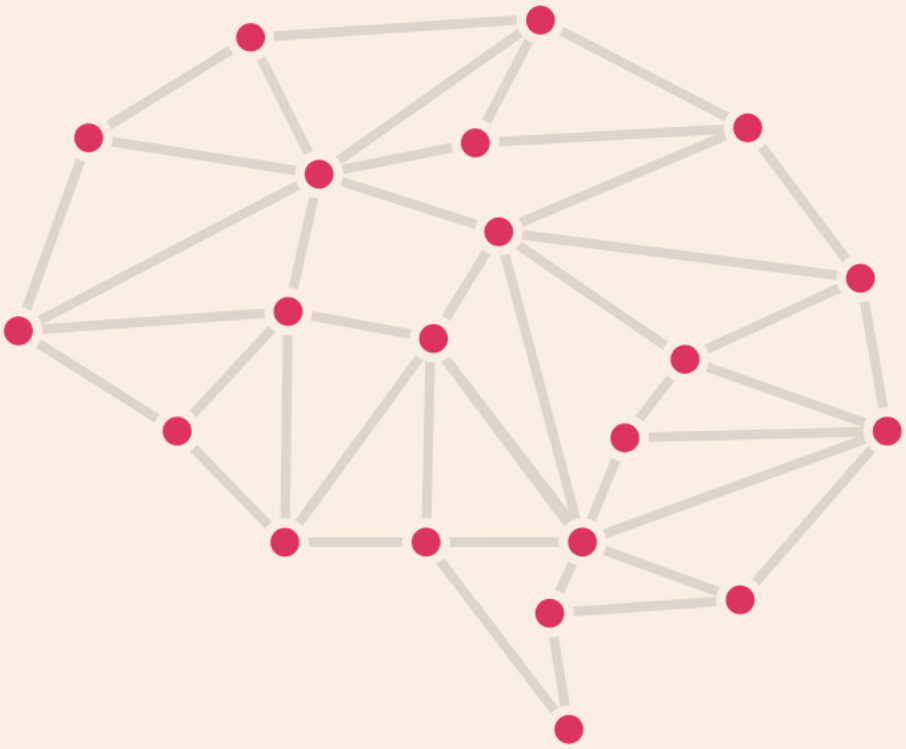
The Stroke Recovery Pocket Guide



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THE STROKE RECOVERY POCKET GUIDE

DR. ELYSE NEWLAND, OTD, OTR/L

For Nanny.

ACKNOWLEDGMENTS

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INTRODUCTION

Almost 800,000 people in the United States have a stroke each year, according to the Centers for Disease Control (CDC).[1]

Studies by the CDC and the American Heart Association (AHA) found that less than half of survivors received outpatient or home health rehab in some states. [2][3] The researchers assume that it was likely due to expensive co-pays or lack of insurance coverage for rehab services.

> Let me state the obvious: Stroke survivors don't get what they need and it's because high-quality therapy is not affordable or accessible.

These statistics probably make you angry; they make me angry. These statistics are also one of the driving forces behind why I'm writing this book, why I started a private practice, and why I'm creating resources for the stroke survivor community.

Who Am I and Why Should You Care?

Hi, I'm Elyse. I have my Doctorate in Occupational Therapy and have been practicing in various settings since 2017. I've always enjoyed working with stroke survivors, but my perspective completely shifted in October of 2019 when my grandmother-in-law had a transient ischemic attack (TIA).

That experience made me realize how traumatic having a stroke is for both the survivor and their loved ones. It also opened my eyes to the lack of resources and fractured continuation of care after initial hospitalization and inpatient rehabilitation.

I've become more and more frustrated with the U.S. healthcare system, and the experience with my grandmother-in-law was the straw that broke the camel's back.

When the pandemic hit in March of 2020, I decided to take a chance on something new. I started a private teletherapy practice for stroke survivors and began developing educational resources, like this book.

What's in This Book?

I had conversations with stroke survivors to find out what they wished they knew in the hospital and after rehab ended. I took what I learned, combined it with my knowledge, and turned it into this pocket guide.

This book provides an overview of the essential information stroke survivors should know. I've packed a lot into this little book. I'll help you understand more about stroke recovery timelines, deal with neuro-fatigue, and everything in between.

My goal is to empower you on your stroke recovery journey. Knowing more about the recovery process and how to advocate for yourself will make *you* your biggest cheerleader!

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1 CDC: Stroke Statistics

https://perma.cc/Y7DC-MZXK

2 CDC Article: **https://perma.cc/XN8H-Y74K**

3 AHA Article: **https://perma.cc/U87A-CGW8**

1

THE FOUR MAIN TYPES OF STROKES

One of the best things you can do as you work through recovery is to learn more about the type of stroke you had. How the stroke occurs and where in the brain it happens will determine what issues you might be dealing with.

So what is a stroke or "brain attack"? In the medical world, a stroke is called a Cerebral Vascular Accident (CVA) which has to do with Latin word origins. Try not to get too excited, but I have a really brief Latin lesson to help you better understand.

Cerebral = "Brain or skull."

Vascular = "Of vessels or tubes."

So when we put them together a CVA is basically an unanticipated injury (accident) that happens within the vessels (vascular) of our brain (cerebral).

There are 4 main types of strokes: Ischemic, Hemorrhagic, Cryptogenic., and Transient Ischemic Attack (TIA).[1] I'll walk you through the basics of each type.

Ischemic

This is the most common type and accounts for 87% of all strokes, per the AHA.[2] An ischemic stroke involves a blood clot in the brain that causes the brain to be without oxygen, resulting in cell death or damage. This is because blood carries oxygen and the brain needs oxygen to function.

Ischemic strokes are typically caused by atherosclerosis (a buildup of plaque in the blood vessels), and atrial fibrillation, or AFib (a common heart rhythm irregularity). [3]

Let's look at the two main types of ischemic strokes: thrombotic and embolic. These are fancy names for blood clots (or particles in the case of some emboli). The difference is in where those clots or particles form and how they get to the brain.

Thrombotic

This type of stroke involves a thrombus, or blood clot, which forms in the blood vessels that supply the brain. These reduce or block the blood flow available which leads to brain cell death.

A thrombus can cause either a sudden onset of symptoms or slow onset over the course of hours/ days. It can occur in large or small vessels depending on the size of the thrombus.

A thrombus that occurs in the small, deep vessels of the brain is called a lacunar infarction. These occur most often in the basal ganglia, internal capsule, thalamus, and brainstem. Thrombotic strokes are most common in adults with high cholesterol, atherosclerosis, and diabetes. [4]

Embolic

An embolus is a particle, most often a blood clot but can be fat, air, or bacteria. In an embolic stroke, the embolus forms/ breaks off in a different part of the body and travels to the brain.

The embolus becomes lodged as it travels through smaller blood vessels, blocking off blood flow. When it becomes lodged, it's normal to see an abrupt onset of issues. It can sometimes become dislodged and symptoms resolve. In other cases, an embolus can cause lasting problems that require extensive therapy.

An embolus often occurs with heart disease or after heart surgery. According to Johns Hopkins, around 15% of those who experience an embolic stroke have AFib. [5]

Hemorrhagic

These strokes make up around 13% of all strokes, per the AHA.[6] A hemorrhagic stroke involves a weak blood vessel that bursts or ruptures causing a brain bleed.

The bleed puts pressure on the brain tissue and results in brain cell death or damage. Hemorrhagic strokes are most commonly caused by uncontrolled high blood pressure, an aneurysm (a blood vessel that ruptures), or an arteriovenous malformation, or AVM (an abnormal tangle of arteries and veins). [7][8]

There are two main types of hemorrhagic strokes: intracerebral and subarachnoid.

Intracerebral Hemorrhage

This type of hemorrhagic stroke is two times more common than those caused by a subarachnoid hemorrhage. [9]

An intracerebral hemorrhage can happen deep in the brain or towards the surface. It occurs when thin-walled arteries in the brain burst and cause blood to flow into the brain tissue. This forms a hematoma: a clotted or partially clotted pool of blood.

The part of the brain that the ruptured artery served now becomes starved of oxygen. This is when brain cell death occurs.

Pressure can also build-up and cause the brain to press against the skull. This may require surgical removal of the hematoma to reduce pressure within the skull.

Subarachnoid Hemorrhage

This type of hemorrhagic stroke occurs in the subarachnoid space between the brain and the skull. [10] This space is filled with cerebrospinal fluid (CSF) which cushions the brain.

Subarachnoid hemorrhages are often caused by a ruptured aneurysm. This causes blood to enter the subarachnoid space, putting pressure on the brain. The area of the brain served by the ruptured artery begins to die due to a lack of oxygen and nutrients.

This bleeding can also interrupt the normal flow of CSF. It can cause the ventricles to enlarge due to the extra fluid in the brain (hydrocephalus). The ventricles are cavities deep in the brain and are responsible for producing and transporting CSF.

Cryptogenic

Almost 25% of ischemic strokes are considered cryptogenic, according to the AHA. [11] This means that the underlying cause of the stroke is unknown. Your doctor will likely request diagnostic imaging (like an MRI and/ or a CAT scan) and blood work to determine if a cause can be found.

Transient Ischemic Attack (TIA)

A TIA is also known as a "mini-stroke." This is when a blockage occurs temporarily in the brain due to a clot but symptoms typically resolve. It's still possible to have severe symptoms similar to having a full-blown stroke, but symptoms either don't last or won't be as severe when the clot clears. It's really important to take a TIA as a warning sign. It typically signals that an actual stroke is in the future.

Know The Signs

Having one stroke can put you at risk for more. Healthy lifestyle changes will help reduce that risk. Make sure you know the symptoms of a stroke. Use the acronym *BE FAST* to help you remember.

B: Balance issues

E: Eye or vision changes

F: Facial drooping

A: Arm numbness or weakness

S: Speech slurring

T: Time to call 911!

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1 AHA: Types of Strokes
https://perma.cc/X8CQ-DUFT
2 AHA: Ischemic Strokes
https://perma.cc/AD5B-85AJ
3 AHA: Atherosclerosis & Stroke
https://perma.cc/XP54-WJAE
4 Harvard Health: Thrombotic Stroke

https://perma.cc/E9PP-DRKM
5 Johns Hopkins: Embolic Stroke
https://perma.cc/C3W5-XZH6
6 AHA: Hemorrhagic Stroke
https://perma.cc/8AB8-2594
7 AHA: High Blood Pressure
https://perma.cc/FEC5-HVJV
8 Mayo Clinic: Brain AVMs
https://perma.cc/AL66-T5MR
9 Johns Hopkins: IC Hemorrhage
https://perma.cc/EA2Y-MJUL
10 Harvard Health: SA Hemorrhage
https://perma.cc/7HKQ-AVNX
11 AHA: Cryptogenic Strokes
https://perma.cc/ZZQ3-UD84

2

TIMELINE FOR STROKE RECOVERY

"How long until I'm better?"

This is the question I hear most often from survivors.

It's difficult to predict how long it will take or how much progress someone will make after a stroke. Stroke recovery is spontaneous, meaning there is no specific pattern or timeline. This can be frustrating to hear.

Here's what we do know: the timeline for the quickest and "most optimal" recovery after a stroke is typically within the first 3 months. This is why many survivors transfer to a rehab facility soon after their stroke. The AHA sums up the reasoning for this:

> "For the first three months after a stroke, the brain is much like a new brain. It's ready to learn, ready to make new connections. This ability for our brains to adjust is known as neuroplasticity and it plays a vital role in recovery. It takes about three months after the stroke for neuroplasticity to return to a more normal state. After that, a survivor can still work on regaining function and practice for improvement, but those improvements may come at a slower pace." [1]

With that in mind, here's the good news: Stroke recovery can continue for years afterward.

There's not only research to back that up; I hear from and see many survivors continue to make progress years after their stroke. [2][3][4]

You may see the quickest recovery happen within that three month time frame and then slow down some. However, it is possible to make progress after that!

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1 AHA: Life After Stroke

https://perma.cc/5Q5D-H3Q4

2 Neuro Research & Practice: Recovery from Stroke

https://perma.cc/2PD7-LWRD

3 Journal of Neurophysiology: Stroke Recovery After One Year

https://perma.cc/5BRT-3MQR

4 Journal of Stroke: Neural Repair

https://perma.cc/XFW4-6MXU

3

MANAGE EXPECTATIONS

One of the many difficult things about stroke recovery is that it's different for every survivor.[1] Every stroke happens somewhat differently and symptoms are never uniform. Some survivors make a 100% recovery within a year. It may take others five years to get back to 70% of their normal. Try your best not to compare yourself and your recovery to another survivor's recovery. Focus on today and your accomplishments.

> Everyone's journey is different.

While you keep working, you can make adaptations to be more independent and continue doing the things that are important to you.

Recognize that it's likely you'll hit a plateau or a mental block at some point in your recovery. You also may feel down or depressed which can lead to decreased motivation and, ultimately, a lack of engagement in your recovery process.

Please know that it's okay and normal to feel this way. Make sure to nurture your mental health as much as your physical health, *but don't stop trying*. If you hit a mental block or feel like you are plateauing, switch up your routine. Try something different, and make sure you seek out mental health care.

> Recovery is a process and a journey. Progress doesn't happen overnight. It takes effort and consistency every day.

You may need to adapt the way you do things for now or over the long haul. You may need to adjust to a new normal. Life may look different now than life before your stroke, but be assured that your life can still be happy and fulfilling even with a changed brain!

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1 Mayo Clinic: Stroke Recovery Expectations
https://perma.cc/8WDV-TT4Y

4

NEUROPLASTICITY

Now that you know a little more about the mechanisms of strokes, timelines, and the expectations for recovery, I'll walk you through the basics of the best stroke recovery tool.

What Is It?

Neuroplasticity is a super science-y word with a pretty simple explanation. Let's look at another quick Latin lesson.

Neuro = "To do with the brain or nervous system."

Plastic = "Able to be molded."

Neuroplasticity is the brain's ability to change and mold.

This essential function allows the brain to adapt and remold when damage has occurred, which is why it's critical in stroke recovery.

A Simple Analogy

Imagine that a person is taking the train to work and has to switch trains twice on their route.

Today, they find that the second train is out of commission and this person has to find a new train route that will take them to work.

Instead of panicking, they look at a map of the train system. They realize there are multiple routes they could take and try one out today.

It goes well and they try a different route the next day until they find one that works well for them.

After a stroke, the injured area of the brain is like that out-of-commission train car.

Neuroplasticity is the map we use to try and find other existing routes to get to a destination. Those new routes are established through motor learning by being actively involved in recovery and repetition.

Diving Deeper

After a stroke, there is brain cell injury or death in the area affected. This is considered to be maladaptive (or bad) neuroplasticity because that area of the brain can no longer effectively communicate with the body or perform cognitive processes. This can lead to weakness on one side of the body, vision changes, speech issues, and difficulty with thinking and memory.

> How do we promote positive neuroplasticity in order to establish new pathways?

Neuroscientists have stated, "Neurons that fire together, wire together." This means that when you're trying to do something specific, the brain activates in a certain pattern, which results in that desired action.

Once the brain has established that pathway and pattern, it's easier for it to complete that pattern again the next time you want to do that specific activity. There are certain ways to maximize those brain changes. [1]

Principles of Neuroplasticity

Scientists used to think that once the brain was injured, that was it! They thought the brain could not make changes to itself. We know better now.

While it is true that as we age, our brain's ability to make neuroplastic changes decreases, it doesn't mean that the brain completely loses the ability to adapt.

> The brain is more like a muscle. We have to use it to make it stronger!

Practicing a task over and over will help rebuild those neural pathways. This leads to better outcomes.

Think about someone learning how to knit. Starting out, that person may fumble with the simplest task and become frustrated. If that person practices knitting every week, in two years they can carry on a conversation while making a sweater.

Or think about driving to a new location. The first time you go, you might take a couple of wrong turns, but the more you drive that route, the more automatic it becomes.

After a stroke, rehabilitation focused on creating neuroplastic changes can make it easier for the healthy parts of your brain to take over the functions of the injured part. [2]

Use It or Lose It

This old saying is especially true in stroke rehab!

Use It to Improve It

Practice may not make perfect, but it will definitely help.

Repetition

Research is still out on exactly how many reps it takes to establish new brain pathways. A small study has shown that 300+ reps in an hour led to arm & hand improvements in the short term and after one month.[3]

Intensity

Doing exercises or activities daily will improve outcomes. The specific study mentioned above had participants doing rehab tasks three times a week for one hour over the course of six weeks.

Relevance

Research shows that doing activities that are important to you actually create better outcomes! So, if you're having difficulty with dexterity and you enjoy cooking, make a meal as part of your therapy!

Time

In addition to all of the above, recognize that brain changes take time. Even if you don't see changes right away, don't stop. Your brain is making changes!

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1 Improve Outcomes with Mental Practice Exercise **https://perma.cc/K2Z5-YDV8**

2 Toronto Stroke Networks: Neuroplasticity
https://perma.cc/8MTH-T586

3 Neurorehab & Neural Repair Journal Article
https://perma.cc/P56M-XJQL

5

ADVOCACY

Throughout your stroke recovery journey, self-advocacy is another important tool to keep in your toolbox. If you have cognitive, speech, or communication issues, having someone to advocate for you at appointments will be helpful.

Some survivors feel like their doctors downplay or don't understand their symptoms, like neuro-fatigue and brain fog.

> Healthcare professionals are experts in their fields, but they're not the experts on *you!* Only you know what it's like to live in your body.

Here are some ways to make sure that you or your advocate communicate effectively at your next appointment.

Track Symptoms

Keeping a log of your symptoms can provide clinicians with objective data. [1] Log how you feel, how often, if medications help, and any physical symptoms you have. This information will help your healthcare team better understand your experiences and decide what steps to take next.

You can print a symptom log from the section at the end of this chapter. If you're unable to write, you can use dictation (speech-to-text)

on IOS and Android devices. [2][3]

Lists

When preparing for your next appointment, make a list of questions you have for the clinician. Having a list of questions will not only help you get the answers you need but will help the clinician, too. It may be helpful to write this list on your phone. Most phones have a memos or notes app you can use and go virtually everywhere with us.

Be Assertive

Project confidence and be a bit forceful in your language. [4] Sometimes you have to spell things out and make it known that your experiences are valid.

This can be difficult if you're introverted or a people-pleaser, but being assertive doesn't mean you have to be aggressive. It just means you've thought about what you need and make those needs known.

Find Another Provider

If you feel like you're not being heard or don't connect with your provider, you have every right to seek out a different clinician. It may reduce your physical and cognitive effort to be seen by a provider that you feel understands you. You don't have to be stuck with someone who you don't connect with or doesn't listen to your concerns.

---

1 Symptom Tracking Log

https://perma.cc/PHH3-T5ZA

2 IOS Dictation Instructions

https://perma.cc/34YK-S5R6

3 Android Dictation Instructions

https://perma.cc/2CYX-R8B2

4 NIH: Talking To Your Doctor

https://perma.cc/VL7C-287W

6

MENTAL HEALTH

Depression and anxiety are unfortunately common in stroke survivors. Mental health changes can be a byproduct of the actual brain injury and/ or the result of the trauma of having a stroke. A research study by Chikri and colleagues in 2006[1], found that post-stroke depression occurs in 20-40% of stroke survivors and that post-stroke anxiety occurs in 20-30% of stroke survivors.

You're not alone, and you're not weak.

You have been through trauma. It's okay to ask for help.

Recognition

Mental health issues are *real* problems. Anxiety, depression, and panic disorder are all real medical diagnoses. Just because they're not visible doesn't mean they're not valid. You don't have to "get over it," and anyone who suggests that needs to take a hike.

Be Kind

It can be easy to beat yourself up or feel like you should be able to handle mental health changes. You have been through trauma. You are allowed to feel how you feel. Be kind to yourself.

Medications

It may seem obvious, but make sure the medications you take aren't causing anxiety or depression as a side effect. Once that's ruled out, talk to your doctor to see if they think you'd benefit from anti-anxiety or antidepressant medication.

Therapy

Mental health therapists can give you specific strategies to help you cope with mental health changes after your stroke. It's also okay to seek out a therapist that you work well with. If you don't have a connection with the first therapist you try, they'll understand if you need to find someone else. If you don't have access to a mental health therapist, consider using apps like *BetterHelp* or *Talkspace*.[23]

Exercise

It can be hard to get involved in physical activity if you're feeling anxious or depressed. It doesn't help that stress hormone levels can rise after a stroke. Research shows that exercise releases endorphins and dopamine. These are our "feel-good hormones" and help improve our mood. Exercise can be especially beneficial for treating depression since it releases the "feel-good" hormones which combat stress. Always talk to your doctor before starting a new exercise routine.

Get Support

Reach out to mental health agencies, join in-person or online support groups, or just get together with friends. Establishing a support system will help you better cope with physical, cognitive, and mental health changes.

Go Outside

Research shows that being in nature can increase joy, decrease worry, and decrease our stress levels.[4] No matter your physical abilities, you can find an activity to do outside. Take a walk, sit outside and read a book, or simply sip a cup of coffee in the great outdoors.

Depression

Depression sucks. There's no way around it. It makes you feel like doing nothing and makes it hard to find joy in life. It can impact your ability to engage in recovery and rehab, even though you know it might help. But there are specific things you can do to effectively deal with depression.

Acknowledge

Depression can make it hard to do what may seem like simple tasks. Congratulate yourself for getting out of bed, making breakfast, or brushing your teeth. Acknowledging even the smallest wins can improve your self-confidence and your mood.

Educate Others

Explain to family and friends how the stroke affected you. Educate your loved ones on how they can best help you. It may be that you don't want someone telling you how many things you have to be grateful for. You might need them to tell you that everything sucks right now, but that they are there for you.

Problem-Solve

Work to identify a problem and set an attainable goal. Work to identify a problem and set an attainable goal. Keyword: *attainable*. Identify possible solutions to the problem and try one. Then reassess to see

what worked and what didn't. This particular strategy is best worked on with a therapist or counselor.

Fear and Anxiety

After having your first stroke, it's common to be fearful and anxious about having another one. Taking preventative steps to reduce the risk of future strokes will help you reduce the fear of having another stroke. There are also coping techniques you can use to deal with momentary and chronic anxiety.

Recognize

The first step to managing anxiety is to understand what makes you anxious. Once you identify your anxiety triggers, then you can work to manage the situations as they arise. Keep a journal of things that cause you to feel anxious, what level of anxiety they produce, and what your typical response is to those triggers.

Mindfulness

We tend to get stuck in our thoughts, especially negative ones, that can cause us to spiral into the land of "what if…" Mindfulness can help direct thoughts away from worries about the future or past, and on to the present moment. This can shift our attention away from negative thoughts. [5] It can also help to reduce our overall stress levels. [6]

Relaxation Strategies

Deep breathing, visualization, yoga or tai chi, and body scanning are all relaxation strategies that can help you relax in the moment.[7] Visualization allows you to picture and "go to your happy place." Body

scanning allows you to check in with yourself and see where you're holding tension.

Stress Management Plan

Create a specific anxiety or stress plan to manage your symptoms.[8] Identify your triggers and establish what you'll do in the moment and afterward to relieve your anxiety symptoms. For example, if you know that watching the news spikes feelings of anxiety, plan to only watch/ read it for 15-20 minutes. In the moment, you could engage in some deep breathing to keep you relaxed, and afterward you could make yourself a cup of hot chocolate or tea.

Panic Attacks

As someone who experiences panic attacks, I understand how absolutely terrifying they can be. Symptoms typically include hyperventilation, tingling hands, arms, or face, and heart palpitations. You might feel like you're having a heart attack, another stroke, or dying. With therapy and certain techniques, you *can* get panic attacks under control.

Distraction

Use distraction to divert your attention away from the symptoms of panic and onto something more positive. For example, turn on a silly tv show when you start feeling the symptoms of an attack. Remember that distraction can be good in the short term but it shouldn't be your long term solution, as it doesn't actually help correct the underlying problem.

Deep Breathing

Breathing from the diaphragm actually stimulates the vagus nerve. This triggers our "rest and digest" system which is the opposite of our "fight or flight" system. Count 4 breaths in and 4 breaths out.

Cognitive Behavioral Therapy (CBT)

CBT for mental health issues could be an entire book on its own (and I know there are many). The goal of CBT is to help you recognize and change negative thought patterns in order to have produce more positive behavioral outcomes.[9]

For example, if you're like me and tend to be a bit of a perfectionist, you might think that if something is not done exactly to your standards, then it's a failure. This is an example of a cognitive distortion, or habitual and inaccurate negative thought patterns. CBT helps to identify those distortions.

There's not been a lot of research on CBT with stroke survivors. However, it is a proven tool for treating anxiety and depression in the general population.

CBT provides strategies to challenge those negative thoughts, rather than give into them. This can lead to more positive thoughts and better outcomes.

CBT is not a quick fix. It takes time and consistency to implement these strategies. It's best to work with a mental health therapist if possible.

A small piece of CBT you can use for panic attacks is to recognize that you are not going insane and that you're not going to die. Tell yourself that it's okay that you feel this way. It's not nice or pleasant, but it will pass.

Mental Health Crisis

If you or someone you know is experiencing a mental health crisis, most of these lines operate 24/ 7 and are free of charge:

- National Suicide Prevention Lifeline: 1-800-273-8255
- Crisis Text Line: Text "HELLO" to 741741
- Veterans Crisis Line: 1-800-273-TALK (8255)
- SAMHSA's National Helpline: 1-800-662-HELP (4357)
- NAMI HelpLine: 1-800-950-NAMI (6264)

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1 Chikri Study on Post-Stroke Anxiety and Depression **https://perma.cc/C9X6-4TNT**

2 BetterHelp App

https://perma.cc/83CJ-3RAN

3 Talkspace App

https://perma.cc/4AR3-AWF9

4 Research Article on Nature & Stress Response

https://perma.cc/HK62-98DY

5 Research on Mindfulness & Attention

https://perma.cc/VX9U-5E83

6 Research Article on Mindfulness & Stress Reduction

https://perma.cc/CE92-FDJT

7 Harvard Health: Relaxation Techniques

https://perma.cc/CDB5-5S3S

8 Elyse's Blog: Resources to Create a Stress Management Plan

https://perma.cc/TA3B-H9M4

9 APA: What is CBT?

https://perma.cc/2ALQ-DJE2

7

SLEEP

In general, mental health and sleep often impact each other. Anxiety can cause racing thoughts and trouble "turning your brain off." Depression can cause you to want to sleep 20 hours a day. Throw a stroke in the mix, and you have the perfect sleep storm.

After a stroke, it's common to sleep and/or nap a lot. Don't beat yourself up about this. You're not being lazy. Sleep is one of those things that we must have for our bodies and brains to repair.

Your brain has sustained an injury. If you were recovering from the flu, you'd also need to rest to regain your strength.

It's also common to have trouble getting to and staying asleep after having a stroke. [1] Be open about sleep issues with your doctor. A research article by Davis and colleagues in 2013, found that 50-70% of stroke survivors have obstructive sleep apnea which can significantly impact sleep quality and quantity. [2]

Your doctor may want you to do a sleep study. Some survivors need to use a CPAP machine to improve sleep quality.

In addition to talking to your doctor, here are some basics of sleep to keep in mind.

The Sleep Paradox

The more we think about "trying" to sleep, the less likely we are to actually sleep. When we put pressure on ourselves to sleep, we activate our "fight or flight" response. So instead of sleeping, we can become anxious and alert.

So while you're lying in bed waiting for sleep, don't think, "I have to fall asleep now." Focus on white noise and do some deep breathing, meditation, or count sheep!

Sleep Hygiene Strategies

Sleep hygiene consists of the activities, routines, and environments you surround yourself with to improve sleep.[3] You've probably heard some of these strategies before, but they bear repeating. They are effective and can help you get a better night's sleep.

Sleep Schedule

Keep a consistent bedtime and wake time even on the weekends. This can help regulate your sleep drive so you get tired around the same time every night.

Nap

If you find that you need to nap, shoot for 90-minutes. This allows your body to cycle through all the stages of sleep, including REM. Try not to nap too close to your bedtime.

Sleep Environment

Light-blocking curtains can reduce stimulation in the bedroom. Limit sound to white noise and keep your bedroom environment cool. These are proven environmental modifications to help the body feel prepared for sleep.

Limit Stimulants

Stop caffeine consumption 4-6 hours before your bedtime. Limit alcohol before bed. Alcohol is a double edged sword. It can help you fall asleep but often leads to disrupted quality.

Limit Screen Use

Stop screen use at least an hour before bed. Avoid using screens if you wake up in the middle of the night. Set your phones to "dark mode" at night. This will change the typical cool blue light to warm yellow light. Warm light mimics the sunset which triggers our brain to prepare for sleep.

Evening Routine

Prepare for sleep with calming activities like reading or taking a warm bath. Your body will learn to associate these activities with sleep and stimulate melatonin production, which is the hormone that triggers our sleep response.

Get Moving

Physical activity builds up our sleep drive, ultimately making us more tired by the end of the day. However, avoid physical activity too close to bedtime as it can cause too much stimulation. Limit to at least 2 hours before bedtime.

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1 AHA: Sleep Issues After Stroke
https://perma.cc/UC3W-5TYU

2 Neurology Clinical Practice Article on OSA After Stroke

https://perma.cc/53N3-KRVB

3 Sleep Hygiene Strategies Adapted from USC's Lifestyle Redesign Course for Sleep Disorders

https:/ / chan.usc.edu/ about-us/ lifestyle-redesign

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FATIGUE

Sleep and fatigue often go hand-in-hand. While getting plenty of good quality sleep is important, it's not the only variable to improve neuro-fatigue, which is different from traditional fatigue. [1]

> Your brain is repairing itself.

This takes time, good nutrition, physical activity, and sometimes compensatory strategies to maximize your energy use!

Like every other aspect of stroke recovery, fatigue is different for every survivor. This can cause you to be slightly more tired than before your stroke, or it might make you want to sleep 23 hours a day.

It's difficult to predict when or if it will completely go away. It can also cause "brain fog," which makes it hard to pay attention and concentrate on things you want to do, as well as remember things and problem-solve.

Here are some things you can do to improve it.[2]

Rest

Listen to your body, especially in the first few months after a stroke. Your brain and body are recovering. Rest when you need to.

Physical Activity

It may seem counterintuitive, but fatigue actually gets worse when we stop being active. This can turn into a nasty cycle because when we don't feel like being active, we get more fatigued. Then we experience more fatigue which makes us not want to engage in physical activity. Try starting with something easy and achievable for you. Something is better than nothing.

Review Sleep Routines

Are you actually getting enough sleep? Do you have trouble falling asleep? Do you wake up often during the night? Is the sleep you're getting good quality? As noted in the last chapter, your doctor may want you to do a sleep study.

Feeling Depressed?

Depression can actually lead to significant fatigue, and fatigue can lead to depression. Make sure that you talk with your doctor if you think you might be depressed. Medication and therapy can be extremely effective.

Educate Others

Explain to your social support system how you feel and how fatigue affects your daily life. It's hard for someone without neuro-fatigue and brain fog to understand what you're going through. It can help to educate them on your experiences.

Christine Miserandino, who has Lupus, came up with a great way to explain chronic fatigue to others using her "Spoon Theory."[3] I think it can be useful to also explain neuro-fatigue to those around you who might not understand.

She stated that each day starts with a limited amount of energy spoons and each time she needs to do something, it may cost one,

two, or more spoons. So, she may not have enough energy to go out with a friend in the evening because she already used too many spoons on cleaning the house and cooking breakfast.

Energy Conservation

You may try to do too much too soon and end up staying exhausted most of the time. Energy conservation is a technique you can use to compensate for the fatigue you feel. Using the 4 Ps of energy conservation can help you get done what you need and want to do while fatigue is present.

Prioritize

Think about the activities that need to be done or you want to do. Start with the most important and put off less important things if you need to. This can be difficult for "type A" or perfectionist personalities. But try to remember that you are healing. Progress, not perfection.

Plan

Plan your day to avoid extra trips. If you have to go out to a doctor's appointment, plan to do your grocery shopping on the same day. Then you can rest when you get home. Plan for rest days in your week. Especially after high energy days (like going to the doctor and grocery shopping). Try to get a good night's rest.

Pace

Slow and steady wins the race. Don't feel like you have to rush to get things done. Take rest breaks when you need them. This is a really hard thing to do, but ask for help if you need it.

Position

Sitting uses a lot less energy than standing. Sit when preparing a meal instead of standing at the counter. Sit when getting ready in the morning. Make sure you have somewhere to comfortably sit in every room.

Activity Pacing

This is another compensatory strategy to help you while fatigue is on-going. Activity pacing helps you set goals and break down tasks into manageable pieces instead of trying to get it all done at once. Here are some ways to integrate activity pacing to manage fatigue.

Breaks

Take regular rest breaks, even if you feel you don't need them at the time. This can help you from overdoing it and give you a better understanding of where your limits are.

Recognize Limitations

As you get to know your new normal after your stroke, you'll start to recognize limitations. Once you know where your limits are, make a promise to yourself to not push past them. Your body and brain will thank you.

Time Box

Set a time limit and don't work past it, even if you feel that you can. Keep your timer in a very visible location so you can see the remaining time you have. When your timer goes off, stop! Take a break and give your body the chance to rest.

Incremental Changes

If you start feeling your energy levels increase, you can make small changes to tasks and activities to encourage progress. For example, let's say you enjoy cooking but standing longer than 5 minutes has been too much. If you feel like your energy level is improving, try standing for 6 minutes while preparing a meal. Small changes add up in the long run.

Coping

Coping with post-stroke fatigue can be frustrating. It's as much an emotional rollercoaster as it is physical. Here are some healthy techniques for coping with fatigue after a stroke.

Journal

Track what things you're able to get done during the day. It will give you an objective measure to track your progress. It also gives you something to share with your doctor or family members to help them better understand what you're experiencing. As I mentioned in chapter 5, if you have difficulty writing, you can use speech-to-text on your phone with the memo or notes app.

Celebrate Success

It's normal to be frustrated by what you can't do. I mentioned in chapter 6 that it's easy to get sucked into negative thought patterns. Take the time to celebrate what you *can* do, especially the small things.

Support

Stay connected with your medical team and let them know how you're feeling. Reach out to friends and family. Look for local and online support groups!

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1 AHA: Fighting Through Fatigue

https://perma.cc/GC6F-QUNG

2 Adapted from USC Lifestyle Redesign for Chronic Pain and Headaches

https:/ / chan.usc.edu/ academics/ continuing-education/ life-management-series/ lifestyle-redesign-for-chronic-pain

3 Christine Miserandino's Spoon Theory

https://perma.cc/C6B7-MXFM

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MEDICATION & MONITORING

Neuro-fatigue, brain fog, and cognitive issues following a stroke can make it hard to remember to take your medications and monitor your health signs**.** But these are necessary measures to keep health in check.

Uncontrolled blood pressure, blood sugar (glucose), and cholesterol are often underlying factors that contribute to someone having a stroke. Keeping these factors under control with medication and lifestyle changes can help reduce the risk of future strokes.

Make sure that you or your advocate talk with your doctor to understand *why* you need to take each medication. It can be easy to dismiss taking medications if you don't know what they're for. Keep a log of all your medications, doses, frequencies, and why you take them. It can be helpful to keep this log on your phone where it can be easily updated!

Remember to Take Medications

If your stroke left you with some short-term memory or attention problems, it can be difficult to remember to take your medications. Don't worry. There are some simple things you can do to help you remember.

Set Alarms

Set an alarm or alarms for the times you need to take your medications. You can do this easily with any smartphone or even use an oven timer. If you use your phone, you can label the alarm, "AM or PM Medications," so you don't forget why you set it in the first place!

Link Activities

Take your medications with an activity you do every day. For example, take morning medication with coffee and evening medication with dinner. By linking the two activities together, you're more likely to remember your medications and make it a daily habit.

Use A Pillbox

If you take a lot of medications, use a pillbox. This can help you organize them on a weekly or monthly basis. A pillbox can also help you recognize when you've missed your medications since they have multiple slots for each day.

Turn Bottles

If you don't use a pillbox, turn your pill bottles over after you take them. This will help you remember which medications you've already taken and alert you if you missed any.

Personal Reminder

Not everyone has this option, but if you have a partner, close friend, relative, or care partner willing to help, have them remind you what medications to take and when to take them.

Monitoring

Taking prescribed medications is really important to keep blood pressure, cholesterol, and blood glucose under control. If you have high blood pressure or diabetes, the other aspect of this is to make sure you're monitoring your blood pressure and blood glucose, per your physician's recommendations.

Why Is This So Important?

Keeping an eye on your blood pressure and glucose readings can give you crucial information. If your blood pressure typically sits around 130/ 85 mm/ Hg and one day it's 170/ 97 mm/ Hg, this can clue you in that something may be wrong, or at least to call your doctor about it!

It's the same with blood glucose. If it's too high or low, it can help inform you of what your next steps need to be.

A few simple ways to keep up with blood pressure and glucose monitoring are to use paper logs, apps on your phone, or an Excel spreadsheet on your computer. See the resources below for printable logs and app recommendations. [1][2][3][4][5]

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1 AHA Blood Pressure Printable Log

https://perma.cc/T7MW-EKA7

2 Johns Hopkins Printable Glucose Logs

https://perma.cc/MDA4-HXDZ

3 Blood Pressure Tracker + App for IOS

https://perma.cc/ZHZ4-ZRB2

4 BP Journal App for Android

https://perma.cc/6R9F-5Z9Z

5 mySugr — Diabetes Tracker Log

For IOS: **https://perma.cc/9SMF-5JTS**

For Android: **https://perma.cc/B9SK-9QJM**

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SET GOALS & CELEBRATE VICTORIES

Let's wrap up this pocket guide with two significant things you should do in your recovery: set goals and celebrate victories. Both of these actions can help improve your mood and increase your motivation, especially on the days you don't feel like doing anything.

Goal Setting

When setting goals, make sure they're SMART. By using the SMART template, you ensure that you're setting attainable goals.[1] It's important to not expect too much of yourself too quickly. Remember, recovery is a journey.

Specific

Make your goals specific to where you are in your recovery. Every survivor is different! Example: Don't just say, "I want to walk better." Instead say, "I want to walk without help from someone else, using my straight cane."

Measurable

Set goals with a measurable aspect so you can actually see progress. Don't just say, "I want to walk further." Instead say, "I want to walk one block with my straight cane."

Achievable

Make sure that your goals are achievable. If you set a goal that's too difficult to achieve, you could become upset and frustrated when you don't reach it.

Realistic

Set goals that are realistic for your specific situation and where you are in your recovery. It can be easy to compare yourself to how others are recovering, but try not to. You're on a unique journey.

Time-Bound

Set a time frame to maintain accountability. Make sure it's realistic and don't ask too much of yourself in a short amount of time.

Celebrate Victories

After you set these SMART goals, make sure you celebrate each time you meet or make progress towards one!

Science has shown that recognizing strengths and celebrating wins (no matter how small) can boost self-confidence.[2][3] When we celebrate a victory, the brain's reward center releases dopamine and we feel really nice![4] Acknowledge your wins with a massage, an at-home facial, take a warm bath, or schedule a game night!

It's especially important after a stroke to recognize every small win. Some people may progress faster than others, but try not to compare. Every stroke survivor is different and so is their recovery. Celebrating the small wins can you help you stay motivated to keep challenging yourself and break plateaus.

It can help to keep a journal. Take 2 minutes at the end of every day and write down your wins, big or small. You'll have something to reflect back on if you feel like you're hitting a wall in your recovery, and you can have a moment to celebrate what went well every day!

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1 SMART Goal Worksheet

https://perma.cc/YKN7-3ZWG

2 Karl E. Weick. Small Wins, 1984.

https://perma.cc/G29M-UH6T

3 Harvard Business Review: The Power of Small Wins

https://perma.cc/L3CY-ZNQN

4 Psychology Today: The Amazing Power of Small Wins

https://perma.cc/5T4S-LE57

AFTERWORD

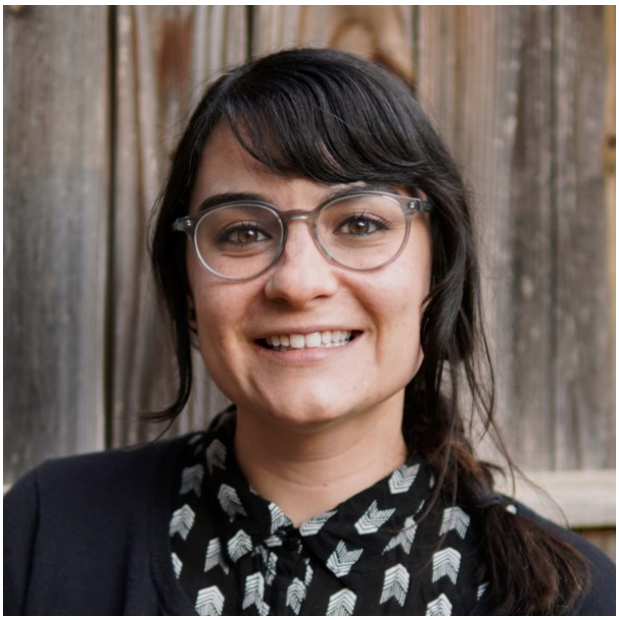
Thank you so much for reading through The Stroke Recovery Pocket Guide. It was an honor to write this book and I gained so much insight from the conversations I had with survivors.

I hope that you found the information in this guide helpful and applicable to your recovery journey. I wish you and your loved ones the best as you continue on this journey.

MEDICAL DISCLAIMER

Please note that all content in this book is for informational purposes only. It is not intended to serve as a substitute for medical advice or treatment from a qualified healthcare provider.

ABOUT THE AUTHOR



Elyse has a Doctorate of Occupational Therapy (OTD) and is Certified by the National Board for Certification of Occupational Therapists. She loves her work but is frustrated with the broken state of U.S. healthcare. She works specifically with stroke survivors and continues to explore ways to route around the system to get survivors the resources they need. Elyse makes stroke information simple via her blog and YouTube videos. She also provides teletherapy for stroke survivors in TN, GA, NC, OR, and CA. You can find her at elysenewland.com This is Elyse's first book.