

A GUIDE FOR THE EMOTIONAL JOURNEY IN STROKE RECOVERY



After a stroke, survivors and their supporters are initially consumed by accessing the healthcare needed to survive and be stabilized. Then, the focus naturally shifts to rehabilitation (physical, occupational, speech, and other) to recover as many lost capabilities as possible. But there is another less visible and sometimes even more challenging aspect of recovery — the emotional journey to rebuild identities and rewarding lives.

Survivors often face dramatic changes to their lives and opportunities — relationships with family and friends, work and income, activities and hobbies, and more. Even survivors who fully recover their capabilities report feeling changed or different from before and this can feel similar to the loss of a loved one. Whole person recovery from stroke is simultaneously a physical and emotional journey. It's the effort to both regain capabilities and rebuild emotional wellness and identity, including a strong sense of self and a rewarding life of meaning, purpose, and pleasure.

This guide introduces emotional recovery after stroke and how to support yourself or someone else during this journey to rebuild.

What is the emotional journey?

There are many aspects to emotional health and wellness after a stroke.

Much of the information that is available about emotional/mental health after stroke discusses recognizing and getting help for mental health conditions, like depression or anxiety, that are common after stroke. Stroke is an injury to the brain and mental health can be complicated by this fact. This guide is not intended to address specific mental health conditions, however, two high-quality resources to learn more are:

- **American Stroke Association - [Emotional Effects of Stroke](#)**
- **UK Stroke Association - [Emotional Changes](#)**

Access Mental Health Support

If you or someone else is experiencing symptoms of depression, anxiety, or emotional distress, it is important to let your healthcare providers know so that they can support you both physically and emotionally.

For immediate support, call or text 988 or use the chat on 988lifeline.org. The 988 Suicide & Crisis Lifeline is a US network of local crisis centers that provides free and confidential emotional support to people in suicidal crisis or emotional distress 24 hours a day, 7 days a week.

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One aspect of emotional recovery that too often receives little attention is the journey to rebuild identity - our sense of self - and a rewarding life after stroke. This component of recovery also requires deliberate focus, energy, and support. Here the focus is on processing the emotions that are natural after a stroke and reimagining and rebuilding a rewarding life.

There is no “right” or “wrong” way to rebuild. For some, there is quick acceptance that their capabilities have changed, their life has changed, and they start building from there. Others focus solely on therapy and regaining capabilities, working and hoping to get back to their old life. How to balance this recovery journey and perhaps shift focus when needed are choices that each person impacted by stroke must decide for themselves.

Grieving the loss

Strokes happen quickly and can leave devastation in their wake, impacting so many areas of life: the ability to walk, talk, use hands and arms, live independently, participate in careers, be a spouse, partner, parent, friend, and so much more. No matter if the stroke was minor or massive, it is normal to experience a sense of loss. These losses may need to be grieved as part of the emotional rebuilding process. Finding support and having a framework to build understanding is a mainstay of dealing with other kinds of loss, and can

be incredibly helpful not only to the survivor but also to their loved ones, who are also experiencing a loss. It can be helpful for the entire support system to recognize this so they can support each other and grieve that loss together.

While there is no singular model for the emotional journey to recover after stroke, many people find it helpful to consider the



Survivor Story - Flannery

After my stroke, I often answered “I’m fine” or “I’m doing well” when people asked how I was, but on the inside, I was struggling to understand what had happened to me and what it meant for my life, my goals, my hopes, and my career.

I wondered “Am I still the same me?” when I couldn’t do all of the things I used to be able to do. Although I had great therapists: speech, physical, and occupational, it wasn’t until months after my stroke that I realized I also needed help to process the emotional impact of this trauma if I wanted to really rebuild my sense of self.

Five Stages of Grief, developed by Elisabeth Kübler-Ross, MD and David Kessler in their 2004 book *On Grief and Grieving: Finding the Meaning of Grief Through the Five Stages of Loss*. While navigating this part of emotional recovery, it is important to remember that grief is not linear and feelings may fluctuate over days, months, and even years. Some people may experience all of the stages while others may experience only some of them. David Kessler recently published *Finding Meaning: The Sixth Stage of Grief* (2020) where he wrote in depth about a new stage of grief - finding meaning. "Your loss is not a test, a lesson, something to handle, a gift, or a blessing. Loss is simply what happens to you in your life. Meaning is what you make happen." As the emotional healing journey moves from the earlier stages of grieving towards acceptance, reflecting on meaning and purpose is an important step towards rebuilding.

Rebuilding your Identity

Grieving is about loss and dealing with that loss. One of the things many survivors may feel the loss of is their identities – their sense of who they are. A critical aspect of recovery is regaining or rebuilding that sense of self – who you are now. Even more important, a sense of who you want to be. After the stroke, it can be easy to remember life pre-stroke and feel frustration when we cannot engage in life in the same way or when people treat us differently. For survivors with aphasia, it may be especially challenging as our ability to communicate is so intricately connected to our identities. This can further compound the feelings of loss and complicate recovery. Rebuilding identities involves reclaiming the pieces that mean the most and redefining meaning and purpose, something everyone can do regardless of changes in abilities.

Key Factors about Identity

Each of us is made up of a variety of identities - As Debra Meyerson writes in her book *Identity Theft: Rediscovering Ourselves After Stroke* (2019), "our identity is not a static thing... It is a mix of our desires and ambitions, our associations and roles, our values and our relationships, and our emotions and thoughts."

Recovery =
Rehabilitation
and
Rebuilding

Identities are dynamic - When a stroke occurs, it can cause dramatic identity impacts; but it's important to remember that each of us is changing all the time, even without a traumatic event like stroke.

Our relationships impact our identities - We are who we are in the context of the people and communities around us. After a stroke, relationships can change but remember that there is choice in who we spend our time with.

Identity is a choice - the question isn't just "who AM I now", it is "who do I WANT TO BE now?" Disabilities may limit choices, but they don't have to dictate who we are.

Throughout life, each of us is writing the story of who we are. Take a minute to think about how you describe yourself – not just what you do, but also the things you most care about. How do your friends and family describe you?

Now, think back on your life... are you the same person as you were five years ago or 10 years ago?

None of us are the same as we were in previous parts of our life and this evolution is natural; what is different after a stroke is that the change happens so quickly, leaving us feeling as if our identities were stolen away. Taking the time to understand and reflect on identity changes is an important part of the process to rebuild a rewarding life.

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A Few Tools for the Emotional Journey

It is vitally important to recognize the value and potential of the emotional journey. Work as long and as hard as possible to regain capabilities, but don't measure recovery against previous abilities. Try to accept that some change may be permanent, and embrace the opportunity to rebuild a full and rewarding life in the face of that change, not a lesser version of life before the stroke.

Some things that might help along the way:

- **Focus on deeper meaning and purpose - not roles, titles, and activities.** There may be aspects of life that will look different post-stroke. Think about what brought meaning, purpose or pleasure and how might satisfaction be found in new and different ways?
- **Set reasonable goals and take time to appreciate small wins – recovery and rebuilding take time.** Create reasonable, time-specific goals to set an achievable pace for the journey ahead. Don't forget to celebrate the wins along the way! This is an important motivating factor to keeping up progress.

- **Build Community** – perhaps it's through a religious community, volunteering, supporting a favorite sports team, or participating in a support group, but make sure to take time to connect with others. The American Stroke Association has a comprehensive listing of support groups and the pandemic has produced a new range of virtual options too.
- **Adapting Activities** – stroke can make it difficult to participate in many activities or types of recreation previously enjoyed, but there are often ways to adapt these activities. Seek out community and internet resources to support new goals and interests.
- **Redefining work** – working after a stroke can look very different. For some, it may mean a return to full-time and for others, part-time is a better option. If returning to a paid position is not an option, consider volunteering for an organization you are passionate about.

A stroke can be a traumatic, life changing experience for survivors and their loved ones. Many people struggle to adjust afterwards. Be patient and know that the journey is a marathon not a sprint. It may take time, but it is possible to discover new ways to connect with loved ones and community and rebuild a life of meaning, purpose, and pleasure. It is important to remember that this is part of your recovery journey, and that you should look for people and other resources to help you along your way.



Additional Resources

[STROKEONWARD.ORG](https://strokeonward.org)

[RELATIONSHIPS UNDER PRESSURE](#)

All relationships are challenging. They all involve friction and stress...

[LIFE ENGAGEMENT: HAPPY, SAD, AND CRUCIAL TO RECOVERY](#)

As we've rebuilt our lives since Debra's stroke 11 years ago...

[ADAPTATION, COMPROMISE AND IDENTITY](#)

We took a two-week cycling vacation with friends...

[FUN, FRIENDS AND COMMUNITY](#)

Seven months after Debra's stroke, her friend invited her to a "girls" 50th birthday week...

[Identity Theft: Rediscovering Ourselves After Stroke \(2019\)](#)

- Debra Meyerson, Ph.D. and Danny Zuckerman. The book that set the foundation for the work at Stroke Onward.

[American Stroke Association: Life After Stroke](#)

ASA link: features a variety of information about stroke rehabilitation and recovery

[STROKEONWARD.ORG](https://strokeonward.org)



Survivor Story - Lisa Tolefree

A few years ago, Lisa was living in Chicago, closely connected with her children and grandchild when out of the blue she woke up one morning unable to speak due to a stroke. Before this, Lisa worked at a university and had recently completed law school with the goal of deepening her social justice work to help tackle the gun violence problem in her community. Although her stroke has changed her trajectory, Lisa is committed to working on social justice, now more focused on people living with aphasia as well as gun violence. "I realize I can't feel sorry for myself because everyone has their own challenges. I'm looking forward to living well with aphasia."