

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.

Stroke survivors and families often feel powerless and are afraid that their disabilities and circumstances are fixed and won't get better. Empowerment after stroke is the best way to regain control. As we learn and practice the skills of recovery, we gradually restore physical, psychological and social functioning and quality of life.

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. We become empowered to take charge of our own recoveries.

As we pass through uncertainty and challenge, we find within us, courage, patience, determination, adaptability, love for others and life, and will to live and thrive. We are stronger than we thought. There is much we can do for ourselves to recover from stroke.

1. Connect with others. Recovery is more effective and easier when done with others.
2. Join a weekly stroke support group with experienced survivors and families.
3. Learn and practice the skills of physical, psychological and social recovery.
4. Learn about self-initiated recovery and practice self-selected functions daily.
5. Turn everyday activities into recovery exercises.
6. Receive periodic therapy to refine goals and practice.
7. Seek proactive medical care and follow directions to protect our health.
8. Practice self-care, make changes in lifestyle, manage health risk factors.
9. Understand that recovery can be continuous, with focus and effort.
10. Use resources in your community that support recovery and enrich lives.

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

The Empowerment Stage of Stroke Recovery

An introduction for stroke professionals

Powerlessness is a consequence of stroke and personal empowerment is the best way for survivors and families to regain control of their lives.

After acute and subacute stroke rehabilitation, there is an inherent limit to what professionals can do and there are actions of recovery that survivors and families must do for themselves. There is need for an additional stage of stroke recovery.

Problematically, after acute and subacute rehabilitation, survivors and families are typically discharged into the unstructured chronic phase of stroke. This is not enough. At this point of time, they need more direction and support to strengthen and consolidate their recoveries.

The empowerment stage of stroke recovery is a new phase that immediately follows subacute care and enables survivors and families to continue their recoveries with weekly education, guidance, interpersonal connection, support, daily practice of targeted functions and periodic rehabilitation to refine recovery efforts.

During the empowerment stage, there is transition from services led by stroke professionals to recovery behaviors initiated by survivors and families themselves, with the guidance and support of experienced facilitators, survivors and families.

As survivors and families are empowered, progress in recovery can occur in many 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.

The empowerment process is cost-effective. The work is done by survivors and families themselves, with the support of a weekly stroke group and community resources. Also, fewer subsequent strokes and hospitalizations save money.

Stroke professionals are in the best position to explain the value and necessity of self-initiated behavior as the next step in recovery. Please discuss personal empowerment with your patients and families. Talk to them about what they can do for themselves to recover from stroke.

With your support, the empowerment stage can become a standard modality of stroke recovery. Please communicate with your colleagues so the concept of patient empowerment is widely accepted and applied.

Please contact us to discuss empowerment resources in your community. For more information, please read “The New Stroke Paradigm” at strokesocal.org.

**Neuroplasticity doesn't stop at six months
and neither does recovery from stroke.**

Empowerment in Weekly Stroke Recovery Groups

1. Neuroplasticity does not stop at six months. Recovery can continue long after subacute care, especially when learning and practicing with others.
2. In weekly stroke recovery groups, survivors and families are empowered to improve their physical, psychological and social functioning.
3. Weekly groups provide education, guidance, support, connection, interaction, encouragement, inspiration and example that the chronic stage does not.
4. In weekly groups, courage, determination, enthusiasm, belonging, caring, trust, acceptance and calm are contagious.
5. The psychological and social distress of stroke is disabling, and weekly groups ease distress, improving participation, outcomes and quality of life.
6. Stroke groups are often the first opportunity for survivors and families to work together because rehabilitation services are only provided to individuals.
7. Monthly groups are too infrequent. Weekly groups combine education, personal connection, interaction and support, and practice of recovery behaviors.
8. In weekly groups, participants learn the skills of recovery sooner with help, rather than later, by trial and error.
9. There is synergy in working with other survivors and families. In weekly groups, participants accomplish more together than they could on their own.
10. Ideally, weekly groups are provided concurrently with individual rehabilitation, augment physical recovery and continue for as long as needed.
11. In weekly groups, the inner struggles of participants often transform to concern for others. Many go on to support the recovery of others as volunteers.
12. Weekly groups are cost-effective. The work is done by participants themselves, and fewer subsequent strokes and hospitalizations save money.

No one should face stroke alone

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 gradually organizes new neural pathways. Optimal recovery requires daily practice of targeted functions and periodic rehabilitation over time.
2. Stroke rehabilitation and recovery typically begin after critical care and medical stabilization. Inpatient and outpatient rehabilitation consists of intensive individual physical, occupational and speech therapy, for up to six months.
3. After subacute rehabilitation, survivors take charge of their own recoveries. They connect with other survivors in weekly support groups and share experience strength and hope. They select functions they want to restore, practice them daily, and turn everyday activities into recovery exercises.
4. After subacute rehabilitation, Bruce Dobkin, M.D., Director, UCLA Neurological Rehabilitation and Research, recommends “pulse therapy,” which is daily practice of self-selected functions and periodic therapy to refine goals and practice.
5. The degree of 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. Stroke recovery is easier and more effective when done with others. The first time that survivors and families work with others is during the empowerment stage of stroke recovery. We must do it ourselves, but we don’t have to do it alone.
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. Goals are good, but we don’t need to make our happiness conditional on some future achievement. We can appreciate the portion of the glass that is filled.
10. Survivors who fully participate in the process of recovery have improved recovery outcomes, health, quality of life and fewer subsequent strokes.

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