

Forming a Life Post Stroke

Alison Bonds Shapiro

Abstract

The impact of Stanley Keleman's work can be seen very clearly in its application to coping with the sudden changes in form and function that result from a major neurological injury. This article first describes a personal journey through recovery from such an injury using the tools of formative psychology. The article then discusses how the author includes those tools in training programs for survivors and family caregivers in both inpatient and outpatient settings. These training programs are designed to teach self-management skills for supporting ongoing neurological recovery and forming a life post injury.

Keywords: Stroke, Neurological injury, Neuroplasticity, Engagement, Internal Narratives, Sensory Awareness, Attention, Agency, Mirror Neurons, Self-compassion

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"...the ability for self-management is an antidote to helplessness. It offers a way to expand what nature has given us; it is a way to form and deepen a life, not simply be formed by life."

Stanley Keleman

At the time I met Stanley Keleman in 1995 when I was 45, I was a classic James Joyce character, living three feet from my body, uncomfortable and not grounded in my own experience. Noticing my distress, my then new husband Bob, a wise and thoughtful man and Stanley's long-term friend, suggested that I might just want to consider working with Stanley.

Warily I climbed the stairs to Stanley's office and sat down in front of him. I was prepared. I was very good at outwitting therapists. I knew a bunch of them personally and had worked with a few professionally. But I didn't know Stanley. The first time I sat across from him, my having said not much more than, "hello", Stanley fixed me within that lovely, wise gaze of his and named the central dilemma of my life. I was stunned but I was sold.

I worked with Stanley personally for two years and I have continued to study Stanley's teachings and learn from him ever since. It's a good thing I have. Ten years after meeting Stanley, six weeks after I turned 55, out of the blue, I suffered two brain stem strokes 24 hours apart.

I hope you never have this experience. But if you are interested in formative psychology, catastrophic neurological injury is quite an opportunity to study what happens to a person when they suddenly can no longer make the shapes they have used to take action or form a sense of self.

I was paralyzed on one side, wildly uncoordinated on the other. I couldn't swallow, focus my eyes, walk or sit up, among many other things. I was terrified. I could not organize my body. I could make very few voluntary shapes. I had a feeding tube. I could not make my throat work. My emotions were untethered from my frame. My roles, my ideas of who I was and would be,

were disconnected from my direct experience. What was I going to do?

My prognosis was poor. It was surprising I was still alive. 50% of brain stem strokes are fatal and I had two. Not good odds. No doctors were willing to hazard a guess as to my possible outcomes. After 10 days in a hospital I was sent to inpatient rehab, deep in despair and confusion.

I was profoundly injured and facing a life of unknown challenges. Although it was not uppermost in my mind at that moment, I was to learn that I had an extraordinary advantage. I had Stanley and I had Stanley's teaching.

How have you affected your own change or been victim to the processes that forced you to change? And how can you participate in the process of self-formation, permitting growth to occur with you taking an active part?.

Stanley Keleman

Most of our physiological models of recovery from accident or illness are passive. We wait to get better. My hand is cut: I put on a bandage and I wait. I get a cold: I go to bed and drink tea and I wait. If the cold develops into bronchitis, I go to the doctor and the doctor gives me medicine that I take and then I wait. This is the model we know.

Stanley, however, had taught me a different model. Stanley taught me to observe, experience, and then take voluntary action. It turns out that with a neurological injury waiting is the single most counterproductive thing any of us can do.

The process that leads to functional gain in neurological recovery is the process of neuroplasticity. When the brain is injured, tissue dies and it is not replaced. Rather than growing new brain tissue the brain will, if given enough incentive and information, attempt to make new connections around the missing brain tissue in order to regain function. It's rather like a detour around a roadblock.

If not given incentive the brain will make a habit of the disability and go on to other activities. This part of the process is called "learned non-use". It's the same process, the constant reorganization of the brain in response to learning. But one direction leads to increased function and forming a satisfying life post injury and the other leads to increased dysfunction and an ever-growing sense of helplessness.

Working with this information is neither as simple as it sounds, nor is the information generally taught to people who suffer neurological injuries or the people who will become their family caregivers. It's not simple because post injury I was living in a body that was radically changed. Doing the most elementary thing, like trying to brush my teeth while sitting in a wheelchair with one hand paralyzed and the other very difficult to control, took all my attention and creative strategies. The tool I was using for anything, my own body, was altered beyond my comprehension. Everything I tried to do was exhausting. Every task was monumentally difficult.

It is hard to describe the sense of helplessness that arises when you suddenly cannot swallow or move significant parts of your body. But embracing helplessness would not have benefitted me. Although I was unaware of it then, I had no time to waste. My brain was changing in response to my injury as I lay there. I could participate in that change and attempt to direct it or not. If I did not, my brain and body would have increasing difficulty in having a conversation with each other and working together.

I did not immediately remember what Stanley taught me. I spent a considerable amount of time feeling absolutely overwhelmed before I began to understand. But after awhile the skills

Stanley had taught me gradually began to reassert themselves. Those skills were not mental constructs. They were embedded in my experience and would not be ignored.

As the skills Stanley taught me began to reassert themselves, I began to observe myself and look for what I could do. I had no time to stop to ask myself if my responses were appropriate. I had to use all my available energy to engage my body to cope with my changed abilities in order to initiate any action I wanted to make. I had to engage my brain and I had to do it NOW. I had to figure out how to form a life. As difficult as it was, once I could again swallow, I had to figure out a strategy that would allow me to get food in my mouth without spilling it all over me.

Even though I was terrified and in deep confusion and grief, because I had studied with Stanley, I also had some context into which to put this experience. Stanley had taught me and I understood in a deeply visceral, lived way that I was a not fixed object. I knew that my body was designed to change and was always changing. I knew that the shapes of my body and my life would and should change over time. I knew that clinging to a fixed idea of myself would not help me.

Internal narratives are profoundly important and those narratives break when a person experiences a catastrophic injury. The simplest stories about who I was no longer served. I couldn't tell myself a story as basic as what I was going to wear. I couldn't dress myself. Those narratives were radically changing and had to be adjusted. But I could not afford to get stuck in thinking about the loss of my stories. As I was to come to understand, my stories would develop and be adjusted primarily through my own actions, not by thinking about them.

Having practiced the formative exercise with Stanley over the years, though at that time I could not have named it as I can now, when my strokes occurred I already had moment-to-moment lived experience of self-directed neuroplasticity. That too was a huge advantage. Despite what the predominant medical opinion was at the time, which said that I was basically a helpless recipient of a temporary neurological process, I had lived the experience of directing a conversation between my brain and my body. I knew in my bones that it was up to me to find a way to work with what was present. And I knew that if I did, I would support whatever process was underway, even if I didn't understand it.

As I began to take intentional action, I engaged my felt sense and opened my awareness. This too Stanley had helped me learn. He helped me understand how to live in the sensory awareness arising in my own body. The formative exercise had shown me the patterns I held and shown me how those patterns showed up in my direct experience.

Because I had learned to be comfortable with and even curious about feeling difficult things in my own sensory experience I could turn towards the exercises my physical therapists were doing with me in the rehabilitation center. I could choose to participate as completely and as deeply as I could, moment to moment. Even if these experiences were weird and distressing, I could choose not to shy away. These days I now know that this quality of attention, of turning towards, is a fundamental tool in functional recovery.

After therapy I used this capacity to focus on my sensory experience when I was in my room, in my bed. I turned my attention to what I felt. And what I felt began to be a clue for me to create my own, tiny, beginning movements in my paralyzed hand. Lying in my bed I focused on the one little twitch that was developing in one thumb joint in the paralyzed hand. I felt it. I focused on it. I savored it. As I did all this, my brain, and therefore my embodied experience, began to change. After a while the twitch got bigger, and then bigger, and then finally after a few days I could make one very small voluntary motion in that thumb joint. That was the start of the process that has resulted in restoration of complete function in that hand.

Since my strokes in 2002 I have studied a great deal of information about neuroplasticity and the way in which the brain restores function after an injury. What is clear is this: engagement, attention and sensory awareness are the keys to restoring function. Engagement, attention and sensory awareness stimulate the brain. Neuroplasticity is the response of the brain to stimulation and we directly influence the process by our own actions. Stanley was right. We can self-direct a great deal of the neuroplastic process.

Everything Stanley ever taught me was in service of my developing and sustaining a sense of agency. According to his teachings, life doesn't just happen to us. We shape our lives by the way we use ourselves to respond to whatever comes our way. The loss of a sense of agency after a neurological injury is immediate and is reinforced moment-to-moment by the experience of paralysis. Regaining a sense of agency is the beginning of hope.

Stanley had trained me to be an observer of my own processes and to intentionally engage in them. I might have been profoundly injured. I might have had no idea how much functional return I would achieve (and I have achieved a great deal over the years) but, because of Stanley, I knew that I could directly participate in the process of discovery of what would be. And I knew that I was the only person who would ever discover how I could form a life after two brain stem strokes. Hope was alive in me. It was up to me to live what Stanley had taught me.

Three years after the strokes, having already formed a remarkable recovery and a very full life, I wanted to give something back. I knew that I had had advantages that others don't have. So three years after the strokes I began to teach.

The financial reality of our insurance reimbursement system is such that therapy is very limited. The hundreds and hundreds of thousands of people experiencing neurological injuries every year and their family caregivers have little access to ongoing help. And so many have little idea how to help themselves.

What once functioned on automatic pilot, for better or worse, now requires intentional, skillful engagement. Often, particularly in the midst of the trauma when choices of engagement are so critical, people don't know how to and why they should engage. I wanted to share what I have been privileged to learn.

These days I teach both inpatients and outpatients and their caregivers. In an inpatient setting I typically give a 1½ hours talk. That's about the maximum that anyone in that situation can tolerate. In an outpatient setting I created and teach a 6 – 8-week course called "Mindful Stroke Recovery". Whenever possible I co-teach with my friend and fellow stroke survivor, Rita Martin, who helps develop both the inpatient talk and the outpatient course and knows a great deal about forming a life in difficult circumstances. Her injury was so great that her speech center was destroyed and she did not speak a word for a year and a half. Today she teaches.

Some people, when they are inpatients, catch on very quickly. Some require much more training. Some embrace helplessness and will not engage. The other day Rita and I gave an inpatient talk and a badly injured man and his wife attended.

As usual, in an acute inpatient rehab setting we had little or no expectation that we would ever see them again. But the next week we were back to give an outpatient class and the two of them happened by the room we were in and came to see us. They could not say enough good things about what had happened for them as a result of what they had learned from us.

They are quick. They understood immediately what was needed, that neuroplasticity meant that other parts of the brain could be recruited to take over the work of the damaged parts. And they understood the critical importance of their own engagement and the way they used themselves in the neuroplastic process and in forming their lives post injury.

In the week since we had first seen them, this man had begun to regain movement in his hand. In that week he had begun to be able to stand. The therapists in the rehab center are brilliant. Their work with him is the key. But his engagement drives their ability to help him. And his wife's understanding of what he is doing and why it is important eases her stress and brings her own restoration of a sense of agency. She now knows that she can intentionally shape her responses to work with and support the changes occurring in both of them.

Together they will find a way to form satisfying lives as he continues to recover. They can not know what those lives will look like. But they do understand now that what they do matters. They say they will come back for the longer outpatient training. We hope they do. There is much to learn.

Teaching the inpatient group is complex. We never know who will come or what conditions and relationships they will bring into the room. The last class included: a 20 year old woman who had recently been diagnosed with a rare, very difficult neurological disorder and had limited mobility, along with her caregiver mother; an older man with a stroke with mobility issues and his caregiver son, both of them just back from a trip to Europe together; a man who had broken his neck and had bilateral mobility issues and his wife who would be his caregiver; a man with a stroke who had cognitive and short term memory issues, along with his devoted and frightened wife; a woman who had communication and cognitive issues and would periodically utter only the words, "help me" along with her husband who was her caregiver; and a man with one-sided paralysis and his extended family including an eight-year old grandchild.

Many people who come to the class have trouble mustering enough energy to attend for an hour or more. Some require another person to periodically tilt them in their wheelchairs for pressure relief. Many have other serious illnesses in addition to their neurological issues. Nurses come in and out to give medication. Some inpatients are in pain or overwhelm and have to leave. In this setting we have a very short window of opportunity to teach something useful to help them form new shapes that will support their recovery efforts and rebuilding their lives.

The primary method of teaching engagement I use in this context is storytelling. Active storytelling provides lived examples of shapes that inpatients and family members previously may not have considered. These shapes include shapes of active engagement, living rich lives with residual disabilities, finding joy and gratitude in the midst of the trauma, and many others. Because the audience witnesses the story and the storyteller, the shapes resonate in them through the actions of their mirror neurons. These resonances then become a sort of scaffold upon which they can try out shapes that might fit for them. It's an invitation. They can feel for a few moments what it would be like to hold a different shape and how that shape might serve them.

The medical reimbursement model has no place for this class. I have been teaching it since 2005 on a volunteer basis. Rita joined me in teaching it in 2008. Because of the HIPPA laws we have no long-term access to the inpatients and able to follow them unless they come back to see us or contact us some other way. However, the rehabilitation professionals who work at the hospital tell us over and over and over again that we change functional outcomes.

Recently, the rehabilitation hospital leadership has been developing an interest in researching the effects of the inpatient talk. If that happens, then there will be a greater opportunity for us to work with and follow people who attend.

The longer, more structured outpatient class has a known role in the medical model. This class is characterized as patient education for disease management. We are already doing preliminary research on this model, with research grant applications in process for funding for more in depth research.

The outpatient class, taught in a 2.5-hour class over 6-8 weeks with “homework” provides far more opportunity for teaching and learning. We teach 6-9 survivor/caregiver couples at a time, using an interactive circle so that all class members become both students and one another’s teachers. We may have spousal couples, partner couples, parent child couples, sibling couples and/or close friend couples. Whatever the couple configuration each couple collectively brings three entities into the room: survivor, caregiver and the relationship between the two. All three have to be met, respected and managed.

Various methods and practices are taught. Stanley’s formative exercise teaches self-awareness through providing someone the opportunity to directly experience the patterns and shapes we make and self-management through learning how to voluntarily make different shapes.

We also teach this and, given the nature of the challenge and the group we teach, we use a variety of methods to do so. Primary techniques include: training attention, self-compassion, sensory awareness, forming the shapes of our lives, mindful movement and compassionate communication. Like Stanley’s work, these practices are grounded in information about how they work and why they work. This understanding is essential in order to make the skills useful as long-term voluntarily applied methods for shaping the lives of the survivors and their caregivers and their relationships to one another.

When we find the joy and meaning in our lives in the process of making itself rather than in the thing made, when we find our satisfaction in the doing, not the having, we can work with any circumstance. We can restore a sense of agency. No matter what we are given in this life, we can use ourselves to form a rich life.

This legacy, this ability to pass on some aspect of his teachings, is Stanley’s gift to me and to all the people whose lives I have the privilege to touch. It is with the deepest gratitude that I acknowledge this gift. Although I know that I am not and never will be a trained formative psychologist, Stanley’s wisdom continues to live in me and influence the lives I encounter.

BIOGRAPHY

Alison Bonds Shapiro, MBA, is a speaker, author and teacher who teaches recovery skills to individuals with neurological injuries, their family caregivers, and rehabilitation service providers. She is the author of *Healing Into Possibility: the Transformational Lessons of a Stroke*, the creator of the Mindful Stroke Recovery course, and the co-producer of the film, *What Now? Sharing Brain Recovery Lessons*.

Email: alison@healingintopossibility.com, Website: www.healingintopossibility.com