



Progress in Recovery

Stroke is overwhelming. At one moment, we are fully functional, and in the next, abilities are taken away and we feel shock, loss, fear, grief, and helplessness to forces beyond our control. In recovery, we call ourselves survivors to remind ourselves that we can move from powerlessness to empowerment and reclaim our lives. Here is a short guide to successful stroke recovery:

Recovery can be continuous with sustained effort

There is a mistaken belief that recovery only occurs during the first year after stroke. In fact, recovery can be ongoing with continuous practice. First, functionality can “return” as injured cells heal. Also, new neural pathways are formed by brain “plasticity” and repeated effort. “How do you get to Carnegie Hall? Practice, practice, practice...”

Recurrent therapies help restore functioning

Peter Rossi, MD, a stroke neurologist, states, “Many studies have shown the functional benefit for physical and occupational therapies, even when provided months to years after stroke, suggesting a latent ability for persons living with stroke to improve the quality of their lives.”

Survivors need to be reminded to use affected limbs and impaired functions.

Early rehabilitation often focuses on adaptation around the injury and disability at that point in time. Gradually, there is often a return of functionality that survivors may not recognize. Survivors need reminders and therapy to use affected parts that have renewed capabilities.

Recovery is gradual, so be patient

Recovery is a biological process, like the growth of children. As survivors, we gradually relearn basic skills, such as how to walk, use a hand, and talk again. We love our children, even as they grow imperceptibly. It will help if we can also be patient, gentle, and loving with ourselves, as well, as we slowly rebuild our lives.

It is possible to have satisfying and meaningful lives, even as we recover

An important step in recovery is to realize that we can enjoy life, even as we recover. It's fine to have goals but we don't need to make happiness conditional on future achievement. It is an act of wisdom to appreciate the portion of the glass that is filled.

If you want to know how much better you can get, look around at others in recovery

Recovery is easier, more effective and enjoyable with others. Join support groups with survivors and families who have the kind of recoveries you admire. Take advantage of the stroke services in your community. Hope, optimism, and progress are contagious.



Empowerment after Stroke

To be empowered is to have the ability, means and opportunity to do something

Loss of control is a major consequence of stroke. To varying degrees, stroke can affect every aspect of living, including mobility, dexterity, communication, strength, energy, thinking, emotions, mood, relationships, roles, and social, residential, occupational and financial stability. Stroke patients and their families frequently feel powerless and fear that their disabilities and circumstances are fixed and won't get better.

This response of fear is understandable, because for millennium, little could be done about stroke. Today, the situation is different, for we now know the causes of stroke and how to prevent them; there have been many medical advances in stroke treatment; and stroke survivors and families can now help themselves to get better and enjoy their lives, even as they recover.

A word to describe how stroke survivors and families regain control is "empowerment," and a good way to begin to reclaim their lives is with "empowerment education." As survivors and families learn and practice the skills of recovery, they experience gradual restoration of physical, psychological and social abilities, which inspires them to strive for more progress.

The progression of empowerment is evident in how survivors see themselves. Stroke "victims" feel overwhelmed and trapped by injury and consequences. "Survivors" have also been injured, but are able to focus on recovery to improve the quality of their lives. "Victors" live satisfying and meaningful lives, with minimal thought of or distraction by limitations of stroke.

Today, we have choices in how to respond to stroke. While we may have limited control during the acute phase of stroke, we have significant control over our recovery, daily life and the ultimate outcome. As we pass through the stages of uncertainty, challenge and healing, we find, within us, courage, patience, determination, adaptability, love for others and life, and will to live and thrive. We discover we are stronger than we thought.

Here are steps to empower recovery after stroke:

- Discover what we can do for ourselves to further our own recovery
- Learn the skills of integrated physical, psychological and social recovery
- Learn about neurological return, plasticity and the process of physical recovery
- Believe that recovery can be continuous, with courage, determination and effort
- Be encouraged by the example of others, learning how they have recovered
- With guidance, make a realistic plan to improve functions of our own choice
- Work for optimal recovery with pulse therapy, practice and interpersonal support
- Appreciate the gradual progress and the unanticipated benefits of recovery
- When we face limits, learn to enjoy whatever portion of the glass is full
- The attached practices empower recovery and can prevent another stroke

Empowerment is an antidote to loss of control and powerlessness

Pulse Therapy with Group Support

Stroke survivors and their families want to get better, and “return,” “plasticity” and “pulse therapy” can help their gradual recovery from stroke.

1. Stroke recovery is a gradual process of biological healing and improved physical, psychological and social functioning that occurs over time as a result of recurrent rehabilitation, recovery activities and daily effort and practice by survivors and families.
2. After a stroke, the recovery process typically begins with two or three weeks of inpatient rehabilitation and then two or three months of outpatient therapy, and focuses on general functionality, based on disabilities at that point in time.
3. A longer-term goal is to gradually restore specific impaired functions, drawing on biological processes of return and plasticity, because the potential for stroke recovery continues with a slow return of capabilities that survivors and families may not recognize.
4. "Return" is spontaneous restoration of lost function, as injured but viable cells heal. "Plasticity" is the brain's ability to reorganize itself and regain function by forming new brain connections that bypass cells that no longer work. Both processes are accelerated by recurrent therapy and regular practice.
5. To improve long-term recovery, Bruce Dobkin, M.D., director of UCLA neurological rehabilitation and research, recommends “pulse therapy” which is periodic, targeted treatment to stimulate specific functions, and regular practice by survivors over a period of weeks and months, until the selected behaviors are incorporated into daily life.
6. Pulse therapy is both a rehabilitative and educational process, and is most effective when stroke survivors understand the potential of return and plasticity, and feel empowered to choose and practice the skills and functions they want to recover.
7. Progress in pulse therapy can be reinforced by participation in weekly support groups that generate psychological forces of hope, courage, empowerment, optimism, persistence, patience and social powers of interaction, support, trust and guidance. Individual and family services can help those who are unable to take part in a group experience.
8. Significantly, the United States District Court settlement of *Jimmo v. Sebelius* on January 23, 2013 expands therapy services for Medicare beneficiaries with chronic conditions or disabilities, which would include pulse therapy.

There are limits to all human endeavors, but knowledge, courage and effort help us discover, attain, accept and value what is possible.



Time and Recovery

Time is a significant factor in stroke. Stroke suddenly changes the arc of our lives, as life plans and schedules are thoroughly up-ended. Further, time is a crucial factor at the onset of stroke. Immediate emergency treatment can lessen the injury of stroke, as “time is brain.”

Experience of time is profound during acute care. Survivors either wake up from a coma in three weeks or, if conscious, every minute seems to last an hour. Also, during this stage, the family must cram vigilance, worry, care giving, personal and work responsibilities into 24 hours.

Experience of time during post-stroke recovery is also a challenge, especially when coping with uncertainty. When will I or he or she get better? How much progress can there be? How long will it take? The answers to questions are often inexact. “We will have to wait and see. Time will tell.” The biological process of recovery is gradual and is an exercise in patience.

According to Einstein’s Theory of Relativity, those traveling at different velocities experience time differently. Reams’ Theory of Relative Recovery postulates that stroke survivors experience time differently from those around them. This differential of time and pace affects survivor’s experience of recovery, themselves and life, their peace of mind and relations with others.

Survivors and those near them move, talk, think, and relate at different speeds and survivors often are often discouraged because they don’t function as fast as they or others want or expect. The disparity in the experience of time can cause frustration. Family or friends may walk ahead of the “slow-poke” or be impatient in conversation and complete the survivor’s sentences.

In optimal recovery, survivors, families and friends learn about the biology of recovery and how to socialize at the same pace and on the same “frequency.” Families and friends develop patience and survivors feel encouraged and safe to engage in social interaction.

In Einstein’s universe, differences in time are difficult to perceive, while after stroke, differences are very apparent, so it helps to look at variations in nature. We aren’t impatient with the slow growth of plants. We accept the biology of plants and enjoy the garden when it comes. Also, we don’t expect a child to walk at six months or talk at one year. Similarly, recovery is easier when survivors and families are bi-temporal and comfortable with two experiences of time.

Perception of time is also a factor in recovery. After stroke, there can be frustrating waits for appointments, information, events or progress. Parenthetically, a study determined that waiting in line at the airport was more onerous than a long walk through the terminal of the same duration. In other words, we are happier when we are active or distracted. A lesson here is to not wait for recovery to happen; recovery is more enjoyable when the focus is on “doing.”

It also helps to remember that life is experienced in the process of living. Stroke recovery may take longer than expected, but we can enjoy our lives, even as we recover, and feel proud of our effort and accomplishment, just as we take pride in our other long-term achievements.

Recovery and the New Health Paradigm

In the new health paradigm, individuals and families accept more responsibility for their health and healthcare. They practice behaviors to achieve wellness and prevent illness, including lifestyle modification and risk factor management, and seek proactive medical care. Healthcare focus changes from treatment done by others, to a process in which patients themselves are more active participants in their own health and healing.

Seventy percent of strokes can be prevented by healthy lifestyle and management of risk factors, which is to say that stroke is prevented by the psychologically and socially driven behavior of individuals and families. One hundred percent of prevention measures for stroke also protect against heart disease, diabetes, and other illness.

In our culture, insufficient attention is paid to wellness and prevention of illness, even though it would produce healthier lives, a more productive population and reduce the cost of healthcare. However, it isn't necessary to wait for society to change. We can improve our own health now. In the new health paradigm, individuals and families are empowered to take better care of themselves.

There are two types of self-care: active and receptive. There is action that we do for ourselves and action taken by health providers on our behalf. Active steps are behaviors no one else can do for us, such as eating well, physical exercise, and management of blood pressure, cholesterol, blood sugar, weight, and alcohol and tobacco use. Receptive methods are services done for us, such as health screenings and medical services such as exams, blood tests, mammography, colonoscopy, medication and other prescriptions.

Significantly, active self-care we do for ourselves is more successful when done with the support of those around us. It is not easy to stop overeating, smoking or drinking if others are not supportive, or to practice self-care while under pressures of the job, or when fast food is a way to get back to work rather than a way to nurture our bodies properly.

In the new health paradigm, we do our part and we use the support of those around us. Synergy with family, friends, co-workers, employers, health care providers and society helps us complete personal health tasks, goals and responsibilities.

We have to do it ourselves but we don't have to do it alone.