

Empowerment after Stroke

A guide for survivors and families

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

Loss of control is a frequent 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. As stroke survivors, we often feel powerless and afraid that our disabilities and circumstances are fixed and won't get better.

Here is a solution. Empowerment is a word that describes how we regain control after stroke. As we learn and practice the skills of recovery, we gradually restore physical, psychological and social functioning and the quality of our lives.

Today, we have choices in how to respond to stroke. While we may have limited control during the acute medical phase, we have significant control over our recovery, daily life and the ultimate outcome.

As we pass through 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 empowerment:

1. Learn how, why and when to accept responsibility for our own recoveries
2. Learn the steps and skills of physical, psychological and social recovery
3. Select functions we want to restore and practice them daily
4. Turn everyday activities into recovery exercises
5. Connect with others, practice recovery skills together, support one another
6. Seek proactive medical care and follow directions to protect our health
7. Practice self-care, make changes in lifestyle, manage health risk factors
8. Believe that recovery can be continuous, with determination and effort
9. Appreciate gradual progress and the unanticipated benefits of recovery
10. Be grateful for and enjoy the portion of the glass that is filled

**Empowerment is the best antidote
to loss of control and powerlessness**

The Empowerment Stage of Stroke Recovery

Survivor Initiated Recovery

After stroke onset, stroke survivors and families now benefit from major advances in medical and rehabilitation services, but science can only do so much, for there are essential steps of recovery that patients and families can only do for themselves.

Early stroke services are emergency and critical care, medical stabilization, and acute and subacute rehabilitation, which last up to six months. Optimally, thereafter, as stroke professionals transition to a supportive role, survivors and families learn and practice the steps and skills of self-initiated stroke recovery.

This is **‘the empowerment stage of stroke recovery’** in which patients and families actively participate in weekly education, guidance, interpersonal connection, daily practice of targeted functions and periodic rehabilitation to refine recovery efforts.

After acute and subacute care, further progress in recovery depends on the behaviors of survivors and the support of their families. They select functions they want to regain, practice them daily and the brain gradually forms new neural pathways. Here are actions that empower stroke survivors and families.

1. Education about the steps and skills of self-initiated stroke recovery
2. Weekly support groups and functional exercise classes
3. Interaction and inspiration with experienced survivors and families
4. Selection of specific functions that survivors want to improve
5. Daily practice of those self-selected functions
6. Everyday activities become recovery exercises
7. Periodic rehabilitation guides and refines daily practice
8. Resources in the community augment functional, physical, psychological and social recovery

As survivors and families are empowered, progress can be made in both anticipated and unexpected ways; in physical functioning; in speech and communication; in thinking, emotions, moods and attitudes; in family and social relationships; in energy and motivation; in interests and passion; in purpose and meaning; in quality of life.

After acute and subacute rehabilitation, survivors and families accept responsibility for their recoveries

Fundamentals of Stroke Recovery

1. Neurological return and plasticity are fundamental mechanisms of stroke recovery. Some functions “return” as injured but viable cells heal. Other functions are restored as the brain organizes new neural pathways around deceased neurons. Both return and neuroplasticity require recurrent rehabilitation and practice of targeted functions.
2. Stroke rehabilitation and recovery typically begin after critical care and medical stabilization. Acute and subacute rehabilitation consists of intensive individual physical, occupational and speech therapy, for about three or four months.
3. After acute and subacute care, Bruce Dobkin M.D., director of UCLA neurological rehabilitation and research recommends periodic rehabilitation to guide daily practice of functions that survivors choose for themselves. This process is “pulse therapy.”
4. **During “the empowerment stage of stroke recovery,” survivors take charge of their own recoveries. They select functions they want to restore and practice them daily. They turn everyday activities into recovery exercises, such as standing, walking, use of the affected hand, speaking, reading, chores, games, socializing.**
5. The degree of their success depends on the amount of effort between therapy sessions. Metaphorically, one must practice daily to play the piano well. “How do you get to Carnegie Hall? Practice, practice, practice.”
6. Early rehabilitation focuses on injury and disability at that point in time. Over time, there is potential for return of additional function. After acute and subacute care, periodic rehabilitation refines practice and recovery activities.
7. There is an old belief that recovery only occurs during the first months after a stroke. In fact, recovery is a continuous process of biological healing and improved functioning that occurs with recurrent rehabilitation and practice.
8. Stroke recovery is a gradual biological process, like the growth of a child. We are patient with infants and toddlers who walk at one year and talk at age two. Can we be similarly gentle with ourselves as we slowly recover.
9. It’s important to remember that we can enjoy life, even as we recover. It’s good to have goals but we don’t need to make our happiness conditional on some achievement. It is an act of wisdom to appreciate the portion of the glass that is filled.
10. Survivors who fully participate in the recovery process have better outcomes, health and fewer subsequent strokes.

**Neuroplasticity does not stop at six months
and neither does recovery from stroke**



The Empowerment Stage of Stroke Recovery

Since 1995, there have been major advances in stroke treatment and rehabilitation, and at the same time, there will always be actions of recovery that survivors must do for themselves.

Stroke survivors become stroke victors as they take charge of their own recoveries and powerlessness transforms to empowerment and stroke professionals then transition to a supportive role.

“The empowerment stage of stroke recovery” enables survivors with weekly education, guidance, interpersonal connection, daily practice of targeted functions and periodic rehabilitation to refine recovery efforts after acute and subacute care.

The Stroke Association recommends that “the empowerment stage of stroke recovery” becomes a universal standard after acute and subacute care. The “empowerment stage” provides definition, direction and hope for recovery that the “chronic stage” does not.

Please read “The New Stroke Paradigm” at strokesocal.org

The Empowerment Stage

In medical terminology, three stages delineate periods of time and intensity of stroke treatment. The acute and subacute phases occur within the first six months and have specified treatment.

In contrast, the chronic stage follows, is long lasting, of indefinite duration, and without specified treatment. A better term is needed to define the period of stroke after acute and subacute care.

After the acute and subacute stages, recovery can continue with planned application of neuroplasticity, recurrent therapy, daily practice of targeted functions, psychological and social support.

After the acute and subacute stages, survivors and families learn and practice the skills of recovery, improve their functioning, regain their independence and restore their quality of life.

This is the empowerment stage of stroke recovery.

Continuity of Care

Continuity of care is coordinated treatment of patients, throughout the evolving stages of an illness and recovery.

Stages of stroke prevention, treatment, rehabilitation and recovery include universal wellness classes, recognition of stroke signs and symptoms, a call to 911, critical care at a stroke center, medical stabilization, acute and subacute rehabilitation, transition to patient initiated recovery, weekly classes and groups, periodic rehabilitation to guide practice of targeted functions, and adaptation to a new normal.

Well planned and coordinated services are essential across the spectrum of stroke. Here are standards that should be but are not yet sufficiently met:

1. Patients and families receive the stroke services they need in each stage of the recovery process and there is smooth preparation and transition to the next phase.
2. Patients and families receive formal education about stroke, the stages of treatment, and their roles and responsibilities in each phase.
3. There is coordination among professionals, facilities, patients and families. Patients and families are included in the communication loop, as appropriate.
4. After medical stabilization, patients and families receive the acute and subacute rehabilitation they need.
5. After acute and subacute rehabilitation, there is preparation and guidance for transition to the empowerment stage of recovery.
6. After acute and subacute care, patients transition from “patients” to “survivors,” as they gradually accept responsibility for their own recoveries

The best time for education is during the acute and subacute stages. Thereafter, survivors and families meet in classes or groups with skilled facilitators and experienced survivors and families who share knowledge and encouragement in each phase of recovery.

Optimally, needed treatment, education, guidance and smooth transitions are provided in each stage of the recovery process.



Stroke Recovery and Momentum

It's hard to get going

Here is a common sentiment about recovery from stroke survivors, "It's hard to get going." A comparison from the natural world can explain why this is so.

In physics, momentum is the energy of an object in motion. For example, a stationary train has no energy of its own. It's just a hunk of metal without a purpose until external force is applied.

When pushed or pulled, the train starts slowly because inertia resists movement. As a locomotive does its job, the train begins to gain speed, energy and momentum of its own. We all know not to stand in front of a moving train.

Personal momentum is life in motion. The movement and momentum of people's lives is derived from a lifetime of activity, interests, passion, education, career, accomplishments, relationships, social and financial forces.

In a conversation, Steven Castle, M.D., director of the West Los Angeles VA Geriatric Clinic, said that the loss of personal momentum significantly affects the health and quality of life of his patients.

Personal momentum is a concern for stroke survivors and families, too. Stroke stops us in our tracks and it is difficult to get moving again. Survivors are slowed by injury, disability; loss of energy; psychological and social distress; residential and financial instability.

Before the stroke, we were active, in motion, had momentum. Then stroke brought us to a dead stop. A stroke recovery program is the best way to restore our lives, with the forces of treatment, education, support and personal effort.

The reason it is hard to get going after stroke is because we are doing something hard. As with inertia, we must overcome the impulse to languish. The forces of recovery must be applied steadily, for if they stop so will we.

**Stroke recovery is like moving a train from a dead stop.
It starts slowly and gains momentum with steady effort.**



Recovery with Others

Stroke survivors and families who recover with others accomplish more than those who are alone

Stroke is an isolating disease that makes recovery more difficult. Physical, psychological and social disabilities affect socialization. Life is often constricted to hospital or home. Survivors don't want to be seen as disabled. Friends withdraw. It's hard to participate if discouraged or depressed.

Therapeutic interaction with other survivors and families is essential to recovery from stroke. Recovery in classes and groups is like being in a nurturing family that engenders connection, support, relationships, love, caring, compassion, understanding, safety, belonging, positive identity, courage and resolve.

Treatment during the acute and subacute stages of stroke focuses on individualized care. The next phase of recovery should include services in group and class settings, because of the power of interpersonal connection and interaction. This will be the first time that survivors and families regularly meet and work together.

After acute and subacute care and during the "empowerment phase:"

1. Survivors and families work with others in weekly classes and groups
2. Together, they learn and apply the steps and skills of recovery
3. They support, encourage and inspire one another with synergistic effect
4. They select functions and skills that they want to regain
5. They practice these functions and skills together in class and daily at home, combining frequency and intensity
6. The goals of individuals are influenced and supported by the group
7. Periodic rehabilitation refines practice in classes, groups and at home
8. Community colleges and other resources augment recovery with adaptive exercise, enrichment classes and activities, volunteerism

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



Time and Recovery

Time is a significant factor in stroke. Stroke changes the arc of our lives, as life plans and schedules are thoroughly up-ended. To begin with, time is crucial at stroke onset. Immediate 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 like an hour. Also, family members cram vigilance, worry, care giving, personal and work tasks into 24 hours.

Time is also a challenge during the recovery process, 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 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.

A useful way to think about recovery from stroke is to compare it to our achievements. We accept that some worthwhile goals in life require long-term commitment. For example, a college education, building a career or raising children all necessitate incremental steps over time. We have been successful before and we can be again.

Also, according to Einstein’s Theory of Relativity, those traveling at different velocities experience time differently. Reams’ Theory of Relative Recovery postulates that stroke survivors also experience velocity and time differently from those around them. This differential affects survivors’ experience of recovery, self, life and relations.

Survivors and those near them move, talk, think, and relate at different speeds and survivors are often discouraged because they don’t function as fast as they or others want or expect. This disparity often causes frustration. Family or friends may impatiently communicate or walk ahead, leaving the “slow-poke” to bring up the rear.

In Einstein’s universe, differences in time are difficult to perceive, while after stroke, differences are apparent and frustrating, so it helps to look at variations in nature. We accept the slow growth of plants and enjoy the garden when it comes. We understand that children walk at one year and talk at two. Recovery is easier when we are comfortable and patient with two experiences of time.

Also, perception of time is a factor in recovery. For example, there are frustrating waits for appointments, information, or progress. Parenthetically, a study determined that a wait in line at the airport was more onerous than a walk through the terminal of the same duration. In other words, we are happier when we are engaged. A lesson is to not wait for recovery to happen; recovery is more enjoyable when the focus is on “doing.”

It helps to remember that life is enjoyed in the process of living. Recovery may take longer than we want, but we can enjoy life now, even as we recover and feel proud of our efforts and accomplishments, just as we take pride in our other long-term achievements.

Functional Exercise Classes

After acute and subacute care, periodic rehabilitation and practice can be augmented by weekly functional exercise classes that reinforce return and plasticity, guide recovery exercises and refine self-selected goals.

Weekly functional exercise classes are the first time that individuals work with other survivors. Meeting in a group generates hope, courage and determination through personal connection, example and inspiration. Paradoxically, while working with others, survivors take personal responsibility for their own recoveries.

In the class, participants select and practice functions that they want to regain. They also learn to make everyday activities into recovery exercises. Here are characteristics of a functional exercise class:

1. Upon completion of individual rehabilitation, stroke survivors are directed to functional exercise classes as the next phase of recovery.
2. The class meets weekly and is supervised by a physical or occupational therapist.
3. The class provides exercises to stimulate and extend range of motion.
4. Participants select specific functions and skills that they want to regain.
5. Participants practice selected functions and skills in class and at home.
6. Participants learn how to make everyday activities into recovery exercises.
7. Recovery is enhanced as participants meet and support each other.
8. Emphasis on continuous neurorepair reinforces daily home practice.
9. The class can meet before or after a stroke support group to coordinate physical, psychological and social recovery.
10. Although services in class settings are not yet reimbursed by insurance, the cost of weekly classes could be covered by the equivalent of a standard co-payment.

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