

The First Year of Stroke Recovery

A guide for survivors and families

After a stroke, survivors have questions, “Will I get better? Will I be able to function? Will I be able to take care of myself and my family? Will I be able to enjoy my life?” Everyone in the family needs to learn about recovery from stroke so they feel hopeful, encouraged and know what they can do to recover.

With education and support, survivors and families learn that recovery is a continuous process. After a stroke, the brain has the ability to repair itself by forming new neural connections. In a process of “neurorepair,” the brain gradually relearns a function with repetition of behaviors, and progress is made over months and even years with regular practice of targeted exercises and skills.

The first months after a stroke is a period of intensive medical and therapy services that consists of emergency and critical care, medical stabilization, and daily inpatient and weekly outpatient therapy. These are the acute and sub-acute phases of treatment and are administered directly by stroke professionals.

After acute and sub-acute care, there is a transition from services provided by professionals to recovery actions initiated by survivors and families themselves, in which they learn and practice skills to renew their bodies and spirits, and regain function. Survivors and families now take charge of their own healing, for there are steps and behaviors of recovery that no one else can do for them.

During the first year of recovery, those new to the challenge of stroke:

- Participate in weekly exercise and support groups;
- Learn the steps and the skills of self-initiated recovery;
- Practice those steps and skills daily at home;
- Meet experienced survivors and families who support and inspire;
- Strengthen recovery with intermittent therapy.

Another important step in recovery is for survivors and families to recognize their own gradual progress, for it can come in both anticipated and unexpected forms; 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.

**Stroke survivors and families can enjoy life even as they recover.
They don’t have to wait for future events or accomplishments.**

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 are afraid that their disabilities and circumstances are fixed and won't get better.

These feelings are understandable, because until recently, little could be done about stroke. Today, the situation is much different because there have been many advances in treatment and stroke survivors and families can enjoy their lives, even as they recover.

A word to describe how stroke survivors and families regain control is "empowerment." As survivors and families learn and practice the skills of recovery, they gradually restore physical, psychological and social abilities, and are inspired to make even more progress.

Progression in empowerment is reflected in how survivors see themselves. "Victims" feel overwhelmed and trapped by injury and consequences. "Survivors" have been injured but focus on recovery, and are determined to improve the quality of their lives. "Victors" lead satisfying and meaningful lives, with minimal distraction by the 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 about the process of physical, psychological and social recovery
- Practice the skills and behaviors of stroke recovery daily
- Proactively seek medical care and follow directions to protect our health
- Practice self-care, make necessary changes in lifestyle, manage health risk factors
- Believe that recovery can be continuous, with courage, determination and effort
- Connect with other survivors and families and learn how they have recovered
- With guidance, make a realistic plan to improve functions of our own choice
- Appreciate the gradual progress and the unanticipated benefits of recovery
- When we face limits, we learn to enjoy whatever portion of the glass is full
- This combination of behaviors strengthens recovery and prevents another stroke

Empowerment is an antidote to loss of control and powerlessness

Pulse Therapy and Long-term Recovery

1. Physical recovery from stroke is a gradual process of biological healing and improved functioning that occurs over time as a result of recurrent rehabilitation and daily practice of the skills and activities of recovery.
2. Optimal stroke rehabilitation begins with two or three weeks of inpatient therapy, a few months of concentrated outpatient therapy and continues with intermittent, targeted services to help survivors achieve long-term goals.
3. Function can often be restored over time by applying the biological processes of return and plasticity. "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 neural connections.
4. After the initial course of rehabilitation, return and plasticity can continue to be applied effectively. Bruce Dobkin, M.D., director of UCLA neurological rehabilitation and research, recommends recurrent "pulse therapy."
5. Intermittent pulse therapy and regular practice activate targeted functions until these behaviors become part of daily life. Success in recovery depends on effort between therapy sessions. Someone who only goes to piano lessons but does not practice will never play well.
6. In addition to individual therapy, pulse therapy can be augmented by participation in weekly groups that conduct recovery exercises, educate about return and plasticity, support self-selected goals, and encourage daily home practice.
7. Stroke isolates and individual therapy can be a solitary experience. Survivors and families need to know that they are not alone. Working in a group generates hope, courage, and determination through personal connection, example and inspiration.
8. Because stroke recovery is gradual, it can be difficult to for survivors to see their own progress. Long-term recovery can be recognized with periodic assessment and comparison of survivor and family self-evaluations over time.
9. Support of recurrent therapy by insurance payers is important for long-term recovery. For example, under the Medicare maintenance standard, beneficiaries with chronic conditions and disabilities may receive additional targeted services year to year, including pulse therapy, to support their ongoing recovery needs.

**Neuroplasticity does not stop at six months
and neither should stroke services**

Stroke Services during the First Year

Functional Exercise and Recovery Classes

We now know that neurorepair and recovery after stroke can be a continuous process, especially with good patient motivation, therapeutic guidance, interpersonal support and daily practice of targeted behaviors and skills.

Universally, this knowledge is not being adequately applied. Individual stroke services are usually provided for the first few months after onset and then treatment effectively stops. Current care and insurance reimbursement practices were established before this understanding came to be and treatment hasn't yet caught up with what is known today.

Here is a possible solution. When individual treatment ends, continued services in a weekly functional exercise and recovery class can augment neurorepair and improve recovery outcomes. Cost-effective services in a group or class could be provided after completion of individual therapy, especially during the first year after stroke onset.

Here are characteristics of a functional exercise and recovery class:

1. Upon completion of individual rehabilitation, stroke survivors are directed to functional exercise and recovery classes as the next phase of their 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. Recovery is enhanced because participants connect with and support each other.
7. Discussion of neurorepair principles and progress reinforce home practice.
8. The class meets before or after a stroke support group in order to coordinate physical, psychological and social recovery.

How would these services be paid for? Although groups and classes are very effective, insurance only pays for individual, but not group stroke services. Until the value of group services is recognized and reimbursed, patients could pay the equivalent of a standard co-pay, which would cover the expense of a group or a class.

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