ranks of a prestigious international communications firm to eventually become a partner. I had also found new purpose in researching and understanding Gen Z (the generation that follows Millennials) and how to market to them authentically and convincingly. I'd even authored a book on the topic. Work was a massive part of my life and my identity. I was proud of my career and profes-

sional accomplishments. I worked hard and was used to the stress of being in pressure-cooker environments. I had suffered occasional migraines from the time I was 16 years old, so the horrible migraines I had on July 22 and 23, 2017, weren't unusual—that is, until I couldn't control them with my standard remedy. Even though I realized the migraine pains were quite different, I didn't know they could also be warning signs of something more sinister.

For 25 years, I had been building a marketing career and caring for my lovely family, including three dynamic teenagers and a wonderful husband. In a moment, that all changed. A few weeks after my first stroke, I felt numb and indifferent to the world around me. I was suffering from debilitating anxiety and depression but didn't know it yet. I assumed they were residual effects from the stroke. But when my mental health issues started to derail my life, I had to be admitted to two mental health facilities, back-to-back, and mustered all my strength and determination to heal and recover. I know firsthand the resolve, discipline, and unwavering commitment to healing it takes for stroke survivors to recuperate, mend, and rehabilitate their lives. Like me, I propose you have what it takes to restore and recover after a stroke touches your life.

Together, we will explore the mental and physical hurdles stroke survivors face, including post-stroke anxiety (PSA) and post-stroke depression (PSD), both of which can accompany recovery. You will find strategies to help you cope and live a fulfilling post-stroke life. You will learn specific methods to help you release the fear, anxiety, and frustration you may feel during recovery. You will discover that you are not alone. You are supported. You can regain your independence, work toward a new life, overcome significant challenges, and find those who love and care to assist you.

Fighting through mental health issues can be more than half the battle back after a brain injury. For some people, it takes years to recover, but recovery is possible. You don't have to fight through the fog alone. Support groups exist on social media outlets like Facebook, Reddit, and Quora. Advances in medical technology and changes in healthcare will be instrumental to your recovery. Medical doctors, mental health professionals, and caregivers can help you overcome the massive hurdles you face.

In these pages, you will learn how to track your mood and name the triggers that are causing stress and dysfunction in your life. You will learn how to identify patterns and make changes accordingly. By tracking your mood and associated factors over time, you can

name specific triggers, develop targeted prevention and management strategies, build self-awareness and confidence in managing your mental health, and improve your quality of life.

Today, I am back to work in the marketing career I love, and I'm living life to the fullest with my family and supportive friends. I've achieved stability in my mental health with the help of medication, exercise, meditation, and therapy. It's something I work on every day, using the tools I've gathered through personal trial and error.

There is power and resilience in the human spirit. Everyone has the strength to overcome their struggles and challenges, and with the right tools and support, you can not only survive after a debilitating stroke; you can thrive.



THE DAYS AND WEEKS AFTER  
THE BRAIN'S BETRAYAL

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*Your body can stand almost anything. It's your mind  
that you have to convince.*

— GEORGE BERKELEY

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**E**very day we tell ourselves stories and make plans about what we're going to do with our lives. We plan the family vacations, the work we must do at the office, the goals and dreams we have for ourselves and our children. We don't think about it ending. We move on autopilot, expecting that everything will be the same day to day.

Then something happens that turns your life upside-down. That sudden headache wasn't because you were stressed about being late for work. The numbness in your hands or feet, the dizziness, the vomiting doesn't add up, usually until it's too late. You end up in the hospital and learn that you have had a stroke that has short-circuited your brain's ability to think, speak, and understand. You find that your body no longer cooperates with you, and you're left with the shock of what is happening to you.

On July 25, 2017, a CT scan revealed that I had two clots—one in my right temporal lobe and another in my neck—that were blocking blood flow to the brain and causing a massive ischemic stroke. The thoughts that were clear in my head came out of my mouth as muddled language. My body betrayed me in its inability to act and respond normally. The suddenness of the attack left me feeling confused and concerned. The days that followed were filled with denial and wonder, fear and faith, concern and confidence. I expected that things would return to normal. What I didn't realize is that a new normal was on its way and things would not go quite as I expected.



## THE PHYSICAL TOLL

Statistics gathered by the American Heart Association (AHA) Statistics Committee and Stroke Statistics Subcommittee show 795,000 people per year suffer from stroke, with ischemic strokes accounting for 87%, hemorrhagic at 10%, and subarachnoid at 3% (Vega, 2022).

Ischemia involves a restricted blood supply to any muscle, tissue, or organ in the body. When blood supply is limited, oxygen doesn't reach vital areas, causing brain cells to die and connections to specific areas of the body to shut down. Sometimes the damage is temporary. Other times it is permanent and, if not caught in time, can even be fatal.

A stroke must be addressed immediately to prevent as much damage as possible. Symptoms can vary and manifest differently in men and women. The physical symptoms of ischemic stroke include (Mayo Clinic, 2022):

- sudden trouble speaking and understanding what others are saying
- paralysis or numbness of the face, arm, or leg on one side of the body
- problems seeing in one or both eyes

- trouble walking and a loss of balance
- sudden and severe headache

If you notice any of these, you must seek emergency help, even if the symptoms stop. A stroke can have ongoing physical manifestations in the body. Since the brain is your body's central operating system, its malfunctioning can manifest in the following ways:

- **Movement and sensation:** Nerve damage can cause contractures, spasticity, and sensory changes. The skin can become hypersensitive. You may feel a constant tingling and possible numbness in your hands, feet, arms, or legs.
- **Loss of motor skills and dexterity:** The effects of a stroke can cause the inability to move normally on one side or the other of the body. You may lose the ability to pick up a spoon or fork, have difficulty walking up and down the stairs, or experience excessive stiffness and muscle pain.
- **Impaired mobility and difficulty with balance and coordination:** This includes gait issues. Standing still can be just as difficult as moving. You may find that your hips no longer align, you lean to one side when you stand, or maybe you have trouble rolling over in bed, as I

did the morning of July 25, 2017. You may be in a wheelchair or need a walker or cane to stay steady on your feet.

- **Paralysis or weakness on one side of the body:** You may experience temporary or permanent paralysis or weakness depending on the type and severity of the stroke. You may lose muscle strength if a blood clot has suffocated and damaged the myelin sheath that protects the cells or cell nerve fibers.
- **Visual impairments and spatial neglect:** Blurred vision, damage to peripheral vision, or other visual impairments occur in approximately 30% of stroke patients (Sand et al., 2013). Some patients may experience a full recovery with medicine and various other methods. Others learn ways to cope with the loss through visual rehabilitation.
- **Chronic pain or discomfort, especially in the affected limb:** Pain that lasts six months or more is considered chronic. Stroke survivors may experience chronic nerve pain or sensitivity. Stress can cause this pain to become more intense. Cognitive behavioral therapy (CBT) is a psychological therapy often used to help patients cope with and overcome chronic pain.

- **Fatigue and decreased endurance during physical activity:** Doing something as simple as washing the dishes can leave you feeling like you've run a marathon. Your energy may decrease significantly.
- **Swallowing difficulties and increased risk of aspiration:** Difficulty swallowing after a stroke is called dysphagia. It takes 50 pairs of coordinating muscles for you to swallow. After a stroke, the nerves that send signals to those muscles may not communicate well. You'll find food going "down the wrong pipe," causing you to choke. Sometimes particles of food enter the lungs in a silent choking called aspiration. You may not even feel it when it happens. About 67% of stroke patients may initially experience dysphagia (Stroke Association, n.d.). This usually requires changing your diet, or drinking thick liquids, until you retrain those muscles.
- **Loss of bladder or bowel control in severe cases:** The muscles in your stomach that help move waste through and out of the body can be affected, causing you to lose control of bodily functions. In severe cases, you may need a catheter or colostomy bag. In milder cases, you can use adult incontinence supplies. Specific

exercises—like Kegels—can help retrain your core muscles.

- **Sensory changes, such as numbness or tingling:** Feet, hands, and limbs may feel like they have fallen asleep. Legs may feel stiff. Chronic burning pain can occur in other areas like the chest and thoracic spine. Physical therapy, daily stretching, and other exercises can help stretch stiff muscles and restore movement.
- **Contractures and spasticity in affected limbs:** Spasticity occurs when the pathways or synapses between neurons in the brain don't properly connect. This may cause stiffening of the joints, painful contractions, involuntary muscle spasms, or nerve pain. It can be difficult to function physically when you experience spasticity. Medication can treat these conditions.

## THE COGNITIVE TOLL

Executive dysfunction is the brain's inability to regulate emotion, thinking, and actions. This happens because the brain has been altered and can no longer process things as it used to. Emotions can get the better of you. Restraint is just out of reach. You may be easily angered

or frustrated, and it comes out in ways it never would have before the stroke. This chemical imbalance in the brain may show up in the way you understand, relate to, and interact with others. This can affect your relationships at home, work, and in the community. You may lose interest in things you were once excited about or feel isolated because no one understands you, and you don't understand yourself, nor can you make yourself clear.

A stroke can also affect your ability to administer self-care effectively. You may lose interest in bathing, showering, and caring for yourself. You may not have the energy or interest in what it takes to go for a walk, take a shower, read a book, or do anything that makes you feel good. These are also warning signs of depression.

Memory problems can occur after a stroke as the hypothalamus, the area of the brain where we store memory, is affected. Your memories are not just the events you recall from your past. Throughout your life, your brain has developed patterns and recordings of things you have learned to do. Through the miracle of memory, you learned how to make sounds and speak, which voices were attached to which person, and how to complete your daily activities. Your memory helps you think clearly, but when this area of the brain is damaged, you may have trouble putting sentences

together, recalling words, or speaking in a way that makes sense. The vowel sounds you learned as a child may elude you. You may suffer from interminable brain fog.

Cognitive distortion also sets the stage for other mental illnesses. You may question yourself and your decisions. Because of the effect on the hypothalamus, you may have difficulty learning new things. Like a child with attention deficit hyperactivity disorder (ADHD), you may quickly lose your train of thought, become easily distracted, and need quiet because of brain overload. All the tabs, buttons, and apps on your phone that once made your life so simple now seem like learning the more than 70,000 characters used in Chinese languages. If you had attention deficit disorder before, the after-effects of a stroke can put that on steroids.

Executive dysfunction also inhibits your ability to plan and make decisions. It isn't easy to imagine a future. Planning seems out of the question. Eventually, you learn to live in the moment and appreciate the present. You understand that dwelling on the past does nothing to move you forward. You realize that all you have ever really had is right now. Every day you wake up can become a gift for you and those who love you.

Additional cognitive effects of stroke may include:

- **Perceptual deficits, including spatial awareness and visual-spatial processing:** The brain naturally receives input from your five senses, processes the information received, and spits out your reactions and decisions. A brain affected by stroke may not process in a cohesive order. This breakdown in brain function can alter your perception, cause sensory overload, and create difficulty understanding direction, distance, and location. A stroke may also impair how you see things concerning yourself, who you are, and where you are in relation to objects and others.
- **Language impairments, such as aphasia and difficulty with comprehension:** Aphasia is a condition that affects the way you speak and your ability to read, write, and understand.
- **Impaired judgment and impaired problem-solving abilities:** Your memory bank helps you recall how to tie your shoes, eat with utensils, and brush your teeth. It even lets you know why you do these things. After a stroke, you may lose the ability to complete simple daily tasks. This is frustrating and scary, but it can also be temporary.



- **Reduced processing speed and information overload:** If you previously worked a high-pressure job as I did, after a stroke, the feeling of overwhelm can happen quickly. Where once you were a meticulous, fast-on-your-feet decision-maker, now it takes you an entire day to figure out breakfast.
- **Disorientation and confusion:** You may experience a constant feeling of being lost in space. Time loses relevance. Your identity is not wrapped up in your job, accomplishments, or who you are as a mother, daughter, sister, or friend.
- **Impaired self-awareness and insight:** A stroke can result in frontal lobe injuries, which cause anosognosia, which affects how you see yourself. You can't recognize your disability even when it is obvious. You may experience proprioception, which is a condition where you can't feel where your body is in space. You may stretch your feet out in front of you, but you can't tell where they are without looking at them. You feel as if you and your body are separate entities.
- **Difficulty with abstract reasoning and mental flexibility:** A stroke can impair your

critical thinking skills. Intelligence isn't as fluid and defined as it once was.

- **Impaired social cognition and difficulty with emotional regulation:** A stroke can affect your ability to recognize loved ones or understand their place in your life. You may not be able to regulate your emotions. You respond in the moment without considering how your response might affect others. You may lose the ability to temper emotions like anger, fear, joy, and sexual conduct.
- **Personality changes and altered social behavior:** Your social environment may change because of chemical changes in your brain that affect how you respond to and live alongside others. Some may need hospitalization in a care center. Others can live successfully at home but may need a caregiver.

## THE EMOTIONAL TOLL

The emotional toll after a stroke can occur in starts and stops. There is the first shock—that sudden, unexpected feeling that stuns you into silence. One moment you are your usual self, and the next, you're on a hospital gurney, wondering what happened and how. You may not remember the last thing you said or did,

and somebody repeatedly asks you silly questions like your name, address, birthday, and what day it is. Even more shocking is that you know the answers in your head but can't quite get them out of your mouth coherently.

### *Confusion*

Confusion follows on the heels of the unknown. You have so many questions. What is happening? How did it happen? Why did it happen? Like a journalist, you search for clues and details, but knowing the answers doesn't make anything easier.

Suddenly you are afraid. You sense danger but can't tell where it's coming from. A puzzle is forming, yet the pieces don't fit neatly together. You experience brain fog, which prevents you from properly analyzing the situation or its implications for your life, both in the present and the future. This makes you panic.

### *Anxiety*

Anxiety, according to the American Heart Association, is commonly associated with stroke, especially in women and those who are single, divorced, or widowed (American Heart Association News, 2019). The debilitating apprehension, impatience, fear, and worry that undermines your self-esteem, self-worth, self-confidence, and mental health is common after a stroke.

Sometimes the anxiety can be as bad or worse than the stroke itself. This was the case for me.

I had a family history of anxiety and depression and had been diagnosed with anxiety 15 years before my first stroke. I knew what it was like to feel intense anxiety, but medication always effectively addressed it. After my stroke, I completed seven weeks of intensive physical, occupational, and speech therapy. I thought I was back to normal, but I panicked when I tried to return to work. My family thought I was rushing things, but I thought I had it all together. However, even medication couldn't stave off the feelings of unease, worry, and depression heading my way. Panic attacks and the side-effects from my new medications kept me on high alert while I slid deeper and deeper into a dark mental hole.

I learned later that I was not alone. One out of every four stroke survivors experience moderate to severe anxiety (American Heart Association News, 2019). Even after physical and cognitive therapies, you may still feel ill at ease in situations you were once accustomed to. Lead researcher Jennifer Beauchamp, from the University of Texas Health Institute for Stroke and Cerebrovascular Diseases, found, "There is a bidirectional relationship between stroke and anxiety" (American Heart Association News, 2019). Attention is

a big part of brain function, and when that attention is divided, moving in two different directions simultaneously, it can cause a kind of overload. This increased activity can result in anxiety, worry, fidgeting, stress, and overwhelm. It can affect your sleep quality, leaving you feeling exhausted yet unable to sleep at the same time.

Dr. Nada El Husseini, a neurologist at Duke University Medical Center in Durham, North Carolina, said, "Anxiety after a stroke may be due to a combination of psychosocial factors and biological changes to the brain caused by the stroke" (American Heart Association News, 2019). This means that your anxiety and depression can be just as affected by your relationships with your spouse, children, family, and coworkers. Social interaction and even the availability of resources may play a part. Marry that with the biological factors involved in stroke or any disorder that affects the brain, and you have a tumultuous cocktail of apprehensive, disorderly emotions.

### ***Anger***

Anger is one of those disorderly emotions that can show itself in frustration, despair, a short temper, and outbursts of rage. Adjusting to a new normal is difficult at best and horrific at worst. After a stroke, your brain and body can be uncooperative and physically changed.

Cognitive impairments can cause emotional outbursts affecting you, your family, loved ones, and caregivers.

The mental and physical stress you are experiencing is difficult for others to understand, especially if you still look “normal.” Other people’s expectations may also have you climbing the walls. No one realizes how changed you are. They can only see the outer physical effects; they can’t see what’s happening inside your body and brain. You, however, are looking out the window of your soul, and you know how drastically you have been affected. It frustrates you that you can’t make anyone understand, so you curl up into yourself and shut out the world, or you do the opposite and lash out in fits of rage. You don’t want to explode on people. You want people to understand, to give you space and time. The fact that you need help and feel alone and abandoned may also anger you, bringing you to uncontrollable tears, fear, and rage in a concentric circle of emotional pain.

According to a study by the Asian Medical Center, “32% of a group of 145 stroke patients reported the inability to control their anger and aggression up to a year after their strokes” (Edward, 2023). This can be attributed to grief, depression, and the neurological damage caused by the stroke. Anger is a part of the grieving process. Stroke survivors may experience

significant losses in bodily functions and mental acuity. These are not trivial injuries. Even when there is recovery, the trauma of the event can remain.

### ***Depression***

Depression is the thief of joy. It is a deep, persistent sadness characterized by a lack of interest and an inability to find pleasure in anything. It can occur on two levels: emotionally and biochemically.

Senator John Fetterman struggled with depression after having a stroke in 2022 while on the campaign trail. When he won his Senate race, even though he physically recovered after the stroke, he wasn't happy. This confused and disheartened his friends, family, and team. He kept sliding deeper into depression until he decided to do something about it before it ruined his life.

On February 15, 2023, Senator Fetterman checked himself into Walter Reed National Military Medical Center, seeking treatment for clinical depression. His depression had escalated during the brutal electoral campaign. By the time he entered office in 2023, his depression was full-blown.

Depression changes the brain's biochemical balance, which alters and distorts your perception. According to the American Stroke Association, "About 30% of people

who have a stroke get depressed. It can occur right away or months or even years later. If left untreated, it can affect your quality of life and make post-stroke recovery difficult” (National Stroke Association, 2022).

Unfortunately, post-stroke depression (PSD) often hides in the shadows, going unnoticed, undiagnosed, and untreated. Because it can occur months or years later, the person experiencing it may not even know why they suddenly can't find peace, feel persistently sad and empty, or constantly tired and drained.

Depression can affect how you think, act, and feel. You are not just being overly emotional or lackluster. Your brain shrinks and changes during depression. It loses its natural ability to function properly due to chemical imbalances and shrinkage. Gray matter is the stuff the brain uses to help us control movement, regulate emotions, and respond to stimuli. Any loss of it can affect how we think, react, move, and live our lives.

In Fetterman's case, he felt he had reached the end of his rope and, though initially hesitant about getting help, he knew that if he didn't, he would not survive the constant malaise taking over his mind and body. Fetterman warned, “That's what's so insidious about depression. Depression, you know, you might win, and you still feel like you lose” (Mueller, 2023). In an interview with Joe Scarborough of MSNBC, Fetterman



delivered an urgent message about seeking treatment, claiming that's what "saved me from my anguish" (Mueller, 2023).

Depression affects how we feel about ourselves and our lives. You may feel hopeless, helpless, powerless, and uncertain. You may despair that there is no hope of improvement. You acknowledge that you can't go back but find that you can't move forward either. You feel stuck and helpless, especially if you must rely on others to take care of you and meet your basic needs.

That feeling of helplessness can lead to feeling out of control. Out of control of your environment, health, body, and life. You find that you cannot make decisions as quickly. Things take more thought and care, which can lead to hopelessness. You want to get better, but you don't know if you can. You may find yourself on the precipice of your present, past, and future. Maybe you feel like you will fall into the cracks, and no one will notice. Or you develop a macabre mindset that says your loved ones would be better off without the burden of you.

### *Grief*

Grief, that sense of loss for what was before and might never be again, is not a linear process. Imagine you are at the funeral of someone you have known

and loved. You know everything about them, including how they chew their food, their favorite television programs, and their life's purpose. They have been in your life forever. Now that person is gone.

Now, imagine that person is you. You have not died, but a part of you is gone. You are not the same person you were before, and the thought that you may never be that person again can be paralyzing, deeply grievous, and depressing.

When you suffer the debilitating effects of a stroke, it can feel like you are attending your own funeral. Saying farewell to the person you once were can be a crushing blow. The identity crisis that follows can be staggering. What's more, people expect that you will get back to who you were. They don't understand, nor can they identify with your struggle.

## THE OVERWHELM

A stroke is a “traumatizing and disorienting experience” (Gordon, 2022). Dr. Catherine Atkins, Ph.D., supervisor of the Cardiac–Medically Complex Psychology Service at NYU Langone Health in New York City, shared, “Having a stroke is like trying to put a puzzle together, but instead of pouring the puzzle out

on the table and assembling the border first, the pieces remain jumbled” (Gordon, 2022).

A stroke leaves physical, mental, and emotional challenges in its wake. You may recover well, but you are never the same person afterward. The frustration of learning to walk, talk, chew, swallow, and go to the bathroom by yourself changes your self-perception. Cognitive challenges from a brain that functions differently cause confusion, anxiety, and feelings of hopelessness, fatigue, and fear. Major depressive disorder (MDD), post-traumatic stress disorder (PTSD), hypervigilance resulting in flashbacks of the event, mood swings, and overwhelming sadness are normal for stroke survivors. You may look fine to everyone else but feel like you’re sinking in quicksand, and no one knows it but you.

You are different from before, and accepting the situation is difficult. Setbacks, expectations of others, expectations of yourself, questioning, and wondering lead to doubt and despair. Will I ever be the same? What if it happens again? Will my spouse, lover, or significant other still love me and see me the same way, or will they leave me because I’m different? Suppose you used to be a powerhouse at work but can’t bring what you once did to the table. In that case, you wonder what will happen to your personal and business relationships.

Will I be able to pay my bills? Will I lose my job? Will I lose my mind? How in the world do I overcome all this? Who am I now, and how am I managing and defining that?

Days before your stroke, you might have gotten up to shower, prepared a meal, ushered the children off to school, brushed your hair, dressed, and gone to work. Reading and understanding a book, conversing, or driving a car weren't complex routines. However, after a stroke, these things can be monumentally complex. Cognitive challenges can cause you to lose your sense of identity, location, and time. You may not remember your address or phone number. You may not remember the city or state you live in. You lose track of time and feel disconnected from the world around you. You feel confused, anxious, depressed, constantly tired, irritable, apathetic, and moody. You wonder if you'll ever be normal again and what *normal* even looks like.

Adjusting to new limitations can be overwhelming. All change is challenging, but when the change involves disabilities and quality of life, it becomes even more so. Chronic pain, mobility issues, speech difficulties, and the brain fog keeping you from understanding what's happening around you can lead to embarrassment and social withdrawal. Concern about whether your partner will still love you, still see you, or if they will

leave you can leave you feeling immobilized and afraid. Whether you can function sexually, satisfy your mate, or enjoy sex is a concern in a relationship. It's heart-breaking when friends stop coming by because they can't bear to see you in the state you're in. Medical bills, financial instability, and loss of income from employment or business all affect your mental stability. Will I need to move? Where will I live? How will I live? Who will be there to help me? Who will take care of me? What if I have another stroke? Will I be a burden? What is the purpose of my life now? These are the questions you ask yourself when feeling overwhelmed.

Overthinking is a natural and normal response after trauma. The saying "the devil is in the details" becomes especially real and omnipresent to you. Going from being independent to needing someone to care for you can be humbling and sometimes humiliating. Suffering through the blank statements and clichés people use to comfort you when they have no idea what you are going through is offensive, annoying, and frustrating. You wonder when the pain will end while they compare your struggle to the time they forgot something on their shopping list. Their attempt to console you only worsens your pain, loneliness, and depression.

Adaptation and rehabilitation after a stroke can make you feel like a helpless child. Getting help when you feel

overwhelmed is critical to your mental and physical recovery. Acknowledge when you are feeling crushed. Avoid suppressing those emotions that make you feel alone. Go into your secret place and cry, scream, throw things, shout if you must. Letting go is not easy. Reach out to someone, whether professionally or personally, and take advantage of their help. There is no shame in that.

#### A DETERMINATION TO HEAL

The first step on the road to recovery is acceptance. This is the courage to accept your present reality while striving to overcome the hurdle of what happened. It is the step-by-step, one-day-at-a-time, one-moment-at-a-time progression that pushes you forward. It is the mental ability to look realistically at where you are to prepare for where you want to be.

Determination requires strength. You may not want to do physical therapy. There may be days when you don't want to get up in the morning, wash your face, brush your teeth, or administer self-care. Determination, however, isn't based on feeling. Instead, it is rooted in desire, that vital force in each of us that causes us to want to be better, to do more. Once you honestly assess where you are, you can decide what tools you'll need, including medical aids,

financial and social support, therapies, and any other needs that arise.

Your determination toolbox must include the following:

- **Motivation:** Inspiration happens outside of us, but motivation comes from the inside. Motivation results in active participation in your rehabilitation and recovery.
- **Patience:** The fortitude to endure is the essence of patience. Allow yourself to fail and start again without judging or beating yourself up. Recovery is a marathon, sometimes a decathlon. It is rarely, if ever, a sprint.
- **Attitude and altitude:** This is the willingness to set realistic goals, keep a positive attitude, believe in your ability to improve, and celebrate your progress—even the smallest improvements.
- **Openness:** Be open to trying and doing things you've never done before. Was going to a therapist taboo in your family? Try it and see what it's all about before making a judgment. Think yoga is only for girls? Take an introductory beginner yoga class and see how your body responds. It's time to let go of the words "never" and "always," as in "I'll never do

that” and “It’s always been like this.” The one thing guaranteed in this life is change. Try new therapies and techniques. Be open to learning new ways of operating in the world.

- **Advocacy:** Seek supportive and appropriate care for yourself. Find a new doctor if your medical team isn’t cutting it for you. If you have trouble articulating your needs, phone a friend who can help. Join a support group, whether online or in person, to learn more about what help is available and how to access it. Engage assistance to help you stand up for yourself.
- **Focus:** Racehorses wear blinders to keep them focused on the finish line. You, too, will have to wear mental blinders to keep you focused on your goals. You can do that by regularly participating in your physical therapy, not skipping appointments with your medical team, and adding positive affirmations, meditation, and mindfulness to your daily routine. Focus on getting well. When your thoughts turn to defeat, get help to make the adjustment, breathe, and put the blinders back on.
- **Resilience:** Resilience is about elasticity—the ability to bounce back after being stretched to capacity. A brand-new rubber band is resilient. Your brain also has an aptitude for resilience,



called neuroplasticity. Neuroplasticity is, by definition, “the ability of the brain to form and reorganize synaptic connections, especially in response to learning or experience or following injury” (Oxford Dictionary). In other words, the brain can reboot. So can you. You may not be who you were, but you will be someone new. There is strength in who you are right now.

- **Diet and lifestyle changes:** You are what you eat. This has never been truer than when dealing with a disease or disorder. Food is a healer. The more junk you consume, the less healing will occur. Change your diet and change your life. If you want to feel healthier and stronger, eat to live, not vice versa. Work on breaking unhealthy eating and lifestyle habits like smoking and excessive drinking, and drug abuse. Seek help and support to do what’s necessary for your quality of life.
- **Appreciation:** Family is not only those born into our circle. Our families include those who love, care for, and support us. Appreciate those who have done and are doing anything to aid you on your journey. Has anyone cooked a meal for you? Driven you to the hospital or to a doctor’s appointment? Held your hand in times of distress? Thank that person. Be grateful for

those in your corner. Don't take anyone for granted. Instead, practice grace and gratitude often.

## INTERACTIVES

Moods are transitory: they come and go, ebb and flow. You experience mood swings from chemical changes in your brain and reactions to external stimuli. In a room filled with loud, screeching children, you may become happy as you engage with them or become irritated by the noise. Psychologists define mood as "a number of persistent feelings that color our perception and evaluation of incoming stimuli" (Optimist Minds, 2023). It is the background to our emotions and emotional responses.

Mood journals can help you track where you are at any given time. The more information you have about how you handle your daily life, what things trigger you, and what makes you feel more positive, the more precise and focused you can be. Keeping a mood journal will help you gather information from the world around you and your responses.

Mood journals can aid in recovery through:

- increased self-awareness and insight into emotional patterns
- improved ability to name and manage triggers
- better understanding of the relationship between mood and behaviors
- enhanced ability to communicate with healthcare providers or therapists
- more effective treatment planning and monitoring
- reduced anxiety and stress by processing emotions in a healthy way
- increased accountability and motivation for self-care and positive coping strategies
- improved sleep and overall well-being
- empowerment and control over mood and mental health
- better ability to recognize and appreciate positive experiences and emotions
- potential for long-term improvement in mood and mental health

Mood journals and mood trackers help you get a vision of your mental health. The most popular apps for tracking mood include (Singh, 2018):

- **Daylio** allows you to select your mood and input any activities you engage in throughout the day. The app takes the data you input and creates a chart showing your patterns and activities and what mood those activities put you in. This will help you decide which activities are beneficial or triggering. You can back up data from the app to Google Drive so it is also available on other devices. The purpose of Daylio is self-improvement through knowledge.
- **Moodpath** centers on assessing your psychological and emotional well-being through writing. Every 14 days, based on what you've written about your mood and activities, the app generates a letter you can share with your therapist. You can also use this tracking system to learn about depression, including how and when it affects you.
- **Pacifica** is a third app to help you manage stress and anxiety. It boasts a meditation library and chat room.
- **Moodnotes** tracks your mood and thinking habits.

Moods are general. Emotions are more specific. Emotion can change your mood, as can a particular

place, event, or trigger. Understanding your mood in any situation can show you what brings positive and negative emotions. This can help you regulate your mood swings. If journaling or using a mood tracker doesn't help, seek the aid of a psychotherapist. You can use mood trackers in conjunction with therapy.



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## MOVING FORWARD WITH PHYSICAL REHAB

**P**hysical therapy can be your best friend and worst nightmare when you have a stroke or disorder that impairs brain function. Your best friend because it helps healing and recovery. Your worst nightmare because the work is often difficult and unrelenting. My physical therapist assisted my first attempts at walking with a gait belt strapped securely around my waist. She would hold firmly to the belt, moving with me as I tried walking in a straight line or up two or three steps. I veered to the left for a while as my left leg wouldn't cooperate as quickly and surely as my right.

You can't put a time limit on recovery. Still, you can help move it along when you commit to physical therapy. How fast or slow you recover depends on your stroke severity and the unique circumstances

surrounding your healing. The most important thing you can do is to take the first step, literally and figuratively. The more I practiced walking, the more stable and confident I became. I realize how lucky I was that my husband caught my stroke in time for me to get immediate medical intervention to remove my clots. My recovery would have looked much different had that not been the case.

#### WHAT DOES PHYSICAL REHAB LOOK LIKE?

The move toward wholeness can be complex. Your personal rehab cocktail may include some or all of the following:

- strengthening exercises for affected muscles
- range-of-motion exercises to improve flexibility
- balance and coordination exercises to prevent falls
- aerobic exercise to improve cardiovascular health
- gait and mobility training to improve walking abilities
- activities of daily living (ADL) training to improve function
- task-specific training to improve specific skills



- use of mobility aids like a cane, walker, or wheelchair
- education on the proper use of assistive devices
- instruction on adaptive techniques for daily living
- modification of living environments to improve accessibility
- provision of custom orthotics or prosthetics (if needed)
- assessment of home safety and modification recommendations
- education on community resources for added support

For two months after my first stroke, I had a rotating combination of intense physical, occupational, and speech therapy for up to three hours daily at St. Luke's Rehabilitation Center, a mile from my house. I wasn't allowed to drive until I "graduated" from my therapy sessions, so my husband, Steve, drove me to rehab every day. I was on short-term disability from my job, so rehab became my full-time job. I focused on graduating from the program, and I put all my time, attention, and energy into that goal.

My personal re-training regimen consisted of the following:

- **Fine motor skills training:** I learned to gradually build up strength in my left hand, which included challenging pinching and pulling exercises. It was odd watching my hand ignore the signals from my brain.
- **Speech therapy:** My speech therapist attached small electrodes to my cheek that sent electric pulses through my face while I practiced facial and mouth exercises using exaggerated movements. I practiced “ohs,” “ahs,” and “oohs,” opening my mouth as wide as possible. This helped me regain my smile after the left side of my face drooped.
- **Gait and mobility training:** This involved casually walking around an indoor track, walking while bouncing a ball in front of me, then doing the same thing while speeding up. I also had to balance on one foot, then the other, stand on a balance trainer, then do that while throwing a ball back and forth with my therapist. Over time, these skills helped my coordination and balance.
- **Task-specific training:** For me, this included speech therapy. I had to do tongue twisters to

increase speech clarity and pronunciation.

Though I didn't have the aphasia many stroke survivors suffer, I still struggled to put words together.

- **Use of mobility aids:** I used a cane for several weeks after my first stroke, but thankfully I could walk on my own without it within a month.

Where you start in your physical and cognitive health will dictate your needs. Your therapist will help you set realistic, achievable goals. Your job is to commit to the process.

## WHY PHYSICAL THERAPY MATTERS

Where you are at the end of your recovery journey depends on what you are willing to do right now. Yes, your brain and body are different. Yes, things may get worse before they get better. Yes, recovery is hard, but giving up can have even more complex and detrimental repercussions. Therapy matters and is essential for your health and mental well-being.

Through therapy, you can experience:

- **Improved physical function and mobility:** For many stroke survivors, learning to walk again can be as much mental as it is physical. A physical therapist can help you set realistic goals and reach them. They can encourage your progress and help you take the next steps. They can recommend exercises specific to your needs and capabilities so you can regain as much independence as possible.
- **Increased strength, balance, and coordination:** In your normal, everyday, hum-drum life, you don't consider what it takes to stand up straight, walk up a flight of steps, or close your eyes as you shower, feeling the warm water cascade over your face and down your back. You don't consider the muscles, nerves, and brain cells that execute these simple processes. That is until those processes fail. The first time I tried to shower after my stroke, I was stunned by how difficult it was to wash my hair with only one working hand. Thankfully, my left hand and arm caught up quickly through physical therapy, and I could shower effectively after the first few weeks. For my safety, I put a special chair in my shower so I

could sit if I felt dizzy or hold onto something if I felt off balance. Physical therapy is essential to recharge the muscles, nerves, and neurons that help you stand upright and support balance as you move. Like a child, you learn to stand up by holding onto a solid surface. You perform exercises to strengthen your hips, and toddling, you move through a set of parallel bars putting one foot tenaciously in front of the other. These exercises help reduce the risk of falling and injury. Alleviating those risks leads to greater independence.

- **Better quality of life:** Life is a balancing act, and whether you need a wheelchair, walker, cane, or other assistive device, physical therapy will help you achieve a better quality of life. Through physical therapy, you become less afraid. You develop confidence. You learn to communicate and move in new ways. Physical therapy can help you become less reliant on assistive devices. Feeling more confident leads to increased social interaction, recreational activity, motivation, and a healthier mental outlook.
- **Reduced pain and discomfort:** Muscles atrophy quickly when not used. Tight muscles that lack flexibility can be painful. Physical

therapy can lessen that pain tremendously. Movement helps increase blood flow and stimulates the body's organs, muscles, and nerve functions. Your body has a memory, and when you move, it signals the brain to remember how to do it. Physical therapy helps retrain the body, relieving the pain and discomfort associated with the aftereffects of a stroke.

When you participate consistently in physical, speech, occupational, or psychological therapy, you reap the benefits of long-term improvement and the possibility of future stroke prevention. Physical therapy, whether done at home or in a facility, can help you recover from paralysis, improve your strength, mobility, and fine motor skills, and contribute in a big way to a better quality of life. It may take time to recover, but the process and the rewards are worth it.

## THE TIMELINE

Physical recovery after a stroke can be a slow and ongoing process. Most recovery may occur in the first few weeks or months after the stroke, but progress can continue for years. The brain is a high-functioning machine. It reboots, reconnecting synapses to live cells

and reconfiguring networks and paths to make the system work again. This takes time. Brain cells are the only cells in the body that, once dead, cannot regenerate. If you cut your finger, the skin will eventually create new cells to patch things up. Brain cells don't exactly work that way. The brain rewires itself, and this takes time. All the systems may not come together as they once did. You and your body may respond more slowly, but given time, you can recover quite a bit of brain function.

If you were in good health before the stroke, you might experience significant recovery within the first six months, as I did. Afterward, the process typically slows. Youth and better general health pre-stroke have the advantage in this context.

However, if you had a severe stroke and your health wasn't in great shape before, it may take years to recover specific motor functions. The brain may be damaged to a greater degree and need more time to reboot. Some people may never fully regain their pre-stroke capabilities, including motor skills and speech.

Rehabilitation therapy is critical, especially in the first six months. Participating in a homebound exercise and physical therapy program, attending a rehab center, or receiving such services in a nursing home can help facilitate recovery.

Therapies beyond the purely physical are also important. Psychotherapy, journaling, and support all shorten the recovery timeline. People who spend time interacting with family, caregivers, and friends and accessing quality health care often have a much better chance of achieving a desirable new normal.

Recovery is a highly individual process and is ongoing for the rest of your life. Your experiences are unique to you and cannot be based on another individual's, even if you are a lot alike. Avoid comparing yourself to others as you go through your process.

#### PHYSICAL THERAPY YOU CAN DO AT HOME

Physical therapy doesn't end when your appointments stop. It is an ongoing process you must continue to maintain your health. To this day, I enjoy an at-home exercise routine that consists of weight training, squats, 20 minutes on my treadmill, and 20 minutes on my elliptical machine. You can also invest in simple equipment like flexible bands, lightweight dumbbells, stress balls, a yoga mat, and a yoga block. Include things like dance therapy and walking in nature. Flint Rehab states, "A consistent home exercise program is one of the best ways to continue recovery well beyond discharge from inpatient rehabilitation" (Flint Rehab, 2020).



Before starting, consider the following factors: Where am I currently in this process? Is there paralysis, and what areas are affected? Is there partial movement? In which areas would I like to see improvement? What quality of movement do I have? These factors are essential when deciding what exercises you need to increase neuroplasticity— “the mechanism the brain uses to rewire and heal itself after injury. It is the key to recovery and learning new skills” (Flint Rehab, 2020). Once you’ve answered these questions and discussed them with your therapist or primary care physician, then you can get started effectively.

Following is a list of full-body stroke exercises recommended by Flint Rehab and available on YouTube that you can do at home (Flint Rehab, 2020):

- Easy Leg Exercises for Stroke Patients
- Core Exercises for Stroke Patients to Improve Balance and Walking
- Arm Exercises for Stroke Patients
- Best Hand Exercises for Stroke Patients at Home

Repetition is key. Your body has a memory; the more you repeat a movement, the more it responds. Practice daily to achieve faster results, especially in the first six

to eight months after a stroke. Incremental movement makes big movement possible.

If you have paralysis, you'll need the help of a home healthcare worker or physical therapist to complete your exercise routine. You'll start with passive exercises until there is recovery in your affected area. Once recovery begins, you can increase activity within your routine. Flint Rehab offers a free stroke exercise ebook, *Full Body Exercises for Stroke Patients*, on their [flintrehab.com](http://flintrehab.com) website. *Your Guide to Exercise After a Stroke—A Guide for People with Stroke and Their Families*, written by Margot Andrew, Margaret Hoessly, and Kate Hedges, is also available in a downloadable PDF at [stroke.org.nz](http://stroke.org.nz).

#### TIPS FOR CAREGIVERS: WHAT NOT TO DO AND WHAT YOU SHOULD NEVER SAY TO A STROKE SURVIVOR

It's common to assume strokes only affect older people. I was only 46. Every year, "about 70,000 Americans under age 45 have strokes. About 10 to 15% occur in children and adults under age 45, and that number is rising" (Sutter Health, 2023). This is especially true of ischemic strokes.

Factors contributing to strokes in adults 45 and under can include (Sutter Health, 2023):

- diabetes
- unhealthy habits like smoking or drug and alcohol abuse
- high blood pressure
- high cholesterol
- genetic blood disorders and heart conditions
- aneurysms
- artery tears
- migraines (which was one of my factors, although I didn't know it at the time)
- polycystic kidney disease
- birth control pills (they think this was a significant contributor to my stroke)

No matter your age or the cause, having a stroke is an emotionally disturbing and physically draining event. Unless you've had a stroke, TBI, or similar event, it's impossible to understand how devastating the physical, emotional, and psychological effects are. Healing and recovery are a long process. What you say to someone during this process is critical to their health and well-being. Avoid making the following statements:

- **You're not trying hard enough.** Unless you've experienced paralysis, temporary or otherwise, you will never know the agony of not being able to curl a finger or wiggle your toes. Never discount a person's struggle just because it's not something you've dealt with. Even if you've overcome and walked a similar path, each person's body reacts and responds in uniquely diverse ways. Don't judge another person by the ruler you use to measure yourself.
- **It's all in your head.** You're right! It is all in their head. That's where strokes happen, in the brain. Just because you can't see it doesn't mean the damage isn't real. Unfortunately, even some physicians make this claim rather than take seriously what their patients are experiencing. When my anxiety and depression were getting to be too much to bear, I went to my neurologist for answers. I sat in his office crying, begging to know what was happening to me. He dismissed me, saying, "Your issues are psychological, not neurological, and you need to see a psychologist." He was telling me, "It's all in your head." I kept crying uncontrollably, and he got up and walked out without saying another word or recommending help. He never came back! I left

his office even more confused and frustrated than I was before my appointment. Had the stroke caused my mental health issues or not? Eight months after my first stroke, I had a car accident and, after being told that I had suffered a second stroke, I asked the hospital neurologist if she knew of any connection between strokes and anxiety and depression. She at once comforted me and told me that, indeed, 50% or more of stroke survivors develop anxiety or depression. She gave me copies of three separate scientific studies proving the neurological connection. Because she was so caring and helpful, I decided to fire my original neurologist and switch to her for my ongoing neurological care. I needed to know that my neurologist indeed heard and cared about me and understood the biological connection between my strokes and mental health decline.

- **You'll never be able to do that again.** While it may be true that the person will never be able to do what they were once able to do, nobody needs to hear this. It is discouraging and condescending. Avoid sending negative messages. Why make someone feel like a failure before they've even begun? They know how

drastically their life has changed. They don't need any reminders from you.

- **You're just being difficult.** The most challenging thing to do in life (sick or well) is to rebuild yourself. To change and grow, you must take a good, hard look at yourself, get rid of the things that don't serve you, and start over. This task is much more difficult if you've lost brain function. Because changes in the brain aren't visible to the naked eye, people may think you are deliberately being difficult when, in fact, you are having problems behaving, thinking, and responding in the way you want or used to.
- **Why can't you be more like you used to be?** This question may stem from your frustration with the person, but you must realize that they want to be the person they used to be. A traumatic event has changed their lives in every way possible. They don't see things the same. Their brain does not process in the same way. Their outlook on life has changed. What used to be important to them may no longer matter. Accept that the person you love and care about has changed. They are trying to accept that too. Don't make them feel guilty and ashamed for something they had no control over. Don't sow or fertilize seeds of

inadequacy. This is counterproductive to the person's healing and recovery.

- **I can't stand to see you like this.** This is one of the most insensitive and self-centered comments you can make to a person healing from a stroke, a bad accident, or any illness. They can't stand to be in that position either—but they don't have a choice. Show compassion and take the focus off yourself and how you feel. Imagine how the other person feels—how abandoned they feel when a loved one doesn't visit them or connect with them because they “can't stand seeing them like that.” Sadly, we live in an era where beauty is the beast. If someone is not aesthetically pleasing or the same person they used to be, they are immediately discarded. This leaves the person feeling useless, hopeless, and thrown out like yesterday's garbage. Put yourself in their shoes before you open your mouth.
- **It's not my responsibility to take care of you.** This comment may come from fear or frustration, but it is not helpful to the patient. Unfortunately, this happens most often with family and friends, the very people you expect to be in your corner when the chips are down.

Caregiving is complicated and often thankless—and you're right; you aren't obligated to take care of anyone. Nevertheless, the most loving, unselfish thing you can do is help someone who needs you. There isn't always a reward at the end of it. Sometimes heartbreak and sorrow follow, but you will have peace of mind knowing you were there for someone, and you did your best to give them all the love and care they needed.

If you don't have time to help someone in need, can you recommend someone who does? Do you know a qualified therapist or life coach who can help? Can you recommend a physician or home healthcare service? It's okay if you don't have the time or wherewithal to be an active helper, but can you offer solutions? That too is caregiving.

## INTERACTIVES

Check out these apps to help track your mood through rehabilitation and beyond.

- **Moodcast** is an app like Daylio. You can link your social media accounts to this app. By entering data about how you feel, you can predict your mood.
- **ImoodJournal** tracks mood, sleep, medication, symptoms, energy levels, cycles, and more.



Also, grab a pen and paper and answer the following questions:

- Do I have a physical therapist? If not, why not?
- Are there resources available in my community that could help me with this?
- Have I talked to my physician about this?
- What does my insurance cover and what do I need to do to take advantage of it?



REBUILDING THE MIND WITH  
COGNITIVE REHAB

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*Dear self, I know you are doing the best you can. I believe in you. Keep going. Love me.*

— PLATINUM PUBLISHING

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**T**he brain is the most powerful organ in the body. It controls our thoughts, memory, emotions, mobility, vision, touch, and every nerve system in the body. This tremendous and wonderfully complicated machine, with its nuances of consciousness, synapses, and neurotransmitters, is still largely a mystery to scientists and the medical community. What we think

we know can change in an instant when something damages the brain.

Cognition is our ability to think, reason, perceive, problem-solve, process knowledge, understand language, and put sentences together. A brain damaged by stroke can lose its cognitive abilities and must be rewired or retrained to function normally. It's easy to get frustrated when the brain doesn't rewire itself on our timeline.

### *Memory, Attention, and Concentration Exercises*

Every teacher knows that young children between the ages of newborn and five learn mostly by visualization and repetition. This doesn't change as we age. The brain needs repetition to store information. After a stroke, you may need to be reminded of what and who you know.

The brain needs exercise. Things like word puzzles, board games involving strategy and memory, sequencing games, reading, and a host of other brain-training games help rewire the brain. These games can include:

- **Card matching:** This is the same memory game you played as a kid. Get a pack of children's matching cards from the store. Spread them out

the floor and turn them facing down. Try to match pictures, numbers, or symbols as you turn them over two at a time.

- **Alphabetizing and sequencing:** My occupational therapist taped letters to both sides of the wall of a long hallway. My task was to touch the out-of-order letters in sequential alphabetical order. For an added twist, she added numbers to the sequence. I had to walk down the hall, touch the letter A, then the number 1, the letter B, then the number 2, and so on. It wasn't easy, but eventually I mastered this exercise.
- **Simon memory games:** You can use these light sequences to improve hand-eye coordination skills. My therapist used differing light sequences on the Dynavision neurological training light board. As each light flashed, whether from the far side of my peripherals or at the top or bottom of the board, I had to press it as I saw it. She recorded these taps into a computer, along with how quickly I could predict and press them, then scored each session. If you don't have the benefit of such a board, you can buy the classic Simon game online to play at home.

- **Mindfulness training:** You can train your brain to focus. Mindfulness is about being present and paying attention to what's happening inside, outside, and all around you. Take a minute to focus on a tree, watch a bird as it flies from one place to another, or sit in silence for 30 seconds at a time. When your mind wanders, don't judge yourself, just gently bring it back into focus.
- **Board games:** Games like Connect Four, Scrabble, Checkers, and Mahjong are strategy games that involve problem solving.
- **Card games:** Go Fish, Gin Rummy, and Uno are helpful for stroke patients because they involve memory and thinking skills.

Cognitive remediation therapy (CRT) is one way to retrain the brain's memory, concentration, organizational, and planning skills. CRT exercises are adaptable and can address specific memory deficits, such as difficulty remembering names, places, or events. The results can be a better quality of life and a return to independence.

CRT exercises and tasks are typically done repetitively using a computer. The level of difficulty increases in line with the person's ability. Tasks focus on attention, memory, organization and planning, problem-solving,

and processing information. These exercises also help improve visual-spatial analysis, abstract reasoning, and other areas of intellectual awareness necessary to function in the world, including having healthy relationships.

The concept of CRT is based on “errorless learning and targeted reinforcement exercises” (Sutton, 2022). Repeating these exercises increases confidence and teaches the participant there is more than one way to look at a problem, and multiple ways to solve it. This can be a healthy reassurance to a stroke survivor.

#### PROBLEM-SOLVING AND DECISION-MAKING THERAPY AND SKILLS DEVELOPMENT

There’s a difference between cognitive rehabilitation and cognitive remediation. CRT is a collaborative rehabilitation intervention that relies on the patient’s cooperation with their physician and psychotherapist. Cognition is the key to learning motor skills. Distraction, lack of attention, and the inability to concentrate can cause mobility and balance issues resulting in falls and injury. Since more than 50% of stroke survivors experience cognitive impairment (Flint Rehab, 2023), especially with distraction and attention, cognitive rehabilitation and remediation are both necessary.

According to Tsaousides and Gordon, “cognitive rehabilitation typically targets neurocognitive processes damaged because of injury or illness and involves a series of interventions designed to retrain previously learned cognitive skills along with compensatory strategies” (Sutton, 2022). What this means is the brain has an awesome ability to change, adapt, and create new pathways for learning called synapses. When brain cells are damaged, the brain redirects traffic to another live area to compensate for the damage and retain cognitive functions. CRT effectively uses this ability, called neuroplasticity, to “[increase] activation and connectivity patterns within and across several brain regions involved in working memory and high-order executive functioning” (Sutton, 2022).

While cognitive rehabilitation uses a non-specific approach, cognitive remediation focuses on particulars. Using the Neuropsychological Educational Approach (NEAR), cognitive remediation exercises are tailored to an individual’s specific needs and allow people to work at their own pace. These exercises may strengthen specific problem-solving skills like counting money, holding and manipulating information, engaging short-term memory, and using prompts as guidance tools.

The benefit of using NEAR and other CRT techniques is the skills can transfer to real-life situations. NEAR



creates a bridge between techniques and skills learned during therapy sessions with skills necessary for daily living and independence. According to the National Institute on Aging, “lifestyle changes, including keeping your mind active, can positively impact brain health and help restore some capabilities” (Holland, 2022). Following are cognitive training exercises you can do on your own or with family and friends.

- **Analytical skills and reasoning:** Enjoy doing crossword puzzles, sudoku, and word searches. You can also find word cards at an office supply store and use them to create, arrange, and rearrange sentences.
- **Concentration, reasoning, organization and memory:** Try games like Guess Who, Qwirkle, and Battleship. These games require partners, so there’s some socialization involved.
- **Memory and motor skills:** Tap-it, Bop-it, and Simon are fun games that sharpen memory and help stroke survivors regain mobility and strength.
- **Critical thinking skills, decision making, and strategy:** Monopoly, Catan, Ticket to Ride, Mahjong, and Yahtzee are games that make you think ahead to the next move. They help you practice decision-making and outcomes.

- **Sequencing and attention:** Everyday tasks can help you relearn these skills. Separating laundry by color, stacking books by size or in alphabetical order, and alphabetizing words in a sentence all require sequencing and attention skills.
- **Problem-solving, mathematical reasoning, and short-term memory:** Get the change out of your pocket or that penny jar you keep in the closet, sort it, and count it. Arrange by coin type. Find ways to make \$1 or any other amount out of the coins you have, using different denominations.
- **Decision-making and analytical skills:** Practice decision-making by weighing pros and cons—eggs or pancakes for breakfast, sugar or honey in your tea, walking outside or getting on the treadmill. Small decisions can make a big difference.

While most stroke survivors suffer some cognitive or physical impairment, CRT can offer hope for recovery. Games and daily tasks can be more than fun; household chores can help you restore impaired cognitive abilities.

## *Language and Communication*

A tell-tale sign of a stroke is a drooping smile. Pre-stroke, I smiled a lot. I had always loved my smile, and others appreciated and complimented me on it too. Post-stroke, I had to work hard to get my smile back. I had also been a strong public speaker, but the stroke impaired my ability to think and remember words and ideas. It was frustrating and scary. I wanted to be able to speak in front of large groups again. To do that, I needed speech therapy.

Speech therapy helps stroke survivors address language impairments, including articulation, fluency, expression, vocabulary, syntax, and grammar. It helps reestablish the brain's ability to understand tone, meaning, and communication. Language and communication therapy is also helpful in training survivors to use alternative communication methods, including sign language, gestures, or assistive technologies. Speech therapists also help patients regain muscle tone in the throat, which allows them to eat and swallow—functions that are problematic for many stroke survivors.

Practicing speech therapy uses the brain's neuroplasticity to recover language functions. Stroke survivors may experience expressive aphasia, which is “caused by damage to the language center of the brain” (Flint Rehab, 2023), or apraxia of speech, which occurs from

damage to the cerebellum. Apraxia occurs when the brain can't access stored information. You can read the instructions but can't follow them. You know how to tie your shoes but can't do it. A lesion in the brain is blocking the neural pathways, like a boulder in the road.

Exercises done with a therapist or at home in a mirror can help you regain brain function in both the language center and the cerebellum. Following is a list of popular exercises used by therapists you can try at home. Try these to exercise facial, tongue, and throat muscles (Flint Rehab, 2023).

- **Tongue in-and-outs:** To train the tongue to move in coordinated patterns, stick your tongue out as far as you can and hold it for two seconds. Pull it back in and hold it for two more seconds. Repeat this ten times.
- **Side-to-side tongue movements:** Open your mouth and, using your tongue, touch the left corner of your mouth. Pull it back, then touch the right corner of your mouth. Try this ten times on each side.
- **Up-and-down tongue movements:** Open your mouth and stick out your tongue. Reach the tongue up toward your nose. Hold for two seconds. Reach the tongue down toward your

chin. Hold for two seconds. Try ten repetitions of this exercise.

- **Smile:** Stand in front of a mirror and smile. Make it as exaggerated as possible. Your goal is to teach the muscles in the face to move again. Hold your smile for two seconds, relax, and try again. Do this at least ten times, several times a day.
- **Lip puckers:** Relax your mouth, then slowly pucker your lips as if about to kiss someone. Hold the kissing position for two seconds, relax, and try again. Complete ten repetitions of this exercise.

Try these to work on pronunciation and language skills (Flint Rehab, 2023).

- **Consonant and vowel pairing repetition:** Write down the consonants that are difficult for you to say. One at a time, pair each consonant with a vowel sound. For example, if r is difficult, try saying “ra,” “re,” “ri,” “ro,” “ru,” “ry.”
- **Sentence production:** Reading aloud is very helpful for those with apraxia. Read one sentence at a time. Take your time and add more as you can.

- **Phonological processing:** Phonology is “the study of speech sound patterns” (Flint Rehab, 2023). For this exercise, get help from a friend, family member, or caregiver. Have them say a word out loud. You tell them how many syllables you hear in that word. They will let you know if you are correct. Feedback is an essential part of this therapy. Don’t get discouraged if you can’t figure it out at first. Keep practicing.

Try these things to integrate therapy, fun, and vocal training (Flint Rehab, 2023).

- **Word games:** Games like Scrabble, Boggle, and Bananagrams incorporate language skills. Sounding out the words and saying them out loud also helps. Pictionary, 20 Questions, and Go Fish require verbalizing, which is an excellent way to practice speech and have a good time.
- **Speech therapy exercise apps:** The CT Speech and Cognitive Therapy App is geared to individual cognitive development based on a personal assessment. You can use it in addition to therapy or after completing work with a therapist.

- **Singing therapy:** Those who suffer from aphasia after a stroke will have trouble doing several of the aforementioned exercises. Singing, however, comes more easily to those struggling to make sounds. Aphasia occurs in the left hemisphere of the brain, but singing is done with the right hemisphere. Those experiencing aphasia can sing words and sounds rather than trying to verbalize them.

Remember that repetition is the key to success, no matter what exercise therapy program you follow.

## EXECUTIVE FUNCTIONING AND OVERWHELM

I returned to work for the second time in late January 2018, about six months after my first stroke and following two back-to-back stays in mental health facilities. Again, I thought I was ready, but about a week after returning to work, my boss pulled me aside to tell me I needed to take on new responsibilities after one of my colleagues left the company. I had to take over all content around marketing to millennials and manage the company's high-profile blog, along with my regular duties of marketing to Gen Z. I was terrified. I didn't know the first thing about marketing to millennials,

who were totally different from Gen Z, my area of expertise. My boss didn't understand what the stroke had stolen from me or care whether I could manage it. He simply assumed I could and would do the job he assigned.

Change is frightening to people with brain injuries or mental health issues. Structure is the key to getting through each day intact. Even before my job expanded, I was stressed about work after my stroke. My daily morning routine took nearly three hours before I could muster the courage to head out the door. I'd wake up, work out, meditate, shower, eat breakfast, meditate, get dressed, then hit the road for the 30-minute drive to work, talking myself off the ledge all the way. Once I got there, I still sat in my car for ten or 15 minutes every day to pull myself together, emotionally, and mentally. As you can imagine, this was draining and unsustainable.

The sudden change in my job responsibilities meant I had to learn new skills, like managing the back end of blogging technology, which I wasn't comfortable doing. My boss expected me to excel in these new duties, because I had always excelled at work. I had the same expectation of myself but was concerned my brain couldn't manage these new duties in addition to my other obligations.



Executive functioning is how our brain thinks, solves problems, acts and reacts, and develops behavior patterns, reasoning, and planning patterns. When you have a stroke, those functions can be severely impaired. I felt like mine were non-existent, but I had to do my job. I wasn't sure I could break down tasks into manageable steps, organize and plan meetings, set goals, and navigate all the new skills I had to learn. I put so much pressure on myself that I grew to hate my job and my boss.

On April 16, 2018, I had a headache at work that plagued me all day. I couldn't think straight and had trouble concentrating. I felt dizzy. On my way to a therapy session that afternoon, I missed my turnoff and ended up causing a car accident. I opted to go to the emergency room to get checked out because I was on blood thinners and didn't want to take any chances.

They took a CT scan of my chest and neck. I hadn't bumped my head, so the doctors weren't overly concerned. They sent me home that evening with painkillers and muscle relaxers. Later that night, I got up to use the bathroom, and passed out on my bathroom floor with a crash that startled Steve awake.

The next morning, after learning about my fainting spell, my sisters insisted I go back to the emergency room. My fainting spell scared them, although I

assumed it was from the painkillers and muscle relaxers. To make a long story short, a magnetic resonance imaging (MRI) scan in the ER showed I had suffered another stroke, or “new stroke activity,” as they called it, whatever that meant. I decided never to return to the job I had grown to despise. I suspected the stress of the job had caused both strokes. And my primary care physician agreed. She told me I should never return to such a pressure-filled position. That’s tough for a Type-A, perfectionist to hear.

## BRAIN EXERCISES YOU CAN DO AT HOME

According to the American Stroke Association, “10% of stroke survivors will make a complete recovery... 25% will have minor impairments in their capabilities... 40% will experience moderate to severe impairment... and 10% will require long-term care” (Holland, 2022). The good news, however, is that recovery can happen even years after a stroke and continue throughout the person’s lifetime. Everything depends on how fast the person gets help, the extent of the brain damage, and the quality of care afterward. The sooner you begin brain exercises and therapy, the better. This usually starts before you leave the hospital. Following are more brain exercises you can do at home.

- **Visuospatial processing games:** You use visual-spatial skills to understand what you see around you, depth perception, analyzing and perceiving details, and the ability to tell where objects are in space. The What's the Difference app challenges you to find the difference between two seemingly identical pictures.
- **Navigation skills:** Reading maps and giving directions is a good way to work on visual-spatial processing. Giving directions uses sequencing and imagination skills.
- **Cooking:** Following a recipe also involves sequencing skills. Have someone help you in the kitchen your first few times until you get the hang of doing multiple tasks at a time.
- **Recreation therapy:** This can include arts and crafts that work on hand-eye coordination. Wii gaming, gardening, jewelry making, calligraphy, and model railroads are also recreational therapies for stroke survivors.

## TIPS FOR CAREGIVERS: WHAT TO SAY TO A STROKE SURVIVOR

There are ways to encourage a stroke survivor with compassion and care. What you say to your stroke survivor loved one can be detrimental or instrumental

to their physical and mental health and recovery. Words are powerful. We create our worlds with them. You can empower a stroke survivor with these phrases.

- **I'm here for you. You're doing great. I believe in you.** These statements are empowering, motivating, and supportive. If only one person believes in you, you can achieve any goal. I was fortunate to have my husband, children, parents, siblings, and friends supporting “Team Angie,” and encouraging me every step of my recovery. Beliefs originate from what we hear, see, sense, and understand in our physical environment. They are the “preset, organized filters to our perceptions of the world—external and internal” (Sathyanarayana Rao et al, 2009). What you are consistently told every day programs your brain to believe in that thing. If someone tells you regularly that they believe in you, you will eventually begin to believe in yourself.
- **Let's work together. We'll get through this together.** One of the major components of recovery for stroke survivors is support. If your loved one had previously been hyper-independent, asking for help may be humiliating. They may feel guilty, embarrassed,

or inferior. The idea of working together with someone, however, shows collaboration.

Collaborations encourage shared responsibilities and a sense of purpose.

- **I'm proud of your progress.** Praise gets better results than pity or punishment. Praise helps a person feel seen. Recovery is hard work and can be defeating. It helps to know that someone sees their struggle and understands and appreciates their efforts.
- **Your feelings are valid and important.** Have you ever told your child, a student, or someone you mentored that what you say to them “goes in one ear and out the other?” We all understand the importance of listening, but most of us don't know how to do it. You can be unwittingly dismissive when you don't understand what people are going through or when you're impatient with the story they need to tell. We all want our feelings and experiences confirmed. It makes us feel like we count.
- **What do you need right now?** Your stroke survivor loved one won't always know what they need, especially long term. Sometimes they can't even think about that. Asking someone what they need in the moment is important because they may just need a hug, someone to

hold their hand, a listening ear, or companionable silence.

- **I love you.** This is the most powerful statement of all. It offers grace and acceptance to someone having a rough time or feeling unattractive and unacceptable. There are various ways to say “I love you.” The after-effects of a stroke can include mood swings and emotional indifference. Don’t worry if the words don’t seem to reach the person in a deep and meaningful way. Try expressing your love in other ways, including, but not limited to:

- Actively listening to whatever they need to say.
- Touch. If this is irritating to the person, don’t force it. ○ Acceptable forms of touch may be lightly touching their hand, arm, or cheek—whatever works for them.
- Eye contact. Look into their eyes. Focus on them, especially if they are trying to communicate with you.
- Gift them with a flower, music, or meditation app.
- Offer a massage or soothe them by brushing their hair. ○ Experiment with new ways to show expressions of love to the one you care about.

- **You are not alone.** There is no one so lonely as the person standing in a crowd of people who still feels isolated. Having a stroke is like that. No matter how difficult things may get, they need to know they don't have to weather the storms alone. These words can be comforting and reassuring.

## INTERACTIVES

The brain needs exercise, but it also needs rest. Include some of the following in your recovery program:

- Take a nap. Set a timer for 30 minutes at midday and take a siesta. Limit it to 30 minutes so you can sleep at night.
- Watch documentaries to keep your brain engaged.
- Listen to or create a podcast. You can share your story with a live audience or learn from the stories of others.
- Play Jenga or try the FitMi and Music Glove apps to improve your fine motor skills.





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SURPRISE FACTOR 1—POST-  
STROKE ANXIETY

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*Never give up on a dream just because of the time it  
will take to accomplish it. The time will pass anyway.*

— EARL NIGHTINGALE

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**P**re-stroke, I had always been a bit of a perfectionist, pursuing achievement, and reaching for that next career goal or accomplishment. I was confident in my skills and abilities. Post-stroke, I experienced immobilizing anxiety concerning my self-worth, my talents, skills, and abilities. Right before my first stroke, I had written a book about marketing to Gen Z and turned it over to the publisher. After my

stroke, I obsessed over the editing process, feeling that my book was awful and wouldn't sell. I agonized over citations and the possibility of plagiarism. Thoughts of failure tormented me. I spent sleepless nights and days paralyzed with fear.

Like most stroke survivors, I experienced intense bouts of anxiety about things I had no control over. To self-soothe, I would sit with my arms wrapped around my knees, rocking back and forth. Day or night, when I felt those waves of panic take over, I would end up in a fetal position, sometimes even on the floor at the bottom the stairs. Nothing I did, however, would ease my distress. I desperately needed help.

## SYMPTOMS OF POST-STROKE ANXIETY

Post-stroke anxiety (PSA) is common for many stroke victims. The fear of a recurring stroke, the possibility of an inability to communicate should it happen while you are alone, and wondering if you can take care of yourself is omnipresent and real. You may be haunted by guilt and shame when dealing with cognitive disorders and the loss of bodily functions. Nightmares, flashbacks, drastic mood swings, heightened sensitivity, and near-constant triggering can make you feel like you're being pulled underwater.

While many people suffer from sudden or frequent panic attacks, others may experience obsessive-compulsive behaviors and irrational phobias. Other major types of anxiety disorders include the following (Cuncic, 2023):

- **Generalized anxiety disorder (GAD):** characterized by “constant worry and anxiety about a wide variety of concerns in the absence of a specific threat.”
- **Social anxiety disorder (SAD):** characterized by “an irrational fear of being observed, judged, or embarrassed that causes severe anxiety in social situations.”
- **Post-traumatic stress disorder (PTSD):** characterized by “anxiety symptoms following a traumatic experience.”

All or some of these things can be present at once. In my book, *A Brain's Betrayal: My Stroke Story*, I share my experience with PSA (Read Doyal, 2020).

Since the stroke, I had changed. My voice had no color, no inflection. I hadn't been sleeping or eating for more than two months and I felt like I was losing my mind. I couldn't write a cohesive sentence or stop editing my book. I'd started word-smithing to the point of obses-

sion. I felt like I was losing my mind. Unfortunately, I was. (p. 34)

I was experiencing all the symptoms of PSA without being able to pinpoint what it was. I experienced the constant worry characterized by GAD. My panic attacks were sudden and frequent. I was obsessive compulsive about my writing and editing work. I had irrational phobias, believing that people were constantly lying to me to make me feel better about my book, which made me feel worse and more obsessive. I was insecure and embarrassed, thinking everyone would think I was a “fraud” or imposter. I felt like I was under a microscope, everyone was watching me, and I was coming up short of their expectations. I wanted my book to be perfect. I wanted my life to be back to normal. I struggled with making things just right and feeling like everything was always all wrong.

The disorders associated with PSA follow specific patterns that fuel fear and anxiety. According to an article in *Very Well Mind* that addresses PSA, “People with anxiety tend to react to unpleasant thoughts, feelings, and situations in a more extreme way and may try to manage those reactions by avoiding triggers. Unfortunately, this type of avoidance only serves to reinforce fears and worries” (Cuncic, 2020). This is what was happening to me.

## POST-STROKE ANXIETY THERAPIES

Anxiety disorders and therapy can be diverse and individually unique. The goal of therapy is to help you assess why you're experiencing anxiety and what triggers make you feel the way you do. Most therapies for anxiety address negative emotions and feelings. They help you discover how to rethink your perceptions and reprogram your reactions.

My family was worried about what was happening to me. My husband Steve felt helpless. Nothing he did or said could soothe me. I was no longer the happy-go-lucky person my family was used to. My sisters suggested going for walks, and they came to my house to walk with me, but that wasn't a magic cure. I still felt anxious and depressed. Rolling myself up into a ball, pacing the floor, and lying down at the bottom of the stairs throughout the day must have been terrifying for my entire family. Where had I gone? How was I going to get back?

My sister Melissa took me to visit a psychiatrist, who suggested I get evaluated for an Intensive Outpatient Program (IOP). Together, Melissa and I headed straight to a behavioral health center for an evaluation. I cried throughout the interview, trying hard to resist the temptation to pull my knees up to my chest, gather

myself into a ball, and gently rock myself for comfort. I had returned to work too soon after the stroke, thinking I would be okay. I was anything but. The added pressure and stress had brought me to a complete and total breakdown. I thought because I had recovered physically so quickly, that I could manage it. After all, I was Angie, my own superhero. But superheroes are only fantasy. The reality hit me like a ton of bricks on my chest, crushing me. My doctor had failed to give me adequate information about the psychological side of what happens after a stroke. I learned for myself how mentally devastating a stroke could be.

There are different kinds of PSA therapy tailored to the individual's symptoms, diagnosis, and severity. Following are some therapies psychologists and psychiatrists recommend (Cuncic, 2023).

- **Cognitive behavioral therapy (CBT):** This therapy is the most widely used for anxiety disorders. The premise of CBT is to change your thought patterns. Since most people with anxiety think in black and white, usually predicated on a worst-case scenario, CBT offers strategies to process your thoughts, accepting that there are shades of gray. “The goal of CBT is to identify and understand your negative thinking and ineffective behavior patterns and

replace them with more realistic thoughts and effective actions and coping mechanisms” (Cuncic, 2023). Once you learn the recommended strategies, you can practice applying them by recognizing the triggers that set you off.

- **Exposure therapy:** This therapy helps treat anxiety disorders, more specifically SAD, PTSD, and specific phobias. Its premise is to treat phobias by facing them head-on using systematic desensitization. This technique involves relaxation training, listing triggers, and exposure to the things that provoke your anxiety. Exposure may include vividly imagining an object or situation, facing that situation or object in real life, or using technology to combine the two.
- **Dialectical behavioral therapy:** This therapy, originally used to treat borderline personality disorder (BPD), helps you see positive versus negative outlooks. You learn to accept your anxiety while learning how to change your perceptions. Therapy includes mindfulness, distress tolerance, interpersonal effectiveness, and emotional regulation. Mindfulness is living in the moment and accepting your anxious thoughts “without being ruled by them” (Cuncic,

2023). Distress tolerance is learning to manage your anxiety in stressful situations. Interpersonal effectiveness involves setting boundaries without guilt and asking for what you need. Emotional regulation teaches you techniques to name and manage your anxiety before it gets out of control.

- **Acceptance and commitment therapy (ACT):**

What are your core values? How do you demonstrate or live those values? This is the premise of ACT. Its two main components are accepting what has happened to you and understanding that you don't have to suppress your feelings, plus learning and committing to emotional strategies that help you withstand the discomfort. Mindfulness is also an important part of ACT.

- **Art therapy:** This nonverbal therapy helps you express yourself through the fine and performing arts. Painting, drawing, sculpting, and dancing are all forms of mindfulness and relaxation therapy using the arts. Art therapy is often coupled with CBT or other therapies.

- **Psychoanalytic therapy:** This therapy is done in consultation with your therapist. Together you will “examine your thoughts, fears, and desires to better understand how you view



yourself and to reduce your anxiety. This is one of the most intensive forms of treatment; it can take years to identify patterns in your way of thinking” (Cuncic, 2023).

- **Interpersonal therapy (IPT):** This type of therapy helps you identify and assess relationships with family and friends, interpersonal conflicts, unresolved grief, and the effects of social, work, and career changes. It was originally developed to treat deep depression. Its goal is to help you “learn healthy ways to express emotions and ways to improve your communication with others” (Cuncic, 2023).

Anxiety is highly treatable when correctly assessed. My first evaluation at the mental health facility included a long line of questioning. Afterward, the evaluator talked to the doctor and told me they were admitting me for in-patient care. I was shocked. I knew how bad I had been feeling, but I didn’t realize how much help I truly needed until that moment.

My husband was relieved. He thought that if they just gave me enough medication to knock me out, I could finally get some much-needed sleep and feel better. Yes, I desperately needed sleep after months of unrelenting

insomnia. But sleep was not the primary thing on the agenda. I had a heavily padded to-do list.

My room at the facility was a blank, desolate, beige space with no pictures on the wall, no clock, and a bed locked in position. I couldn't even raise the head of the bed without calling a nurse. They locked up my personal belongings and I had to relinquish my cell phone, sending it home with Steve. As soon as Steve left on that first morning, a staff member gave me a daily schedule, packed with hourly group sessions and appointments with the staff psychiatrist. In between, I could work on puzzles, color, play cards with other patients, read books, or watch limited TV. I've never been a fan of puzzles, adult coloring, or card games, and when I tried to read one of the few books available, I couldn't concentrate enough to understand the words on the pages.

There were patients in the facility suffering from hallucinations. Several teens and young adults were there for attempting suicide, and there was a population of recovering addicts detoxing. I felt alone and scared, like I was being punished for my inability to cope. I thought I was "normal," not like everyone else. I didn't realize we were all suffering from the trauma and brain abnormalities that plagued our lives.

The nurses gave me medication to help me sleep, a journal, and a dull pencil to write down my innermost thoughts. I stayed in the facility for five days before being sent home. I later threw away my journal because it distressed me to read the dark thoughts and feelings I had about myself. I remember constantly calling myself a “fraud, stupid, and worthless piece of shit” (Read Doyal, 2020). The medication did help me sleep but it didn’t remove those negative thoughts.

This is why getting the right therapy is vital to your recovery. Medications alone can only do so much and take you so far. Medication is an uncertain science full of experimentation, especially regarding the brain, which operates so differently in every person. There are no guarantees when you add PSA therapies to your medical treatments. However, you do have a much better chance of long-term recovery.

Inpatient mental health facilities aren’t cure-alls either. They exist to help patients in crisis. You don’t get much—if any—one-on-one therapy in a crisis center. All they can do is mitigate the immediate crisis and help you find a path to mental health healing. It’s the work you do after your release and the access you have to other therapeutic care that set you up for recovery. Do your due diligence and research what your medical insurance covers for mental health. You may be surprised at

what it includes. Check out your local community resources as well. See the resources at the end of this book. Help is out there.

## THE TRUTH ABOUT ANXIETY, DEPRESSION, AND THERAPY

I shared that at one point, I had become manic, obsessive, and paranoid, belittling myself and ignoring the encouragement of family and friends. I was intensely fearful of failure, my thoughts of inadequacy keeping me up late into the night and early morning and leaving me in a puddle on the floor. Panic attacks and anxiety manifest in different ways, including:

- racing heart or palpitations that make you feel like you're having a heart attack
- intense fear or terror
- shortness of breath or hyperventilation
- chest pain or discomfort
- sweating or chills
- trembling or shaking
- nausea or stomach discomfort
- feeling of choking or suffocation
- dizziness or lightheadedness
- tingling or numbness in the extremities
- fear of losing control or going crazy

- sense of impending doom or death

There were times after my stroke when I felt the weight of the world on my chest in a very real way. On those occasions, I would try to self-soothe by putting one hand on my chest, taking deep breaths, and imagining it was my mother's loving hand soothing the child in me. Other times I had recurring dizziness and lightheadedness. I would stand up, see tiny electric stars in my peripheral vision, and feel like I was going to pass out. On two occasions, I did pass out and woke up on the floor wondering how I got there. I learned later that two of my new medications were causing my blood pressure to drop dangerously low, and I needed them recalibrated. After a few months of experimentation, my doctors and I found the medication combination that worked best for me.

It also took time and a sad revelation to realize that my distrust stemmed from the fact that "anxiety and depression were lying to me" (Read Doyal, 2020) and I believed their false accusations. During my time at Shawnee Mission Behavioral Health (SMBH), unlike many of the patients, I had visitors every day. You were allowed visitors during lunch or for an hour in the evening. I was fortunate to see family members every single visiting period, but I was too ashamed to let any of my friends know I was there. Some residents never

had visitors. This happens quite often in rehabilitation facilities. People don't realize how important family support is to recovery. Everyone needs someone who can act as an advocate in these situations, making sure the person is being properly cared for and not being abused or getting the wrong treatment. The neglect the patient feels when left to face these situations alone can be mentally and physically devastating and even life-threatening. I was fortunate and continue to be grateful for my support team, especially my husband and sisters who insisted I never experience a day without someone there beside me.

I was eventually diagnosed with generalized anxiety disorder (GAD) and major depressive disorder (MDD). My primary goal while I was in SMBH was to get out! I wrote in my book, *A Brain's Betrayal: My Stroke Story* (Read Doyal, 2020):

You do what's required of you to get out as soon as possible because it's scary, BORING, and lonely. So, you go to all the group sessions, you show up on time for every meal, you take your meds without complaint, and you tell the psychiatrist what he/she wants to hear. I just kept thinking, "If I could just go home, I'd feel so much better." Because you end up feeling like you're going CRAZY (or getting worse) just by being there. (p. 39)

Being stripped of who you were and knew before your stroke can destroy your self-esteem, confidence, and self-worth. If you were as career driven and focused as I was, this can crush your ego. I was a budding author, but I couldn't put two words together. I couldn't concentrate or remember things. I was stripped of everything I had been really good at. Who was I without those things? I had no idea.

Once you come to the end of your rope, you can learn what's really important if you're open to therapy. Therapy can help you get in tune with your core values. Family has always been important to me. Therapy helped me to reconnect. It also eventually allowed me to help another family member going through a mental health crisis.

My psychiatrist, Dr. Brown, ordered tests to figure out whether my cognitive deficiencies were from brain damage from the stroke, or from the depression and anxiety. He discovered that though the stroke was the cause of my anxiety and depression, the anxiety and depression fueled my cognitive impairments. It was a concentric circle of personal agony.

When I left SMBH, I wasn't healed or cured. I simply followed instructions to get released. I went home thinking I could do it on my own, that I would be better off at home, that I would be okay. This is one of the

most dangerous things you can do when dealing with mental health problems. You are not a reliable source in that state. Like a drug addict, the first step is admitting you can't do it alone, that you need help. The next step is outsourcing that help to professionals and committing to do the work.

Unfortunately, I left the hospital without a game plan for the next several days. I was supposed to start their intensive outpatient program (IOP) three days after my release, but the three days in between were the darkest, scariest, most difficult days of my life. My insomnia, pacing, and rocking had returned with a vengeance. At 2:00 am, my first night home, I stood in my bathroom examining all my medications. For the first time ever, I considered swallowing them all and taking my own life.

Suicidal ideation is common for those experiencing deep depression. That's why it's so dangerous to rely on yourself as the authority in your life during depressive moments. Depression and anxiety will lie to you, telling you that you are worthless, unloved, unwanted, and nothing more than a burden to those around you. You think that everyone will be better off if you aren't alive. Depression will bombard you with reasons you are an idiot, a failure, and unlovable. The more you think on these things, the deeper you spiral until your thoughts



are completely out of control and taking your life seems like the only solution.

The American Foundation for Suicide Prevention released a fact sheet saying more than 12 million people in the United States experience suicidal thoughts, and 1.4 million complete suicides per year. People suffering from PTSD, anxiety disorders, depression, substance abuse, and other psychiatric disorders are “at higher risk of suicide” (Robb-Dover, 2022). Most people don’t want to discuss this subject, but you cannot heal what you hide.

Guilt, and my love for my family, kept me from taking my life that night. I felt guilty that God had allowed me to survive a stroke, yet I didn’t want to continue living. But I couldn’t leave my family with the immense grief I knew they would experience if I followed through on my thoughts.

Steve was so worried about me at one point he posted a message on Facebook calling on “Team Angie” for their support to help me through “new, stroke-related setbacks.” I was livid! How dare he have people thinking I was a victim? That I couldn’t take care of myself? How dare he expose my personal weaknesses? It’s odd that no matter how damaged and in need of help we human beings are, we still want to protect our image.

I didn't think anyone would understand what I was going through, and I didn't want them to find out. I didn't want their pity and I didn't have the energy for explanations or answers. I didn't want anyone to think I was weak.

Steve did find a roundabout way of getting me the help I needed. He quietly contacted a select group of people. Close friends and family brought me lunch daily and sat with me for hours to listen to me rant about my unrealistic expectations and concerns. Of course, they tried to soothe me, but I was in a constant state of distrust and didn't believe them. My family was livid that SMBH had sent me home in the condition I was in, but I can't blame the facility. I gave them only what was needed to get out. I played the game. I didn't realize that I was losing by not being honest with them or myself.

My sisters, Pam, and Melissa were at the top of Steve's contact list. On the day I was supposed to start the IOP, I didn't want to go, and I didn't have the heart to wake Steve, who had not slept well in days because of his concern for me. I texted my sisters and told them I wasn't going. I thought just telling them would put an end to it. Boy, was I grossly mistaken. Following is the actual account of what happened as recorded in my

book, *A Brain's Betrayal: My Stroke Story* (Read Doyal, 2020):

Melissa called to try to talk me down from my panicked state and convince me to go. She also told me Pam was on her way over. When Pam got to our house, she said, "Get up. Get dressed! I'm taking you!" I didn't have the strength. I couldn't get off the floor. But she wouldn't take no for an answer, so she helped me put on clothes. She got me into the passenger side of her car – looking as bad as I felt (I know for sure I didn't have on a bra and hadn't brushed my hair or teeth). I couldn't care less about those things. By that point Steve was awake and really mad at me for not waking him up in time to take me to the IOP. (Poor guy was as exhausted as I was after trying to take care of me for the three days I'd been home since being released from SMBH.) He was trying to hold down his job, the house, the kids, and keep our lives on track while my behavior was going off the rails. (p. 43)

Pam didn't take me to outpatient therapy that morning. She insisted instead on taking me to Cottonwood Springs, a newer facility that housed patients according to psychiatric need and diagnosis, instead of lumping everyone all together. There was also a courtyard where patients could go outside and get fresh air and sunshine, so it sounded nice. I was evaluated and

admitted to Cottonwood Springs that same morning. Steve, Pam, and Melissa were incredibly supportive, reassuring me, hugging me, and loving me. It is not lost on me how fortunate I am to have such a strong support system. I wish everyone did!

Cottonwood Springs wasn't perfect, but the facility saved lives, which was the ultimate reason for its existence. I was there for a week before being released and this time, I was no longer in crisis. I went home December 15, 2017, and started outpatient therapy before Christmas. Melissa, who had done the groundwork to find Cottonwood Springs, also found the Anxiety Center at Renew Counseling Center, an outpatient facility that catered to my specific needs.

After all that, my brain was finally reset to restoration mode. It was a slow process, but I was finally sleeping, sometimes up to 12 hours a night. That meant Steve was also finally able to get some rest, or at least I hoped he was. I wasn't fully "cured." When it comes to depression and anxiety, you may always need a reboot. Avoid judging yourself about that. Check the resources the end of the book if you are stuck in suicidal ideation or feeling depressed, sad, or anxious. Know that help is there for you when you need it. You only have to ask.

## TIPS FOR CAREGIVERS: HOW TO HELP A STROKE SURVIVOR DEAL WITH ANXIETY AND DEPRESSION

One of the best things you can do for a stroke survivor struggling with anxiety and depression is to remain calm and nonjudgmental. Their experience is not your experience, even if you have suffered from anxiety and depression. Some other tips to apply are to:

- offer reassurance and comfort
- help them practice deep breathing or relaxation techniques
- help them focus on the present moment
- avoid trying to reason with them or minimize their experience
- stay with them until the panic attack subsides
- help them identify triggers and develop coping strategies
- avoid making physical contact unless they request it
- provide a quiet and safe environment if possible

## INTERACTIVES

### *DIY Anxiety Therapy*

- Practice deep breathing and relaxation techniques.
- Exercise regularly to reduce tension and improve mood.
- Eat healthy foods.
- Limit caffeine, alcohol, and nicotine intake.
- Get enough sleep and establish a consistent sleep routine.
- Identify and challenge negative thoughts.
- Connect with supportive friends and family.
- Try mindfulness meditation or therapy.
- Write down worries and develop coping strategies.
- Take anti-anxiety medications or antidepressants as prescribed.
- Engage your senses and get outside.
- Notice situations or activities that may trigger your panic attacks and try to avoid or minimize them if possible.

### *Mood Diary*

Are you attending any therapy sessions? How do you feel about your therapist? Are the sessions helping you,

and if so, how? If not, why not? List your supporters. Do you have friends, family, relatives, or a community that can advocate for you or help you in some way? Is there anyone or any place you can go to find resources? Record all of this in a journal or your mood diary.

### *Apps to Investigate*

- **Moodkit CBT** by Thriveport helps you apply what you are learning in mental health therapy. It helps you identify triggers and change unhealthy thinking patterns. You can create journal entries and track your mood over time.
- **Worry Watch** offers coping techniques to help you deal with anxiety. It features guided anxiety journaling, guided coping techniques, guided mood check-in, and guided positive reinforcements.





SURPRISE FACTOR 2—POST-  
STROKE DEPRESSION

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*You're braver than you believe, and stronger than you seem, and smarter than you think.*

— A.A. MILNE

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**P**eople describe depression as being sad; though that may be true, depression goes much deeper than that. Constant negative thoughts can change the brain's chemistry. Trauma can change brain chemistry. Physical disability can affect nerves that change brain chemistry. My stroke caused my anxiety and depression. My anxiety and depression changed the chemical balance within my brain and made me more susceptible

to another stroke. Depression goes much deeper than temporary sadness. In fact, I felt more numb than sad.

## SYMPTOMS OF POST-STROKE DEPRESSION

Therapy and medication helped relieve my anxiety and finally sleep at night. Still, depression made its way to the forefront. Depression shows up in persistent feelings of sadness, hopelessness, or emptiness. I was no longer interested in the things I used to enjoy. Even though I was finally getting enough sleep, I still didn't care much about what I wore or how I looked. I was eating again, but I was void of emotion. This dragged on for months.

Depression can show up in lots of different ways. You can experience a change in appetite that includes overeating, not eating enough, or eating nothing. You can gain weight excessively or lose it. Sleep patterns can be interrupted, or you can sleep all day as a way of escape. You may feel constantly fatigued or lackluster for no clear reason. Physical manifestations can include headaches, nausea, and other stomach problems. Like Eeyore from Winnie the Pooh, you can feel unmotivated and unenthusiastic, withdrawing from social activities and interactions. You isolate, self-medicate, and adopt unhealthy habits to ease the pain of how you feel. Feelings of inadequacy, worthlessness, guilt, and

shame hamper your ability to cope with stress. You despise yourself for who you are and who you are not. You consider yourself unworthy, unacceptable, and unnecessary. Thoughts of suicide follow, and you wrestle them, only for them to return. Without help, you face an ongoing struggle with possibly dire consequences.

I completed my intensive outpatient therapy in mid-January. Intense was a suitable word for my sessions. The counselors themselves had survived anxiety and depression, so they knew how it all worked. It was comforting to know that I was collaborating with people who understood what I was going through. The program aimed to help people find new ways to cope with their disorders. The therapy included mindfulness training and learning the tools necessary to cope with our condition. By the end of the six-week program, I felt more normal. I was ready to go back to work. Or so I thought. My family thought I was rushing things again, but I pressed ahead. It's tough to stop someone whose internal compass has always been set to *go*.

I had previously accepted an engagement for January 25th to speak about my book on marketing to Gen Z. I'm a woman of my word, so when I say I'm going to do something, I don't back down. I was given an hour slot and a camera crew to film a promotional video for my

book. I was nervous. Panic set in. I had to use the tools I learned in therapy. With my heart in my throat, I began by telling a story about my stroke since it occurred exactly six months to the day earlier. From there I went into my presentation. The audience loved the presentation, and I got rave reviews, yet I still questioned myself. I was angry with myself for not using the entire hour for the presentation and instead splitting it into 30 minutes for the lecture and 30 minutes for questions. The questions were excellent, and I answered them easily. I knew my topic like the back of my hand. I should have been proud of myself, but the old program was still repeating in my head. Everyone said I was good. Even reviewing the tape, I saw that I did a nice job. But it wasn't perfect. I needed to be perfect.

## PERFECTIONISM AND DEPRESSION

Perfectionism and depression feed off one another. Perfectionist personalities are more prone to anxiety and depression. Depression, in turn, increases the need to be perfect. Around and around it goes, making you increasingly unhappy and dissatisfied with yourself and others.

Perfection defined is “a personality trait characterized by efforts toward and desires for flawlessness. Perfectionists set unrealistically high standards for

themselves, others, or both. Although perfectionism can boost performance in some cases, it often undermines the achievement of goals when people succumb to highly critical attitudes” (Newman & SOL Mental Health, 2021). Perfectionism manifests in obsessive behaviors: high perfectionism and perfectionistic striving.

A study from 2021 called *Is Perfectionism a Vulnerability Factor for Depressive Symptoms, a Complication of Depressive Symptoms, or Both?* determined that high perfectionists “overreact to errors, often second-guess their actions, experience discrepancy between their actual self and their ideal self, and fear disapproval from others” (Newman & SOL Mental Health, 2021). Those whose behaviors manifest in perfectionistic striving differ slightly in that they “typically hold lofty goals [for themselves] and have internalized expectations of success and productivity... associated with high achievement” (Newman & SOL Mental Health, 2021). This often holds true for people who’ve achieved significant accomplishments in their field, especially those in the public eye.

The study found five key relationships between depression and perfectionism (Newman & SOL Mental Health, 2021):

- **“Perfectionistic concerns can lead to increased depressive symptoms over time.”** You can be your own worst critic. When you fall into excessive self-criticism and self-deprecation, constantly overreacting to mistakes and errors in judgment, you open the door for depressing thoughts to stroll in and make themselves at home.
- **“People higher in perfectionistic concerns perceive and encounter more negative social interactions.”** You can become socially disconnected because you perceive others as looking at you or thinking negatively about you. You feel like an oddball or the black sheep, so keep your distance. You are socially isolated. You also respond poorly to stress. These things combined lead to social anxiety and depression.
- **“People high in perfectionistic concerns may see themselves as having less emotional control.”** You have this notion that you must be perfect. In your mind, feeling depressed equates to failure because you can’t control your emotions. Perfectionism is about controlling

the narrative and perception. Losing that control feels like weakness.

- **“Unrealistic goals can lead to a higher frequency of perceived failures.”** You have set lofty goals for yourself. You are used to being a high achiever. You strive for perfection in everything you do. Failure is not an option. Doing well is not good enough. You must be the best, but your best is not good enough. You have to be better than anyone else.
- **“People with self-oriented perfectionism are more vulnerable to depressive symptoms.”** Perfectionistic striving is not the result of depression. Instead, the reverse is true. Those who strive to be perfect tend to become depressed because perfection is an unattainable goal.

There is absolutely nothing wrong with striving to do your best. There is nothing wrong with setting high goals and working hard to achieve them. However, perfection becoming all-consuming can lead to obsessive behaviors that spur depression, resulting in low self-esteem, feelings of helplessness, hopelessness, and maladaptive coping behaviors. When you have a stroke, these symptoms can intensify.

Treating depression through psychotherapy, medications, meditation, CBT, and self-compassion can eventually remove the driving forces that lead to perfectionism. Changing your daily habits and your mindset can also help you get into a better headspace. The same therapies that work for anxiety are also helpful with perfectionist tendencies.

## THERAPIES FOR POST-STROKE DEPRESSION

Psychotherapy, often called talk therapy, when combined with an antidepressant, has proven to be the most effective treatment for depression (Schimelpfening, 2022). Other helpful therapies include (Schimelpfening, 2022):

- **Cognitive therapy:** This therapy focuses on changing cognitive distortions or patterns of negative thinking.
- **Behavioral activation therapy:** This focuses on ways to increase enjoyment through chosen activities.
- **Physical exercise** can also help improve your mood and reduce stress. Walk on a treadmill. Ride a bike. Lift weights seated or standing. Activate your physical body.



- **CBT:** We addressed this in the previous chapter. CBT focuses on working through things like overthinking and overgeneralization associated with depression. Homework includes journaling, practice exercises, relaxation, readings, and worksheets.
- **Dialectical behavior therapy:** We also covered this in Chapter 4. It involves practicing validation and incorporates mindfulness. You acknowledge your negative emotions instead of burying them and learn new ways to cope.

These therapy approaches can include one-on-one work, family therapy, group therapy, and couples therapy. Each type has a specific audience. Family therapy is helpful when a family dynamic contributes to the overall mental health of the patient. Group therapy usually involves a small group of about 15 people or less with similar issues, allowing everyone to receive help and support. It is also the least expensive of the therapies. Couples therapy helps married couples or those in committed relationships. It is not uncommon for PSD to affect your relationships. Use whatever approaches work best for you and your family.

## DIY DEPRESSION THERAPY

There are also ways you can help yourself through depressive behavior. For example, nutrition is medicine: You really are what you eat. Nutritionist May Simpkin for *Healthista* claims that diet and depression are interconnected. She says food plays a pivotal role in how the body works—an often-overlooked role. Food is fuel for the brain as well as the body. Simpkin recommends seven diet changes to help stave off depression (Simpkin, 2018):

- **Get enough protein.** Protein is made up of amino acids. Serotonin and dopamine, the feel-good neurotransmitters, are made up of amino acids, aka protein.
- **B vitamins are your friend.** They play a crucial role in converting amino acids to neurotransmitters. If you're not getting enough B vitamins, you're not making enough dopamine and serotonin. Doctors often recommend supplements for stroke patients and those suffering from depression. Foods rich in B vitamins include whole grains, spinach, kidney beans, chickpeas, lentils, quinoa, salmon, eggs, and pecans.

- **Healthy fats are essential.** Nerve cells are made up of fat. Some fats are unhealthy. Still, essential fats are necessary and can be found in oily fish (salmon, sardines, mackerel), avocados, and walnuts.
- **Treat your gut well.** Gut health can have a good or bad effect on mood. “About 95% of serotonin is produced in the gut” (Simpkin, 2018). Eat plenty of fiber to produce good bacteria, eliminate sweets that produce bad gut bacteria, and consume fermented foods like kimchi, miso, sauerkraut, and pickles. You can also try probiotics for better gut health.
- **Stay away from the sweet stuff.** The less refined white sugar you consume, the better. The blood absorbs sugar quickly, so you get a sugar rush, but a crash comes afterward that can leave you feeling sluggish, fatigued, and—you guessed it—anxious and depressed. Try complex carbohydrates like sweet potatoes, whole grains, carrots, parsnips, and butternut squash. Pair them with proteins to release sugar more slowly into the bloodstream.
- **Keep your hormones in check.** Estrogen and progesterone “can influence the pathways that antidepressant medications also act upon, affecting how the neurotransmitters serotonin,

dopamine, and GABA work on the brain” (Simpkin, 2018). Eating vegetables, beans, and pulses that contain phytoestrogens can help balance the hormones.

- **Reduce weight to a healthy level.** A 2015 study published in the *Journal of Psychiatric Research* “established that obesity may be a contributing factor to the inflammatory profile of depressed patients” (Simpkin, 2018). Losing weight may also help alleviate depression.

Fish oil and folic acid supplements also help treat depression. Eating lean proteins can reduce the risk of a repeat stroke. Avoid alcohol and drugs because they can worsen depression symptoms. Healthy lifestyle choices, including the foods you eat, can significantly reduce the incidence of stroke and depression.

You can do other things as well. Try something new. Meditation and yoga are great for relaxation and focus. Travel somewhere you’ve never been before or set small achievable goals. Make time for fun. Get involved by volunteering or sharing your story to help others improve. Change your routine. Get some sun. Build a supportive network of friends you can talk to and share things with. Take on new, rewarding responsibilities, and make sure to reward yourself. Celebrate every time

you accomplish one of your goals, no matter how small and insignificant it may seem.

## TIPS FOR CAREGIVERS: HOW TO HELP A DEPRESSED STROKE SURVIVOR

There are several ways to help someone with depression. Help doesn't have to be complicated. Keep it simple. Try these nine ways offered by Intrepid Mental Wellness (n.d.):

- **Educate yourself**, especially if you've never suffered from depression. Do some research. Talk to a counselor, physician, or helpline to get information.
- **Take it seriously**. People suffering from depression can't just snap out of it. Depression doesn't work that way. There is no cure-all or easy fix. Never tell a depressed person to cheer up, get over it, or just smile more. They would if they could, and you telling them to do so just makes it worse.
- **Become a good listener**. Listen to understand, not to advise. Depressed people are often afraid of being judged or unheard. Offer to be a nonjudgmental listening ear. Don't push or pry.

- **Offer practical help.** Depressed people don't always take care of themselves. Offer to cook a meal or bring one over. Help with the dishes, open the mail, help organize the bills. Find a need and meet it.
- **Keep them in the loop.** Depressed people tend to isolate themselves. They want to be invited but don't have the energy to go anywhere. Invite them anyway. Offer to escort them. Show up for them. Don't push but do offer.
- **Don't try to be an expert.** No one cares how much you know unless they know how much you care. Keep that in mind.
- **Don't belittle the condition.** It's better to admit you don't understand than to say, "I know how you feel," or "everybody gets low sometimes." Those statements are not helpful. Depression is a debilitating condition. Be careful of saying something that might sound condescending.
- **Be prepared to act in an emergency.** If you think your loved one, friend, or the person you care for is a danger to themselves, you must act. Call 911. Don't leave. Don't desert them if they are talking about harming themselves. Always take this seriously, even if they've said it before but didn't act on their threats.

- **Be patient.** Dealing with a person with depression can be frustrating. You may tire of hearing them complain, cry, or constantly speak negatively about their life and themselves. Take a walk if you need to. Breathe. Get some downtime for yourself, but don't abandon them. They need you, even when they don't realize or appreciate it.

## INTERACTIVES

Check out the following meditation and mindfulness videos available for viewing on YouTube.

- *Guided Meditation and Visualization for Stroke Recovery*, by Patricia Fente on YouTube
- *Brain Healing Music After Stroke – Healing Music for Stroke Patients – Brain Wave Therapy – Live*, by Relaxability on YouTube
- *Pain Relief and Body Healing Guided Meditation / Mindful Movement*, by The Mindful Movement on YouTube





COMPLEMENTARY THERAPIES  
FOR STROKE SURVIVORS

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*Start by doing what's necessary; then do what's possible; and suddenly you are doing the impossible.*

— SAINT FRANCIS OF ASSISI

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**T**raditional medicine doesn't always work when dealing with certain types of diseases and malfunctions in the body. Sometimes you have to think outside the box. Increasingly more physicians, especially those who work with patients suffering from neuropathic diseases or disorders, are turning to alternative and complementary forms of healing and recovery. Pain management doctors may recommend

cannabinoids, meditation, and mindfulness. Primary care physicians may combine exercises like yoga and taking long walks with traditional medicines. Others may recommend supplements for anxiety and discomfort or acupuncture for nerve pain. Speak with your medical team to discuss what alternatives may work for you.

## CBD AND MEDICAL MARIJUANA

A network of naturally occurring receptors in the body receives signals from active cells that help regulate sleep, mood, hunger, memory, and more. This complex receptor system is called the endocannabinoid system (ECS). Scientists and medical professionals began studying this system related to the use of the endocannabinoid THC found in the hemp plant. They found that there are two primary cannabinoid receptors—CB1 and CB2. “CB1 receptors... are mostly found in the central nervous system. CB2 receptors... are mostly found in your peripheral nervous system, especially immune cells” (Raypole, 2019). THC in the body can bind to both CB1 and CB2 receptors, having varying effects. In some people it can ease anxiety, depression, and physical and nerve pain, while overstimulating others and even causing acute paranoia.

Another chemical present in the hemp plant is the chemical compound CBD or cannabidiol. When this chemical interacts with CB1 and CB2 it can alleviate anxiety and some neuropathic pain. Since “only 40% to 60% of patients [with neuropathic pain] ... find partial relief from their symptoms with conventional treatments” (Cooke, 2021), CBD, which medical practitioners often recommend, is a homeopathic alternative. Unlike its cousin, THC, CBD is not psychoactive. In other words, CBD will not make you high.

The job of the ECS is to help balance hormones and other chemicals that help the body function properly. It's the body's feedback system wherein nerves send and receive messages. When you experience nerve pain, it's because there's an interruption or dysfunction in the messaging system. That fiery pain you feel, which runs through you like electricity, is the energy between nerve cells missing its mark. Using CBD can (Cooke, 2021):

- protect the nerve cells and brain
- support nerve cell regeneration
- block pain transmission
- regulate electrical activity in the brain
- alleviate anxiety and depression
- support sleep

CBD comes packaged in the form of edibles, oils, and tinctures you can mix in food, swallow, or hold under your tongue for quick absorption. They're also available in creams you can apply to your skin to decrease neuropathic pain, numbness, and tingling. The desired dose and form depend on your need and pain levels. Consult your physician if you are not sure what you should use or how it may interact with other medications you are taking.

CBD helped relieve my anxiety. In fact, my husband and I decided to open our own CBD store based on how helpful it was to me. Opening and managing that store gave me a new purpose and re-engaged my mind. This helped me to recover mentally and emotionally. I had somewhere to go during the day and something worthwhile to do. It kept me busy and focused on a purpose outside of myself. Running our store brought me back to me. I was able to rebuild my self-confidence and, after almost a year, felt strong enough to go back to the corporate world of marketing and resume the career I had previously enjoyed. But this time, per doctor's orders, I deliberately took a step back from high-pressure roles.

## SUPPLEMENTS FOR ANXIETY AND DEPRESSION

According to the National Institutes of Health (NIH), “In 2020 more than 21 million U.S. adults experienced a major depressive episode” (Anzlovar, 2023). Flint Rehab states, “more than half of all stroke survivors experience a post-stroke cognitive impairment” (Flint Rehab, 2023). The Anxiety and Depression Association of America said that “generalized anxiety disorder (GAD) affects around 6.8 million adults” (Berry, 2023).

About a month after my first stroke, I felt numb and indifferent to the world around me. I was suffering from debilitating anxiety and depression. I was admitted to two inpatient mental health facilities and had to muster all my strength and determination to heal and recover. I was 46, a healthy and active mother of three, and a professional. I thought that I could easily recover and return to the life I had been building for 25 years because I had been used to overcoming challenges. But it didn’t happen that way. I needed help. Medications, exercises, meditation, and therapy helped me through my struggles. I also learned that vitamins and minerals are critical to a healthy nervous system.

Specific vitamins and mineral supplements can help with anxiety and depression, but they’re not all created

equal. Vitamin D and the B vitamins play an essential role in brain health. Vitamin D is absorbed through the skin when you walk out into the sunshine. It regulates your mood, stabilizes your nervous system, and supports brain health. Spend time in the sun. Take a walk on a sunny day and notice how you feel. Eat vitamin-D-rich foods like salmon, mackerel, eggs, cheese, mushrooms, spinach, and melons. Drink some orange juice whether from concentrate, raw, or other forms. Vitamin D may be difficult to get if you are vegetarian or vegan because it's not present in all vegetables. Vitamin D supplements are an alternative or addition to your diet. "Vitamin D is unlikely to interact with anti-anxiety medications" (Berry, 2023). Check with your doctor before adding this or any supplement, as it may interfere with other medications.

The B vitamins are complex. They are "a group of eight different nutrients that work together to manage many processes in the body, including stress levels" (Berry, 2023). Vitamin B<sub>12</sub> helps reduce anxiety and depression and converts food into energy in the body. When you are depressed, you lack the energy and motivation to do anything. Vitamin B<sub>12</sub> is naturally present in a balanced diet, but when you are depressed, you will most likely not eat right or at all. Vitamin-B-complex supplements hold all the necessary B vitamins, including (Berry, 2023):

- **Vitamin B<sub>1</sub>**: thiamin, vital to the healthy growth and function of organs, including the brain and heart.
- **Vitamin B<sub>2</sub>**: riboflavin, to break down fats and drugs.
- **vitamin B<sub>3</sub>**: niacin, to support healthy skin, nerves, and digestion. Doctors often prescribe this. In high doses, it can improve cholesterol levels.
- **Vitamin B<sub>5</sub>**: pantothenic acid is essential for the health of the brain and nervous system.
- **Vitamin B<sub>6</sub>**: pyridoxine helps the body make new red blood cells, which carry oxygen throughout the body and strengthen the immune system.
- **Vitamin B<sub>7</sub>**: biotin is essential for healthy hair, nails, and nerve function.
- **Vitamin B<sub>9</sub>**: folic acid—or folate, its natural form—is used to make DNA strands and other genetic material. Before and during pregnancy, folic acid helps reduce the risk of certain birth defects.
- **Vitamin B<sub>12</sub>**: cobalamin is needed for the body's nerve and blood cells. It prevents pernicious anemia, which is a vitamin B<sub>12</sub> deficiency.

Physicians concerned about brain and heart health often recommend the combination of B and D vitamins. Though B vitamins might not help in all cases, they can help when taken regularly. Vitamin D is naturally produced in the human body, but you may not get enough from the foods you eat. Supplements, then, are an asset to your regular diet.

Magnesium is another vital nutrient for bodily functions that help you deal with anxiety. Foods high in magnesium include spinach, quinoa, almonds, cashews, dark chocolate, black beans, and whole wheat (Berry, 2023). If you're not eating enough of these, you can take magnesium in low doses. Doses of less than 100 milligrams. Higher doses can cause diarrhea and should not be taken without consulting your primary care physician. Antidepressants, antipsychotics, and antibiotics can make magnesium ineffective.

Another supplement found in black and green tea, called L-theanine, also helps with anxiety. It works as a sedative, so must be taken in doses of less than 200 milligrams. It will react with midazolam and should not be combined with other sedatives.

Multivitamins and multiminerals can also be helpful as they hold more than one of the necessary dietary nutrients. Multivitamins tend not to interfere with anxiety and depression medications. Studies in 2018 and 2019



found that supplements with vitamins B, C, calcium, magnesium, and zinc “significantly decreased anxiety in young adults” and “may benefit people who have mood disorders, like anxiety” (Berry, 2023).

You can find most supplements at your local drug or grocery store, or online. Fruits and vegetables have natural healing properties. They restore and rejuvenate the brain and body. Good supplements can be great substitutes for not getting enough essential nutrients. You can add omega-3 fatty acids, valerian root, chamomile, lavender, and lemon balm supplements for nutritional balance and to decrease anxiety, increasing relaxation and rest. Seek medical advice before adding any of these and don't substitute supplements for medications unless recommended by your doctor. Always consider efficacy, risk factors, possible medication interactions, and dietary certifications.

## NATURAL AND HOLISTIC THERAPIES

You can add other natural and holistic therapies to your daily regimen to help regain dexterity and brain function. Following are several doctor-recommended therapies.

### *Acupuncture*

Acupuncture is a form of ancient Chinese medicine used as a complementary or alternative therapy for pain, anxiety, and stress relief. Research from 2014 shows “acupuncture releases endorphins and may help stimulate blood flow. An increase in endorphins may provide a boost for the mind and body, which could cause relief from some depression symptoms” (Rice, 2021).

### *Aromatherapy*

Aromatherapy uses aromatic scents made from essential oils that help to soothe and calm. These natural plant oils are “derived from the roots, leaves, seeds, blossoms, bark, and stems of plants by steaming or pressing” (Wynn, 2022). Scents trigger reactions in the body and brain through the limbic system, which is responsible for your emotions. Lavender is one of the most popular aromatherapy scents. Bergamot, chamomile, clary sage, frankincense, lemon, neroli, rose, sandalwood, sweet marjoram, and ylang ylang are other aromatic scents used in varying combinations for psychological and medicinal therapies.

These scents can be found in oils, lotions, candles, incense, and bath products. Oils must be diluted in specific ways and used knowledgeably and responsibly.

They are not substitutes for medication but can be used in addition to other treatments.

### ***Art and Music Therapy***

For centuries, artistic creativity and the performing arts have promoted healing. Aphasia, which affects a person's ability to communicate, is one of the most common side effects of a stroke. Music, art, dance, and movement can be used not only as communication tools but also for treating depression and anxiety.

According to research published in 2020 in the *Topics and Stroke Rehabilitation* journal, persons who played instruments or listened to music twice a week experienced improvements in their mood (Sullivan, 2022). Music soothes and satisfies the listener and creates a connection with others who may be listening with them. Music therapy is used in nursing homes with Alzheimer's and stroke patients to help stimulate memory. It "stimulates many parts of the brain at once, allowing damaged neural pathways to reconnect" (Sullivan, 2022).

I learned to play the piano as a young child. This was one of my go-to therapies after my stroke. I didn't try any of the complicated classical pieces I had once known. I stuck to simple notes and chords which helped restore dexterity in my hands and rewire my

brain. At times, it was also calming to just sit and play. Drumming has helped others recover dexterity. It has been used in helping patients with traumatic brain injuries (TBI) create new neural pathways in the brain, connecting them once again to movement.

Hand exercises also included therapy clay that I rolled, twisted, flattened, and pinched into various shapes. Manipulating play dough is a favorite pastime of children but can also help develop fine motor skills in adults. Art therapy—abstract painting, pottery, sculpting, drawing, or whatever form you prefer—when combined with psychological counseling and talk therapy, is highly effective in mitigating depression and anxiety. In fact, anything that keeps your hands busy can help alleviate anxiety and depression.

### ***Dance and Movement***

Dance and movement help release pent-up emotions and increase calm. Dance is a way to speak when words won't come. It is also a form of movement meditation that can help you connect with yourself and others. Some dance studios offer dance and movement classes for students who use mobility devices, including wheelchairs, walkers, canes, and other mobility aids.

Dance doesn't have to involve intricate movement. Try a simple two-step, moving from side to side. When

comfortable, add corresponding side-to-side arm movements. Play uplifting music. How do you feel as you are dancing? Do you feel lighter, happier, more content? Lift your feet, one at a time, off the floor. How does that feel for you? If you cannot stand, dance with your arms and hands. Rotate your hands to music. Wiggle and stretch your fingers. Smile. Nod your head up and down, left to right. Notice how you feel throughout your body.

Movement can be a kind of poetry in motion, restoring the body's motor skills and alleviating negative energies. For more information and stories about dance movement and healing from anxiety, grief, and depression, check out the following short videos on YouTube:

- *Living with Depression: A Dance/Movement Therapy Moment*, by the American Dance Therapy Association
- *Moving Through Grief: A Dance/Movement Therapy Moment*, by the American Dance Therapy Association
- *Dance/Movement Therapy and Anxiety*, by the American Dance Therapy Association

## *Yoga*

Connecting the mind and body through body poses, meditation, breathing, observation, and yoga is as old as time. It has significant benefits for stroke patients, you don't have to be super flexible to participate, and it's uniquely adaptable. Even those with paralysis can start a yoga practice through mindfulness, meditation, and breathwork. If you're in a wheelchair, you can do chair yoga. Yoga can encompass visual scanning techniques for patients with occipital lobe nerve damage. Yoga can improve impaired cognitive skills because of its attention to sustained movement and sequencing.

At 51, Isabelle, a yoga instructor, suffered a stroke. She practiced visualizing herself doing various yoga poses when she could not physically complete them. She continued practicing the breathwork and mental techniques she had used in her classroom. "Each day, she'd lie in bed and visualize those yoga poses, and then try to practice them in real life. And every day, Isabelle noticed that she could do the pose a little better" (Flint Rehab, 2021). In three months' time, Isabelle miraculously recovered. Healing begins in the mind.

Practicing yoga can help you release stress and anxiety. Below are three YouTube yoga and breathing workouts you can try.

- *Chair Yoga for Stroke Survivors*, by Abigail Atkinson
- *Seated Yoga Based Exercise and Practice for Stroke Survivors*, by the American Stroke Foundation: Next Step
- *Adult Speech and Therapy Breathing Exercises*, by County Durham and Darlington NHS Foundation

## INTERACTIVES

Have you tried any of the aforementioned complementary therapies? Which ones have you tried? Write the answer to these questions down in your journal. Alongside each therapy, write down how you felt after each attempt. Use your mood journal to track how each therapy makes you feel. Are there changes in your mood after dancing or listening to music? What scents make you feel calmer? Do you prefer tinctures, edibles, or vaping CBD, and why?

The more you know about what works best for you, the clearer your path to healing will become.





BEYOND THE STROKE—  
SUPPORTING YOUR LOVED ONE’S  
NEW LIFE

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*Be willing to be a beginner every single morning.*

— MEISTER ECKHART

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**A**ccording to a 2020 survey by the National Alliance for Caregiving (NAC) and AARP, “almost 53 million Americans are providing unpaid care to a family member or a friend. The number of caregivers increased by about 9.5 million in five years, from 2015 to 2020” (Walker, 2022). Worry, concern, frustration, sleepless nights, hospital runs, meals to prepare, laundry to do—it can all take a huge toll on the people giving care. Practicing self-care is essential for

those caring for a loved one after a stroke. You too will need support. After a stroke, your loved one will face daily challenges. As a caregiver, you will be on the front lines. Be willing to begin every day with a fresh outlook for yourself and the one you love so you both can not only survive but thrive.

### WHAT CAREGIVERS SHOULD KNOW WHEN THEIR FAMILY MEMBER IS A STROKE SURVIVOR

One of the most challenging jobs for a loved one to do for a family member, spouse, or child is the task of caregiving. It is physically, mentally, and emotionally demanding work. Creating a supportive recovery environment takes love, patience, compassion, and resourcefulness. Several factors can contribute to how long your loved one takes to recover. These factors include pre-stroke health and wellness, how much the brain and body were affected, and post-stroke access to adequate healthcare, rehabilitation, and support. National Medical Director of Vascular Surgery and Endovascular Therapy, Dr. Joseph Ricotta, recommends seven things to consider when taking care of someone who has had a stroke (Ricotta, 2017):

- **Ask questions... then ask some more.** What are your loved one's medications and the side effects of those meds? What accommodations do you need to make in your home, life, and surrounding environment? Will you need to put handrails in your bathroom? What equipment will you need? How will you pay for it? What other medical concerns may arise from the stroke or the medications?
- **Reduce future risks.** Make sure your patient is following the doctor's orders. Stroke patients are at risk of a second stroke if they don't follow prescribed protocols. Be attentive to diet and exercise, which are extremely important to recovery. Whenever possible, avoid skipping doctor's appointments. At every appointment, your physician and therapists should look for areas of progression or regression. Ask questions to know what's going on at every stage.
- **Understand that recovery depends on multiple factors.** How much the brain is affected, how much support the patient gets, access to adequate healthcare, and the quality of the person's mental and physical health before the stroke are all factors that affect recovery time and necessary protocols. You can't rush

the process. The brain heals when it heals. As the brain recovers, so does the body—and vice versa. The rate at which stroke victims recover is unique to the individual. The caregiver must learn about the effects of stroke and potential complications.

- **Rate of change varies.** The rehabilitation process may happen within the first three to six months, or it may take a few years. Don't judge the recovery by the speed. Small changes take place every day that will continue over a long period. Be patient with yourself and your loved one.
- **Pay attention to changes in behavior and mood.** Depression following a stroke is relatively common, especially if the stroke has caused a significant change in a person's independence, career life, family life, and sense of self. A depressed mental state can hinder recovery as the person doesn't feel motivated to take part in any activities, including eating, going to doctor's appointments, exercise, or socializing. If your loved one is continually struggling, make sure they get the help they need from a licensed professional who can prescribe medication and other healing therapies.

- **Understand their insurance coverage.**

Medical and life insurance can be tricky. Ask questions about what will be covered, what will not, and at what percentage. Know what to expect from your insurance agent and try to speak with the same one each time. Document everything, as you will find the same questions will be asked of you repeatedly. Speak with your loved one's doctor, case manager, social worker, rehab center, therapists, and anyone else involved about how much of the services are covered and for how long. Do your due diligence concerning medical power of attorney and advance directives so you know what's required and what to expect.

- **Be prepared.** The road to recovery may get rocky, but it is not necessarily insurmountable. Strokes don't happen on a schedule, but when they do, the best thing you can do is get curious. Ask questions. Talk to qualified professionals. Speak to a vascular surgeon, your loved one's neurologist, and your primary care physician about what to expect. Get recommendations as soon as possible for additional care and support. A stroke is a scary event for the person it has happened to and those who love them. Recovery doesn't happen in a straight line. It

can be slow and unpredictable. Be prepared for physical, cognitive, emotional, and behavioral changes. The more prepared you are for what happens after, the less rocky the process will be.

### *How to Be a Good Caregiver*

I have had fantastic caregivers. I'm grateful for my husband, my children, my sisters, my parents, and a host of others who looked out for me and took extraordinary care of me. From my first stroke, my husband and children were my greatest support. If not for Steve's quick thinking and attentiveness during my first stroke, I would have had a very different outcome. My sisters were adamant that I follow the advice of my neurologist to return to the emergency room for a CT brain scan the day after my car accident. I'm glad I learned early on not to resist them. Steve drove me to my rehabilitation sessions almost every day for two months. He stood by me when I was going through deep depression, paranoia, and manic obsessiveness. He continued to encourage me in every way he could during the recovery process. I am grateful to all the caregivers in my life. I know that the journey has not been an easy one. Sometimes I'm sure they felt as lost and confused as I did.

As a caregiver, you need community and communication. Community includes your network of professional helpers, daycare centers, mental health facilities, support groups, extended family, neighbors, and any other persons qualified to join your team. Those qualifications include caring, compassion, expertise, motivation, and trustworthiness. As a caregiver, the sooner you find who these people are, the better. Better care equals better recovery.

There was a time when I had difficulty speaking and conveying my thoughts. It seemed that my brain wasn't lining things up right. I knew what I wanted to say but couldn't find the words. I had trouble remembering, focusing, and writing. I needed someone to communicate my thoughts for me, to understand what I was trying to say but couldn't adequately vocalize. That's frustrating for both the patient and the caregiver. You must develop a new style of communication. You might develop your own sign language. As a caregiver, patience, and the ability to listen to spoken and unspoken words are essential. You must also learn to recognize and understand body language and facial expressions. What does the person look like when they're in pain? What do they look like when surprised, afraid, or laughing without sound when something is funny? You will find communication tools that work for you and your loved one. Do they have any hand

coordination? Try a tablet with big letters. Eye-writing technology, a computer interface system, writes messages for people who cannot speak or use their hands. They write using eye movements. Check with your medical team to find out what technology is available in your area.

Another important aspect of caring is learning to read the room. A person who suddenly loses their ability to do even the most menial daily tasks is often frustrated and hates feeling like a burden. They still want to be able to do things for themselves. Take safety precautions but allow them to do what they can. Try not to hover or make the person feel useless without you. Offer help, but if they are adamant, don't insist. Stay close enough to keep them safe. Address their physical need for both help and space. Be patient, not condescending or judgmental, concerning their cognitive ability. Learn how to count to ten, breathe, listen, affirm, de-escalate, or walk away when either you or they feel overwhelmed with any emotion.

People with brain injuries function better with a routine. Develop a daily routine for meals, washing, showering, laundry day, and hygiene rituals, including bath time, shower time, and brushing teeth. These routines help create stability. Avoid surprises as much as possible. If there is a doctor's appointment, give



plenty of reminders. Schedule a tour of any facility you are considering, including adult daycares, rehabilitation centers, and mental health facilities. Inspect what you expect. Visit early in the morning, mid-afternoon, and night so you can see how things work. Check out the policies. Is there an open door for family visits? What's the daily routine? What safety precautions are in place, and how often are they checked and modified? Keep a binder documenting your loved one's care to use when visiting doctors or other specialists.

Everyone, whether caring for a stroke survivor or not, should learn FAST—Face, Arms, Speech, and Time. Is the person's face drooping? Is the person experiencing weakness in one or both arms? Is the person's speech slurred, or are they having trouble speaking? If so, it's time to call 911.

A stroke changes a person in unimaginable ways depending upon its severity. As a caregiver, your goal is to help your charge get the best care and optimal quality of life possible. A good caregiver acknowledges that and allows the person to grow into their best possible new self.

## CAREGIVER STRESS

When you travel by plane, the flight attendant gives some information before the aircraft reaches its maximum altitude. Flight attendants tell you where the exits are and ask the person seated next to the exits if they will help in an emergency. They tell you about a mask that will drop down from above if the cabin runs out of oxygen. They tell you to put the oxygen mask over your face before helping someone else if you are traveling with a child. Believe it or not, one of the best ways to be a good caregiver is to first take care of yourself.

Caregiving is extremely taxing, whether you are a professional, a parent, or someone caring for a loved one, neighbor, or friend. The responsibility for another person's health and well-being requires a great deal of time and effort. According to Marilyn Wei, MD, "Over time, caregiver stress can lead to burnout, a condition marked by irritability, fatigue, problems with sleep, feelings of helplessness or hopelessness, and social isolation" (Wei, 2018). Caregiving is stressful. The weight of it can take its toll on the most resolute, caring human being, leaving depression, strained relationships, exhaustion, isolation, and illness in its wake. Self-care is critical because you can't pour from an empty cup.

Without self-care, burnout is inevitable. Signs of burnout can include fatigue, irritability, insomnia, or poor sleep quality. The brain sweeps itself clean when you get enough sleep. Without the downloading process that happens during sleep, you can feel overwhelmed and become abrasive. You may suffer from headaches, migraines, and difficulty concentrating. You can feel scattered, depressed, and ineffective. Loss of sleep can also affect your appetite. You can find yourself constantly snacking, overeating, eating unhealthily, or emotionally eating when you're not hungry, leading to excessive weight gain and disease in the body.

When you are experiencing exhaustion, you tend to be short on patience. This can drastically affect you and the person you are caring for. When you feel overwhelmed, you tend to withdraw from the person you are caring for, the situation you live in, and society as a whole. You look for quiet, and isolation seems good to you. At extreme levels, this stress overload can cause you to neglect your hygiene, the cleanliness of your personal space, and personal responsibilities like paying bills, answering phone calls, and making or keeping appointments. Substance abuse and other unhealthy coping habits can creep in like stealth bombs in your life.

Your stress can affect the quality of care you give a loved one or client. Knowing that you may not always get it right, you will have to learn how to strike a balance in your life. Forgive yourself when you don't, and don't judge. Celebrate when you can.

## SELF-CARE FOR THE CAREGIVER

Having a stroke affects not only the person who has the stroke but also everyone associated with them. A stroke is an automatic emergency, as time is of the essence when it comes to preventing brain damage. The caregiver often finds themselves suddenly tasked with figuring out the finances and dealing with legal issues like power of attorney, wills, advance directives, and guardianship. Your immune system can weaken as you lose sleep and cortisol levels rise. You may experience headaches, gastrointestinal problems, and aches and pains that seem to come from nowhere. When stress builds up in the body without an outlet, it implodes on the nervous system, cells, and neurological system. You burn out when you burn the candle at both ends.

Some self-care methods caregivers can use are listed below (Wei, 2018).

- **Self-compassion:** Give yourself the same understanding, care, concern, and forgiveness you give to the person receiving care. Avoid judging yourself when you get angry or frustrated. Extend as much grace to yourself as you do to others.
- **Take a breath:** It's common practice to tell yourself or someone else to count to 10 so they can calm down. Caregiving requires patience and sometimes your patience runs out. When it does, walk away and take a few deep breaths. Give yourself ten minutes to breathe deeply, calm down, and get centered. You are worth ten minutes a day. Give yourself downtime. Think of breathing in calm and relaxation when you inhale. On your exhale, see yourself in your mind's eye releasing negative energy. Inhale for a count of five, hold, then inhale for two more counts, hold. Let go slowly and steadily. Do this four or five times or until you can feel calm.
- **Develop a mind/body practice:** Take up tai chi, yoga, qigong, mindfulness, or meditation. Deepen the connection to your body so you can feel the signs of your temper or stress rising.

The more you know how your body reacts to stress, the better you can respond.

- **Diet, exercise, and sleep:** Watch your mouth. What are you putting in it? Remember that food is medicine. Nutritious meals and snacks will give you the energy to keep going. Avoid skipping meals and snacking on the go. Prep meals and snacks so they will be ready when you are. Your brain reboots when you sleep. A good night's sleep will help you feel refreshed. Adequate sleep is your brain's restart button. Take a 15-minute power nap in the afternoon. Take a walk to revive. Movement prevents stagnation in the mind and body.
- **Get support:** Don't try to do this thing alone. You are not a superhero. Join a support group. Phone a friend when you are in need. Get an adult sitter service. Take advantage of recreational centers for the disabled and other community programs. There is help, whether online or in the community. Maintaining friendships and connections at every level will help alleviate any feelings of isolation. You are not alone. Others are going through what you are going through. Reach out.
- **Delegate tasks to others** that are difficult, challenging, or too time-consuming for you.

You don't have to know it all or do it all.

- **Take a break:** You deserve to relax and restore. Pursue a hobby, talk to a professional, paint, draw, dance, or learn something new to give you a respite from serving.
- **Set boundaries:** Know your limitations. If you can't do something, say so. Don't let anyone guilt into doing more than you can do.

You and the person you are caring for both have to survive and thrive. For that to happen, you must pay attention to your own needs. Fill your own cup. Put the mask on yourself first.

## INTERACTIVES

If you are a caregiver, check out these meditation and mindfulness apps to get some peace of mind. They feature both guided, musical, and silent meditations.

- Headspace
- Meditation Oasis
- Insight Time

Take some time to meditate. Write down any insights you get and how you feel afterward in your mood diary.





## SELF-ADVOCACY AND SELF-AWARENESS

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*You can rise up from anything. You can completely recreate yourself. Nothing is permanent. You're not stuck. You can learn something new. You can create new habits. All that matters is that you decide today and never look back.*

— NICK KYRGIOS

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**W**hen you are young, you learn to respect authority and those who have it. Teachers, doctors, and public servants are not to be questioned. This ideology stays with you as an adult, especially for women. Yale University psychologist Stanley Milgrim

conducted several experiments in the 1960s to determine how people tended to listen to authority figures and do what they said, no matter whether the person in authority was right or wrong, good or bad (McLeod, 2023.) The experiment proved we learn to be obedient to authority figures in our formative years, and that sticks with us throughout our lives.

Taking responsibility for your health and well-being is essential to your recovery. If you don't feel comfortable with a doctor or therapist, you have the right to say so. If you know your body and are unsure what the doctor recommends is correct, get a second opinion. Medicine is a science, a series of experiments to find out how to cure diseases and disorders in the body and brain. It's not an exact science. You have the right to question everything and read the fine print. Self-advocacy and self-awareness are essential keys to your recovery now and in the future. If you or your loved one cannot advocate for themselves, find a sincere, qualified person who will stand in the gap for you or them.

## KNOWING YOURSELF AND YOUR BODY

We are all born with this wonderfully intricate thing called a body. We grow into it and as we grow, we learn what feels good to us, what hurts, why it hurts, and where and how it hurts. We know what triggers our

emotions and makes us stand still in awe. Having lived in your body all-your life, you know when something is amiss, even when you can't quite figure out what that something is.

Because you know your body, you are the subject matter expert when it comes time to talk to your doctor. You can tell them where it hurts and why you think something is wrong. You can ask questions, tell them how your body normally functions, and why this or that minor detail seems important to you.

Body awareness is essential. You are more than skin and bones. The more you are connected to and aware of your body and how it works, the sooner you can sense when something is off. Your body has proprioceptive and vestibular systems that alert you to how you move and support balance. The proprioceptive system lets you know where your body is in space. The vestibular system involves the inner ear and is responsible for helping you keep your “balance, posture, and head stability” (Hoshaw, 2021). When you feel dizzy, your vestibular system is off. When you can't feel where your feet or legs are, as sometimes happens during a stroke, your proprioceptive system is off.

Your body speaks to you in a language you can easily understand. When it needs food, your stomach may growl, or you may get lightheaded. Lack of hydration

or high blood pressure can bring on a headache or migraines. When your body isn't producing enough insulin, as in the case of diabetes, you experience an unquenchable thirst, fatigue, and a need to urinate often. When you work out to the point of fatiguing your muscles and feeling pushed to the max, your body signals you to stop. When you recognize what your body is telling you, you are experiencing body awareness.

Body awareness also involves how your body responds in social situations. Do you tense up around certain people? Have you ever had a gut feeling that something just isn't right? Has a place or situation made you feel peaceful? Your body responds when you feel lonely, when your libido is activated, and when you are tired. According to *Healthline*, "Understanding what your body is communicating can help you better meet your own needs, leading to greater health and emotional satisfaction" (Hoshaw, 2021).

Benefits of body awareness include (Hoshaw, 2021):

- **Better balance and stability:** When you're aware of your body—where and how it moves in space—you can better train your body to do what you want it to do. You can learn how to

walk and talk again after a stroke when you know how your body moves.

- **Weight management:** When you are not attuned to your body, you may eat when you feel emotional or keep eating even though you feel full. When you know your body, you will know when enough is enough. You will also recognize why you are eating that ice cream in the middle of the night. People who have low body awareness tend to gain more weight.
- **Pain management:** People who are unaware of their body and how it works tend to have “lower self-esteem, less physical contact, and more depressive symptoms,” while those who did have a mind-body connection experienced “greater self-acceptance, vitality, and lower sensory pain” (Hoshaw, 2021).

When your proprioceptive and vestibular systems are balanced, you will feel less anxious, depressed, and dizzy. You will be more at peace with the world around you as well. You’ll better understand what you need. You will know when you’re really hungry, thirsty, or tired. You’ll be more likely to start self-care, reach out for help, or seek therapy because you know what you need.

## KNOWING WHEN TO SEEK PROFESSIONAL HELP

One important lesson I learned was the importance of being my own health advocate. I suffered horrible side effects from a psych medication my primary care physician prescribed. I begged her to take me off it and try something else. She refused. She also never told me a woman in her 40s shouldn't be on birth control because of a higher risk of stroke. I finally realized that I didn't have to settle for a doctor or specialist who didn't take me seriously or show genuine concern or care for my needs.

Never settle for a physician who dismisses your concerns or tells you, "It's all in your head," especially after a stroke. Make sure your care team truly cares about you.

I found a much more thorough primary care physician who is genuinely concerned for my overall health and well-being. Now, I have a great team of medical professionals who take care of me. I feel safe, heard, and cared for. If that is not how you feel about your physician, therapist, or caregiver, it's time to look in another direction.

## DECIDING IF YOUR PHYSICIAN, THERAPIST, OR CAREGIVER IS THE RIGHT FIT FOR YOU

When choosing a primary care physician, a therapist, or a home healthcare worker, look for certain basic criteria. Here are ten of them (Stanborough, 2020):

- Communication is a key part of good care. Do you feel heard? Does your physician genuinely listen to your concerns? Do they offer solutions or referrals? Do you feel like your therapist genuinely cares or are they zoned out and waiting for the clock to run down? Does your doctor rush you through the process? Do you feel like a number without a name? Does the doctor remember your name and speak to you in a manner that is respectful, not condescending?
- Is your therapist, physician, and caregiver easily accessible in an emergency, when you have questions, or when you need to make an appointment?
- What are others saying about your chosen doctor or caregiver program? Check out reviews on Yelp and other sources. Google the physician's name and see what comes up. Do your due diligence.

- Accessibility is important. How far is the doctor's office from your home? Does the physician or therapist offer virtual visits?
- Is your primary care physician connected with a hospital in your area? Where will procedures like lab tests, bloodwork, surgeries, and x-rays occur?
- Is the doctor familiar with your particular disorder? Ensure your doctor is board certified and connected with a hospital in your area. Check out the American Board of Medical Specialties to see if your doctor's name is on it. Insurance companies also provide rating systems for physicians, dentists, and other medical practitioners. Medicare offers a physician comparison tool to help you identify the best physician for you.
- How do the staff treat you on the phone and in person? Are they friendly, patient, and kind? Do they help you resolve issues about billing, appointments and cancellations, or interactions with the doctor? Do they keep your privacy and treat you with respect?
- Is it a group or individual practice? Who will you be seeing—the doctor, a nurse practitioner, an intern, or someone else? Knowing who you are going to see



consistently gives you confidence in the practice.

- Can your physician accommodate your unique needs? Is your doctor experienced in dealing with people with disabilities, trauma survivors, or those with anxiety and depression disorders? This is important if you are going to be comfortable and at ease with your physician, therapist, or caregiver.

## LEARNING THE POWER OF “NO” AND “ENOUGH”

The word “no” is about building boundaries. Children start saying “no” around age two. They are testing their boundaries—and yours. Starting in the pre-teen years, you want to fit in, so your “no” becomes a “maybe” and “why not?”. Then you become an adult answering to bosses and bill collectors. You quiet your “no” to get a promotion or a salary advance for fear of losing your job. But there is power in the word “no.”

The word “no” is like a two-sided coin, with one side being positive and the other negative. On the plus side, “no” is an act of confidence. It means you are comfortable setting boundaries, and you know when enough is enough for you. The flip side is an uncomfortable place of fear and trepidation. You want to be liked. You don’t

want to risk being misunderstood. It's easier to go along to get along.

Saying no is sometimes considered “impolite and inconsiderate. We feel more obligated to go along with things we don't want to do to be socially accepted” (Moore, 2021). Saying “no” is part of self-care. Setting boundaries, removing or exempting yourself from situations that are not good for you, can build self-confidence. That includes standing up for yourself and being your own advocate when it comes to your health care.

Understand why you're saying “no.” Are you using it to isolate yourself because you are depressed? Are you withdrawing out of anxiety or fear? It's okay to withdraw from time to time when you need to, but if you continually try to avoid interaction, there's probably more going on. Talk with a therapist to help you find the deeper issue.

Setting clear boundaries is healthy. Keisha Moore, Licensed Clinical Social Worker with the Menninger Clinic, specializes in anxiety, depression, disabilities, and other life-changing health issues. She says, “saying no to certain things can be an act of self-care by creating time or energy for things that help you feel better about yourself, your relationships, or your overall experience in this world” (Moore, 2021). It's okay to opt out to take care of yourself. It's okay to not

be okay. It's okay to need a break to read a book, sleep in, or do something that makes you happy. "No" is not necessarily negative. Recognize that it's also your right to say "no" and "enough" when you feel unheard and improperly treated by a physician, therapist, or caregiver.

## INTERACTIVES

Change is often difficult and stressful. Adding activities to your daily agenda that help you get in tune with your body, make you feel stronger, and more conscious of your mind-body connection can help you make the adjustments you need to move forward. All physical exercise helps increase body awareness. Listed below are a few helpful exercises and therapies (Hoshaw, 2021).

- Try these simple balance exercises:
  - Stand on one foot for a full minute. Switch and stand on the other. Make sure there is a stable surface nearby that you can hold onto if you lose your balance.
  - Walk across the room in a straight line putting one foot in front of the other.
  - Stand next to a wall or solid surface for balance. Lift your left leg as high as you can, then extend

it straight out in front of you. Hold for a few seconds, then put it down. Do the same on the opposite side. Try this for ten counts.

- Try tai chi, also known as “meditation in motion” (Hoshaw, 2022). To get started, check out *Top Ten Tai Chi Moves for Beginners* on YouTube.
- Try walking backward to engage muscles that you don’t use very often. Be sure you’re in a safe place with no obstacles in the way before you try this exercise.
- Try meditation and mindfulness to get in touch with your mind and body.
- Body scan meditation is simply a way of getting quiet and paying attention to the sensations in your body. Find a quiet space, lie on your back, and focus on your breathing. Pay attention to the rise and fall of your abdomen, your chest, the air coming out of your nostrils, and any other sensations you feel. Starting at your feet, notice how they feel. How are they naturally positioned? Don’t judge anything. Do you feel numbness, tingling, tightness? Is there any pain there? Move up to your ankles, then your shins and calves, your knees, and your thighs. Continue to scan your entire body from your

toes to the top of your head and hair. If your mind wanders and gets distracted, just come back to it. Body scan is about getting in touch with yourself. It can also help you relax, ease anxiety, and sleep better. Some helpful apps are Insight Timer, Headspace, Calm, and My Life Meditation.

- Movement meditation involves various kinds of movement. Take a walk and pay close attention to your feet touching the ground. Do you walk heel-toe? Are your feet sliding or heavy? Is there pain anywhere in the foot as you walk? It's about noticing, not judging or fixing.
- Physical, occupational, or somatic therapy is offered by experts in body awareness.
  - Physical therapy: Helps you improve mobility and movement.
  - Occupational therapy: Helps you with fine motor skills so you can do simple things like tie your shoes, roll over in bed, and brush your teeth. This therapy helps you get back to living your daily life.
  - Somatic therapy: Relaxation, meditation, and breathing exercises are used to calm the mind and deal with trauma.



## CONCLUSION

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*To love who you are, you cannot hate the experiences that shape you.*

— ANDREA DYKSTRA

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In September 2019, I started a new job as a senior communications manager for a large company, a deliberate step down into middle-management vs. a more demanding upper-management position. This was not an easy decision, but it was a necessary step to put my long-term health before my ego.

During COVID-19, the company mandated we work from home. Working from home gave me flashbacks of

the days when I couldn't leave the house during my disability leave and depression, so I developed a fake commute to help maintain my mental health. I would get up, get dressed, drive halfway to the job site, and then return home as if driving into work. I would begin my workday as if I were in the office. When it was time to return to the office and the company asked for volunteers, I was the first to raise my hand.

Having a stroke is a harrowing, traumatic experience that can leave physical, psychological, financial, and relational devastation in its wake. Worse yet are the invisible scars that, if not correctly diagnosed, can drastically alter a person's mental and physical health for the rest of their lives. Post-stroke anxiety and post-stroke depression are two of the nastiest surprises after a stroke. But there is hope. With the proper diagnosis, medication, mood journaling, meditation, various self-care strategies, and therapy, you can overcome them. But you must put in the work.

With the right tools, a knowledgeable medical team, support, and determination, you can recover from a stroke. You can advocate for yourself, and when you can't, support is at your fingertips through social media groups, community resources, online apps, friends, family, and neighbors. Seek out and take advantage of this help.



Physical therapy, speech therapy, and mobility aids are all a part of the process. Devote yourself to your prescribed therapy regimen and, little by little, you will see change. Discouragement is part of the process, but don't give up.

I've been to hell and back, but I am on the mend. I've continued my marketing and publishing career, seeking opportunities to write more books and help more people. I have learned to appreciate my journey and am grateful to be able to share it with you.

Know that you have the power to get beyond the stroke. You are infinitely more than what happened to you. A stroke is not the end of your story. You can begin again.



## ADDITIONAL RESOURCES

### READING

- *A Brain's Betrayal: My Stroke Story*, by Angie Read Doyal, published by Fast Pencil Publishing.
- *Your Guide to Exercise After a Stroke: A Guide for People with Stroke and Their Families*, by Maargot Andrew, Margaret Hoessly, and Kate Hedges. Available as a downloadable PDF from [stroke.org.nz](http://stroke.org.nz)
- *Caregiver Guide to Stroke: Practical Tips and Resources for New Caregivers*, by the American Stroke Association. Available as a downloadable PDF from [www.stroke.org/-/media/Stroke-Files/Caregiver-](http://www.stroke.org/-/media/Stroke-Files/Caregiver-)

Support/Caregivers-Guide-to-Stroke/  
CaregiverGuideToStroke\_2020.pdf

## YOUTUBE VIDEOS

- *Arm Exercises for Stroke Patients (Best Tabletop Home Exercises)*, by Flint Rehab.
- *Best Hand Exercises for Stroke Patients at Home*, by Flint Rehab.
- *Core Exercises for Stroke Patients to Improve Balance and Walking (Gait)*, by Flint Rehab.
- *Easy Leg Exercises for Stroke Patients (Guided by a Physical Therapist)*, by Flint Rehab.

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I vowed I'd never write another book after I experienced a mental breakdown shortly after completing my first book, "Marketing to Gen Z: The Rules for Reaching This Vast—And Very Different—Generation of Influencers." I associated every ounce of that negativity with writing a book. However, as I regained my health and ability to think straight, I realized it was the anxiety and depression hijacking my confidence all along. After my strokes, I had new, important stories to tell. Stories I hoped could help people living through similar situations. That's why I decided to write this book, and I hope to keep writing as long as I have helpful insight and information to share.

I could not have taken this massive step without the endless love and support of my dear husband, Steve. You never question or stand in the way of my crazy ideas and impulses. You encourage me to set big goals and back me up when I try to achieve them. You have been my rock for nearly 16 years, and I don't know

where I'd be today if not for you. You saved my life on the morning of July 25, 2017, by recognizing the symptoms of a stroke and calling 911 at once, despite my protests. Thank God you didn't listen to me.

And, of course, I thank my kids, Sammy, Henry, and Gabby, for believing in me and giving me the strength to continue fighting. And to my mom, Linda, 'bonus' mom, Lissa, and my sisters, Pam and Melissa, you are such strong women, and you've taught me how to be strong too. You stood by me, nudged me in the right direction, and did the research to help me find the best resources to make it through a dark and scary time. You lifted me up when I was so far down and lost myself. You helped me get back to "me."

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