The New Stroke Paradigm
Empowerment of Individuals,
Families and Communities

For millennia, stroke was a mystery, was once called “apoplexy” (a sudden blow delivered by the gods) and nothing could be done about it. Even in the 20th century, there were limits. The injury could not be arrested, and it was believed that recovery only occurred during the first months or year after onset.

Today, accredited stroke centers, t-PA (a medication to dissolve clots), blood flow restoration devices and other comprehensive care are lifesaving advances in treatment of acute stroke. Also, progress in rehabilitation has been made with targeted application of neurological return and plasticity. Acute and subacute rehabilitation is provided widely.

The next major advance in stroke care should be to empower individuals, families and communities for there are essential actions of prevention, treatment and recovery that no one else can do for them.

Optimally, after acute and subacute rehabilitation, survivors and families gradually accept responsibility for their own recoveries. In the New Stroke Paradigm, this is defined as the empowerment stage of stroke recovery.

Reams Freedman, MA, MFT
Director and Stroke Victor
Reviewer Comments

“I think the document provides a comprehensive, well thought out framework for stroke care through all the stages of the disease.”

Jeffrey L. Saver, MD, FAHA, FAAN, FANA
Professor of Neurology
David Geffen School of Medicine at UCLA
Director, UCLA Comprehensive Stroke Center

“This is a good conception of an overall “holistic” stroke care continuum. Pulse therapy and greater involvement of support groups is a good model.”

S. Thomas Carmichael, MD, PhD
Professor of Neurology
David Geffen School of Medicine at UCLA
Vice Chair for Research and Programs

Contents

The New Stroke Paradigm – Page 3
The Power of Community – Page 7
Prevention through Wellness – Page 13
Call 911 - Every Minute Counts – Page 21
Empowerment after Stroke – Page 25
Psychological and Social Recovery – Page 37
SASC Stroke Recovery Groups and Community Resources – Page 43
Stroke Services in Your Community – Page 53
Author – Page 57
The New Stroke Paradigm

Introduction

For millennia, stroke was a mystery, was once called “apoplexy” (a sudden blow delivered by the gods) and nothing could be done about it. Even in the 20th century, there were limits. The injury could not be arrested, and it was believed that recovery only occurred during the first months or year after onset.

Today, accredited stroke centers, t-PA (a medication to dissolve clots), blood flow restoration devices and other comprehensive care are lifesaving advances in treatment of acute stroke. Also, progress in rehabilitation has been made with targeted application of neurological return and plasticity. Acute and subacute rehabilitation is provided widely.

The next major advance in stroke care should be to empower individuals, families and communities for there are essential actions of prevention, treatment and recovery that no one else can do for them.

1. Seventy percent of strokes can be prevented when individuals and families practice a healthy lifestyle, manage risk factors and get proactive medical care.

2. For advanced stroke treatment to be successful, families, friends or bystanders must immediately recognize signs and symptoms, call 911 and get the patient to an accredited stroke center as soon as possible.

3. Acute and subacute treatments typically end at about four months and, thereafter, survivors take charge of their own recoveries. The New Stroke Paradigm has named this the “Empowerment Stage” of stroke recovery.

4. After a stroke, survivors and families prevent subsequent strokes and protect against other illness with self-care, healthy lifestyle, management of risk factors and proactive medical care.

5. Communities, concerned individuals, families, businesses, civic organizations, health professionals and facilities all have a vested interest in the success of a stroke system of care, and have much to contribute.

Here are suggestions to empower individuals, families and the public. They are formally educated about their roles and responsibilities to prevent, treat and recover from stroke. After acute and subacute treatment, recovery continues with periodic rehabilitation and daily practice of targeted functions. Treatment is coordinated among providers and facilities, so survivors and families are prepared for each stage of treatment. Rehabilitation and reimbursement practices are based on current knowledge of neural repair.

Please read “The New Stroke Paradigm.”
Premise and Promise

Because of advances in prevention, treatment, rehabilitation and recovery, this is what the new stroke paradigm can look like today.

1. Individuals and families protect themselves against stroke and other illness by participation in universal wellness and prevention education and practice.

2. An informed public knows the signs and symptoms of stroke and calls 911 immediately, which is critical to restoration of blood flow to the brain.

3. Emergency and critical care is provided at accredited stroke centers.

4. A period of acute inpatient and subacute outpatient rehabilitation is provided after medical stabilization, based on individual needs of each patient.

5. After acute and subacute treatment, recovery continues with periodic rehabilitation and daily practice of targeted functions.

6. Survivors and families now take charge of their own recoveries, as stroke professionals transition to a supportive role.

7. Weekly functional exercise classes and support groups guide and empower survivors and families with the synergy of interpersonal connection.

8. Caregivers and family members receive education and support at each stage of the stroke continuum.

9. Survivors and families prevent subsequent strokes and other illness with practice of healthy behavior in wellness classes and teams.

10. With continuity of care, each stage of treatment gets the support it needs. Patients and families are prepared for and supported at each stage of the recovery process.

11. After acute and subacute treatment, outpatient services can be provided at low-cost, improve healthcare outcomes and reduce future medical expense.

Survivors and families who participate in coordinated physical, psychological and social therapies that emphasize education, guidance, interpersonal support, empowerment, practice of recovery skills and self-care, make more progress in functional recovery, have fewer subsequent strokes and have a better quality of life than those who do not.

Are these services available in your community?
Paradigm Perspective

I knew little about stroke, until I had one. Many years later, based on my experience and that of fellow survivors and their families, here is some of what I’ve learned, followed by ideas that I hope can be a new paradigm for stroke prevention, treatment and recovery, founded on empowerment of individuals and families and integration of stroke services.

Prevention through Wellness

Stroke, heart disease, diabetes, cancer and other illness can be prevented with healthy lifestyle, attention to health risk factors and proactive medical care. All respond to the same universal self-care practices. Working with others in teams at home, work, school, in church and neighborhoods is an effective and enjoyable way to protect our health.

Call 911

A vital goal of emergency stroke care is to restore blood flow to the brain as soon as possible. Those who participate in prevention and wellness programs learn the signs and symptoms of stroke and to call 911 immediately. Treatment at an accredited stroke center can stop, reduce or reverse the injury of stroke.

Family Crisis

After a stroke, patients and families need education about stroke and recovery, emotional and social support and guidance to resources, provided by a hotline, knowledgeable health professionals, experienced survivors and caregivers, and weekly support groups.

Recovery from Stroke

Stroke recovery is a gradual process of biological healing and improved physical, psychological and social functioning that occurs over time with recurrent rehabilitation, education, support, guidance, daily recovery effort and practice by survivors and families.

Empowerment

Initially after stroke, survivors and families experience loss of control and depend on health professionals. On hospital discharge, they often feel anxious because they go home without that support. A next stage of recovery is for them to learn what they can do for themselves to get better, through a process of empowerment and the skills of recovery.

Recovery is an inside job

While the help of others is vital in recovery, survivors and families need to know their role and responsibilities, for there are actions that no one else can do for them. Healing from stroke is an inside job that is strengthened by hope, courage, optimism and trust, and persistent and patient practice of the behaviors of recovery.
Recovery with Others

While there are actions that stroke survivors and families can only do for themselves, they don’t have to do it alone. On return home, the next phase of recovery begins with outpatient therapy and support of a community of experienced survivors and families, who understand, encourage and inspire. No one should be or feel alone after stroke.

Return and Plasticity

The path to neurological recovery is "return," which is restoration of lost function, as injured but viable cells heal, and "plasticity," which is the brain’s ability to reorganize itself and regain function by forming new connections around deceased cells, and both occur best with recurrent therapy and daily practice by survivors and families.

Simple. Not Easy

Rehabilitation research shows that survivors, who work with simple tools at home, can recover as well as those who work with expensive equipment. A key determinant of success in recovery is regular practice, like learning to play a musical instrument.

Psychological and Social Recovery

Stroke impacts psychological and social functioning, sense of self, independence, security and stability, concerns for the future, and roles and relationships. Stroke affects how survivors and families think, feel, relate and experience life, and this needs to be addressed with the same vigor as physical, occupational and speech therapies.

Attitudes of Recovery

After a stroke, it is understandable to initially dwell on losses. However, in recovery, focus gradually changes as survivors and families concentrate on ways to heal and resume their lives. Powerlessness is transformed into empowerment, disabilities to capabilities, resignation to acceptance, and bitterness to enjoyment of the gift of life.

Progress in Recovery

When survivors and families are frustrated by seemingly slow progress, it helps to know that recovery is a biological process, like the growth of children. No one expects a child to walk at six months or talk at one year. Survivors and families can have satisfying lives, even as they gradually recover, just as they enjoy their children at every age.

Community

We all live in community and much of our ability to protect ourselves comes from what we do together. Each of us has a stake in the challenge of stroke and other illness and every individual, family, health professional, hospital, employer, business, civic agency, college and religious order can be part of the solution.
The Power of Community
Contents

The New Stroke Paradigm – Page 3

The Power of Community – Page 7

Prevention through Wellness – Page 13

Call 911 - Every Minute Counts – Page 21

Empowerment after Stroke – Page 25

Psychological and Social Recovery – Page 37

SASC Stroke Recovery Groups and Community Resources – Page 43

Stroke Services in Your Community – Page 53

Author – Page 57
Stroke and Community

The National Institutes of Health, the American and National Stroke Associations conduct essential research, establish national guidelines for advanced stroke care and provide vital education about wellness, prevention, treatment and recovery. It’s time to apply this knowledge locally, in the community.

We all live together in community and much of our strength and many of our personal and social accomplishments come from what we do with others. We can apply that synergy to combat stroke.

Every person has a stake in how the challenges of stroke are confronted, and every individual, family, hospital, health professional, college, community leader and agency, religious organization, business and corporation can be part of the solution.

Stroke is more than a sudden event. The cause of stroke and the process of treatment and recovery take place on a continuum over many years. Stroke is a complex disease and strategies should be multi-dimensional and take place when and where stroke begins and recovery occurs, in the home and community.

There have been major advances in stroke prevention, acute care, rehabilitation and recovery: 1) Strokes can be prevented. 2) Accredited stroke centers restore brain circulation. 3) Neurorepair improves functional recovery 4) Survivors and families learn skills and adaptations that enable them to enjoy their lives, even as they recover.

Significantly, these advancements aren’t available to all Southern Californians because they are unevenly distributed over a vast area and population. Stroke prevention, treatment and recovery would be enhanced if services were provided locally, close to where and how people live.

Southern California has significant incidence and prevalence of stroke. While the nature of the disease is universal, the communities in which stroke occurs vary, according to population, culture, ethnicity and language.

Each region and community has its own unique resources, which may include hospitals, health professionals, colleges, community leaders and organizations, religious centers, business sponsors, concerned persons, especially those affected by stroke, and stroke support groups.

Essential advances against stroke need to occur in the community so that services and progress are available to all. The Stroke Association assists communities to develop optimal services in their respective neighborhoods throughout Southern California.
**Stroke Services in the Community**

The Stroke Association of Southern California is a vital resource in the continuum of stroke services and complements the advanced care of accredited stroke centers and the educational media and research of the American and National Stroke Associations with direct and personal services in the community. This is what SASC can do with support:

1. Prevention and wellness classes support healthy lifestyle, health risk mitigation and medical care that protect against stroke, heart disease, diabetes and other illness.

2. SASC prepares the public to recognize signs and symptoms, immediately call 911 and go to a certified stroke center to restore brain circulation.

3. When families contact the SASC helpline in a state of distress, they receive expert and compassionate guidance to resources and support.

4. In stroke recovery groups, survivors and families learn and practice the skills and adaptations needed to live well and enjoy life, even as they recover.

5. The psychological and social trauma of stroke is eased with education, support, expressive activities, adaptive exercise and professional services as needed.

6. SASC supports continual physical, psychological and social services throughout the continuum of stroke in the hospital, at home and in the community.

7. SASC is committed to serve uninsured, underserved and high-risk populations.

8. SASC supports advances in stroke care by representing survivors, families, and the public-at-large on various scientific advisory committees.

9. In the research project, “Trajectories of Stroke Recovery,” SASC examines the correlated factors that contribute to optimal stroke recovery.

10. SASC helps communities develop collaborative prevention, treatment and recovery services that make use of the resources and strengths in each locality.

The Stroke Association is a non-profit 501 (3)(c) organization (Tax ID 95-2809676) and can expand these services and accomplish these goals in more communities and regions of Southern California with the support of concerned individuals, families, healthcare providers and payers, local government and civic organizations and businesses.

**Please support these efforts to improve health and prevent stroke and related illness in your community.**
The Power of Community

The Stroke Association of Southern California functions best with the support of survivors, families, support groups; health professionals, concerned persons; civic, religious, educational and business organizations that are committed to universal wellness, stroke prevention, treatment and recovery.

1. A professional staff and board of directors are dedicated to universal wellness and stroke prevention, treatment and recovery.

2. Health professionals, stroke centers and rehabilitation facilities provide expert medical care to support wellness, prevention, treatment and recovery.

3. Experienced stroke survivors and families serve as advisors and advocates, and provide support, example and inspiration in the hospital, home and community.

4. Weekly support groups help those new to stroke learn optimal recovery skills and adaptations with the support of experienced survivors and families.

5. All community partners support universal wellness and prevention practices that protect against stroke, heart disease, diabetes, and other illness.

6. Employers create a healthy work environment. Healthy employees are more able to be productive employees.

7. At churches, synagogues, mosques and temples, congregants, who are health professionals, monitor blood pressure, cholesterol and other health risk factors.

8. Individuals and families, with professional abilities, social connections and financial means, use their resources to support specific projects and programs.

9. Concerned civic, educational, business and religious organizations contribute administrative, financial and marketing expertise, skills and resources.

10. Community colleges educate about health and wellness, provide adaptive exercise for the disabled and offer adult classes that enrich life after stroke.

11. Grocery stores provide information and easy access to healthy choices. Restaurants prominently offer choices from the Mediterranean diet.

An effect of stroke may be powerlessness, however, community can overpower stroke.
Community (noun)

A group of people living in the same place or having a characteristic in common.

Association (noun)

A group of individuals or organizations that have a common interest or purpose
Prevention through Wellness
Contents

The New Stroke Paradigm – Page 3

The Power of Community – Page 7

Prevention through Wellness – Page 13

Call 911 - Every Minute Counts – Page 21

Empowerment after Stroke – Page 25

Psychological and Social Recovery – Page 37

SASC Stroke Recovery Groups and Community Resources – Page 43

Stroke Services in Your Community – Page 53

Author – Page 57
Prevention through Wellness

Stroke prevention education provides instruction about healthy behavior. “This is what you do to prevent stroke.” However, education is only the first step because stroke can only be prevented after certain behaviors have been completed.

Patients are often asked how they want to receive health education; in writing, with media or in person. A friend said, “I’d like to have it IV.” He was joking, but it is true that health education can be passive, and to be effective, action is also needed.

Fortunately, the steps we must take to protect ourselves are well-understood and straightforward. It is also motivating to know that these steps prevent other illnesses such as heart disease and diabetes.

To a large extent, stroke and other illness are caused by unhealthy lifestyle, neglected health risk factors, and medical conditions that can be corrected. These all respond to self-care: Maintain blood pressure, cholesterol and blood sugar at healthy levels; eat a Mediterranean diet which is low in saturated fats, and includes fruits, vegetables, complex carbohydrates and olive oil; exercise moderately daily; maintain a healthy body weight; don’t smoke, use drugs and reduce alcohol intake, and get proactive medical care.

Here are steps to better health:

1. Understand the importance of self-care
2. Know what to do to protect our health
3. Understand our personal risk factors
4. Practice self-care and wellness behaviors
5. Accept that healthy behaviors need to be done regularly
6. Fit self-care into our daily routine
7. Value ourselves so we follow-through
8. Seek and receive medical care, psychological and social support

Optimal prevention services are more than education and include empowerment and action (daily practice over time) to accomplish lifestyle changes, exercise, nutrition, attention to risk factors and proactive medical care. Please join others in behaviors that prevent stroke and other illnesses.
Universal Wellness Practice

Why does the Stroke Association emphasize universal wellness? Seventy percent of strokes can be prevented by healthy lifestyle, attention to risk factors, and proactive medical care. These actions also protect against heart disease, diabetes, and other illness.

The National Stroke Association, the American Stroke Association, the American Heart Association, the American Cancer Society and the American Diabetes Association all recommend the same behaviors for wellness and disease prevention.

To practice means to repeat a behavior to achieve a goal, and to work in a profession that requires extensive education and experience. SASC encourages regular practice of universally healthy behaviors with the support of health professionals and organizations.

The Stroke Association supports regular practice of universally healthy behaviors and encourages those who want to protect their health to join with others to achieve personal health goals.

1. Form a wellness team at home, work, church, school or in your neighborhood to learn and practice the behaviors of self-care
2. Make your home a “good food zone” and make healthy choices when dining out
3. Exercise regularly and safely, selecting activities you enjoy, according to your health needs, and with your doctor’s approval
4. Reduce unhealthy demands and stresses of your personal and work life
5. Access the healthcare you need and work with your doctor for good health
6. Manage health risk factors such as high blood pressure, cholesterol, heart conditions and diabetes
7. Know how to recognize and respond to medical emergencies

We all need encouragement and support. It’s not easy to regularly eat well, exercise, maintain weight, manage stress and health risks, stop smoking, moderate drinking, go to the doctor and care for our families while under pressure of personal and work responsibilities, especially when fast foods and other short cuts that bypass healthy behaviors are so accessible.

While there are some healthy behaviors no one else can do for us, self-care is easier, more effective and enjoyable when done with others who are also committed to good health.

Join with others and form a wellness team.
The New Health Paradigm

In the new paradigm, stroke survivors and families accept more responsibility for their health and healthcare. They practice wellness behaviors and recovery skills, including lifestyle modification, risk factor management and proactive medical care. Healthcare focus changes from treatment done by others and more to a process in which individuals and families are 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 lower 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 healthcare; active and receptive. There are actions that we do for ourselves and actions 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 medical exams, blood tests, mammography, colonoscopy, prescriptions and other procedures and treatments.

Paradoxically, self-care is more successful when done with the support of others. It is not easy to stop overeating, smoking or drinking if others are not supportive. Also, practice of self-care is harder when under pressures of the job, or when fast food is the easiest 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 help us complete personal health tasks, goals and responsibilities.

We must do it ourselves, but we don’t have to do it alone.
Wellness Goals

➢ Understand the power of universal wellness and self-care practice
➢ Form a wellness team and work with others
➢ Set and achieve wellness goals
➢ Access needed health services
➢ Receive essential family, social and psychological support
➢ Overcome challenges of stress and distress, illness and injury

Universal Wellness Practice

The Wellness Practice supports behaviors that are universally healthy and protect against stroke, heart disease, diabetes and other illness.

To practice is to repeat a behavior to achieve a goal. It also means to work in a profession that requires education and experience.

At the Wellness Practice, members work with others to achieve personal objectives. Health professionals educate, guide and support.

For more information, please contact:

Health Empowerment on the Westside

health@strokesocal.org
(310) 575-1699
Health Empowerment

Even with modern medicine, much capacity for wellness lies within the capabilities and recuperative powers of individuals and families.

In fact, for optimal health and healing, there is some self-care behaviors that no one can do for us, though wellness practices are more enjoyable and effective when done with others.

The Wellness Practice stimulates optimism and motivates participants to make vital commitments to their health. Knowledge, encouragement, and support are empowering.

At the Wellness Practice, working with others, participants assess wellness needs, make plan for improvement, and work to accomplish health objectives.

The Wellness Practice

Wellness is a state of integrated physical, psychological and social health achieved through nutrition; activity, exercise; stress management, relaxation and recreation; focus and mindfulness; creative and emotional expression; nurturing relationships; proactive healthcare; balance of body, mind and spirit.

Group activities and wellness teams are encouraged. Working with others can be more productive and satisfying than making personal change alone.

Willpower is a common approach in fitness regimens. The slogan of a local fitness trainer is “We will make you do it.” The Wellness Practice encourages willingness because wellness is easier and more effective when participants “want to do it.”

Regular participation is encouraged because wellness is a process and not a destination, and goals are best achieved gradually over time.
Call 911 - Every Minute Counts
Contents

The New Stroke Paradigm – Page 3

The Power of Community – Page 7

Prevention through Wellness – Page 13

Call 911 - Every Minute Counts – Page 21

Empowerment after Stroke – Page 25

Psychological and Social Recovery – Page 37

SASC Stroke Recovery Groups
and Community Resources – Page 43

Stroke Services in Your Community – Page 53

Author – Page 57
Call 911 - Every Minute Counts

During a stroke, time is brain and every minute counts. Death of brain cells begin with the first symptoms and will continue until the patient receives hospital and stroke center care.

When a stroke occurs, with each minute of delay, the brain loses 1.9 million neurons, 14 billion synapses, and 7.5 miles of myelinated fibers.

A major factor in stroke care is time to treatment. Recognition of symptoms, the call to 911, hospital transit, assessment, MRI or CAT scan, diagnosis, treatment decisions and other critical care all take valuable time.

In regard to time, think minutes. The much-publicized treatment window for stroke defines when care is too late and can’t succeed and not when it should begin. There may be a window, but the door to recovery closes fast.

Frequently, 911 is not called because symptoms don’t seem serious or are thought to have another cause. Call for help even if you are not sure it’s a stroke. Let the doctors make the diagnosis.

Paramedics and Stroke Centers in Los Angeles are ready 24/7 to provide advanced stroke treatment, but for those specialized skills, medications and equipment to be of value, we all must recognize the symptoms of stroke and call 911 immediately.
Call 911 Immediately
The public’s role in case of stroke

Stroke is caused by interruption of circulation to the brain. Ischemia or blockage of blood flow is the most common cause (88%) of stroke. Essential treatment is to rapidly restore flow of blood and oxygen. There are now dramatically effective treatments. If you call 911 immediately and the patient is taken to an accredited stroke center, the injuries of stroke may be stopped, reduced or reversed.

When given promptly in the hospital, according to guidelines for ischemic stroke, tissue plasminogen activator (tPA) can dissolve blood clots. “Patients treated with tPA were at least 30 percent more likely to have minimal or no disability at three months,” NEJM Vol. 333:1581-88, Dec 1995

Also, blood flow restoration devices have “proved effective at removing a clot and restoring blood flow in 61 percent of patients.” UCLA Vital Signs, Summer 2012

While there is a well-publicized window within which treatments must be administered, the window defines the time at which treatment will no longer succeed, not when it should begin. Brain cells begin to die at the onset of stroke and time is required for emergency treatment, a CAT scan or MRI, and comprehensive stroke care, so call 911 immediately when there are signs and symptoms of stroke.

Delay in treatment often occurs because stroke symptoms do not trigger sufficient alarm. When we have severe pain, trouble breathing or bleeding, we call for help. In stroke, initial signs and symptoms are often not recognized as serious and can be misinterpreted as migraine, fatigue, stress or intoxication, so learn the signs and symptoms of stroke:

- Sudden numbness or weakness of the face, arm, leg on one side of the body
- Sudden difficulty speaking or understanding
- Sudden confusion and disorientation
- Sudden change or loss of vision
- Sudden dizziness, unsteadiness or falls
- Sudden severe headache
- In case of a TIA or “mini-stroke,” seek help even if signs and symptoms go away
- If you are not sure it’s a stroke, call 911. Let experts make the diagnosis

The Joint Commission, the American Stroke Association and the National Stroke Association all recommend that that 911 is called and patients are taken to an accredited stroke center immediately.
Empowerment after Stroke
Contents

The New Stroke Paradigm – Page 3

The Power of Community – Page 7

Prevention through Wellness – Page 13

Call 911 - Every Minute Counts – Page 21

Empowerment after Stroke – Page 25

Psychological and Social Recovery – Page 37

SASC Stroke Recovery Groups
and Community Resources – Page 43

Stroke Services in Your Community – Page 53

Author – Page 57
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 enjoyable 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. Challenge ourselves.
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 community resources to support and enrich our recovery and life.

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 stroke professionals can do for survivors and families and there are actions of recovery that they must do for themselves. There is need for an additional stage of stroke recovery.

The new Empowerment Stage of Stroke Recovery immediately follows subacute rehabilitation. It is not enough for survivors to be discharged to the unstructured chronic stage. They need direction and support to strengthen and consolidate their recoveries.

The empowerment stage 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 gradual 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 survivors 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, patience, 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.

1. 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.

2. 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.

3. 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.

4. 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.”

5. 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.

6. 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.

7. 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.

8. 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.

9. 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.
Dear Doctor,

After stroke patients and families are discharged from the hospital, they may come to you with questions and concerns about what happens next.

After concentrated inpatient and outpatient treatment, they may fear that nothing more can be done for them. They need to know that they are now in the empowerment stage of stroke recovery and much more can be done.

In the empowerment stage, patients and families learn and practice the steps and skills of recovery and transform from states of powerlessness to capability, dependence to independence and distress to optimism.

And they can recover with others. Please tell patients and families that experienced leaders, groups, survivors and families will guide, support, encourage and inspire them.

After acute and subacute care, there is a necessary transition from professional services to actions that survivors and families must do for themselves. Health professionals can help patients make that change.

“Continuity of care” is an important concept. Please explain to your patients that transition to services and support in the community is the next step in the process of recovery.

Would you please contact the Stroke Association or refer patients and families when they can benefit from “empowerment after stroke?”

Sincerely yours,

Reams Freedman, MA, MFT
Director and Stroke Survivor

(Today, stroke can be prevented, successfully treated and survivors and families can enjoy life, even as they recover.)
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. During subacute rehabilitation, patients and families are prepared for transition to the empowerment stage of stroke recovery.

6. In the empowerment stage, “patients” become “survivors,” as they gradually learn and practice what they can do for themselves to recover from stroke.

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., co-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, like moving a standing train. 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 important to recovery from stroke. Recovery in classes and groups is like being in a nurturing family that provides 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

The New Stroke Paradigm ● Page 34
(310) 575-1699 ● strokesocal.org
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.
Psychological and Social Recovery
Contents

The New Stroke Paradigm – Page 3

The Power of Community – Page 7

Prevention through Wellness – Page 13

Call 911 - Every Minute Counts – Page 21

Empowerment after Stroke – Page 25

Psychological and Social Recovery – Page 37

SASC Stroke Recovery Groups and Community Resources – Page 43

Stroke Services in Your Community – Page 53

Author – Page 57
Psychological and Social Recovery

Recovery from stroke is generally known to consist of biological healing (return), reorganization of neural pathways (neuroplasticity) and gradual restoration of physical functioning. However, it’s much more than that. Psychological and social healing is also essential to optimal stroke recovery.

Stroke is emotionally and socially traumatic. For survivors, it is devastating to be unable to move, talk or to suffer other effects. For family and friends, it is painful to see a loved one ill and disabled, and caregivers are faced with constant responsibility.

Significantly, much pain after stroke is felt as psychological and social distress. To varying degrees, survivors and caregivers may feel powerless, afraid, anxious, angry, frustrated, depressed, discouraged, disabled, limited, diminished, dependent, cut off from family and friends, self-doubt, self-blame, with challenge to self-identity and self-worth.

While the medical and physical effects of stroke are necessarily treated first, psychological and social injuries need treatment, too, with education and guidance, interpersonal connection, support and encouragement, practice of the skills of recovery, and targeted psychotherapeutic intervention and medication as appropriate.

Psychological and social services are important because they empower survivors and families to manage the distress and disruption of stroke and stimulate essential drives for recovery, such as determination to live and thrive, and desire to connect with others.

In recovery, survivors and families discover their inner strength and resilience as healthy behaviors are generated and sustained by the psychological forces of courage, hope, optimism, determination, persistence, patience and the social powers of connection, interaction, support, trust, encouragement, guidance and example.

Further, survivors and caregivers who participate in a process of psychosocial and social healing, personal empowerment and self-care make more progress in physical recovery, have fewer subsequent strokes and better quality of life than those who do not.

Education and support in a group is an effective way to address the psychological and social effects of stroke. Experienced facilitators guide resolution of recurrent issues of stroke and recovery. Survivors and caregivers who aren’t ready for a group experience can be helped in individual and family settings.

Weekly recovery groups help mood, thinking, attitudes and beliefs; stimulate interests, passion, expression and activity; enhance spirit, promote adaptability, strengthen social connections, relationships and friendships; bolster residential and financial stability; and connect participants with other services in the community.

Psychological and social support is the invisible hand of stroke recovery

Najma Davis, DSW
Psychological and Social Effects of Stroke

Here are ways that emotion, thinking, beliefs, attitude, relationships impact stroke recovery.

1. After a stroke, survivors and families often feel powerless, loss, grief, fear, anger, bitter, depressed, isolated or overwhelmed. They have questions. “Will I get better? Will I be independent again? What’s going to happen to my family? How will we manage?”

2. In recovery with others, there’s help and answers to these questions and feelings. In the process of recovery, with education, guidance and support, survivors and families can feel hopeful, calm, connected, empowered, capable, valued, valuable and grateful.

3. Why recovery is so “slow?” Recovery from stroke needs to be understood as a gradual biological process. We accept that it takes an infant a year to walk and two years to talk. Also, it takes time to get a college education or learn a skill, yet there is satisfaction in accomplishing an important goal.

4. Stroke provides an important lesson about patience and persistence. Gradually, survivors and families learn to enjoy their lives and progress today, even as they “work” to recover. They don’t have to wait for some future achievement or event to be happy.

5. In recovery, survivors and families learn to appreciate the portion of the glass that is full, and satisfaction and meaning is found in the mixture of challenges, limitations, capabilities, pleasures and opportunities in life now.

6. Stroke affects self-worth. Survivors feel diminished when they can’t do normal tasks and caregivers feel ineffective when they are unable to do all they expect of themselves. In recovery, expectations are reframed and satisfaction is found in simple achievements.

7. Survivors and families are often isolated as stroke constricts their lives to a small space. It’s hard to recover when feeling confined, alone, vulnerable and fragile. Recovery is easier when experienced survivors and families reach out with guidance and support.

8. After stroke, relationships are more difficult because of the limiting effects of stroke, the pressures of caregiving and changes in friendships. Discussion, guidance and practice of social interaction in support groups help restore vital social connections.

9. When survivors and families feel powerless, vulnerable and afraid, the example of others helps access inner reserves of strength and courage. Also, interaction in support groups engender feelings of connection, friendship, empathy, compassion and hope.

10. After a stroke, survivors and caregivers walk, talk, act, and think at different speeds. This disparity can cause survivors to feel left out or behind and frustration for family and friends. In recovery, everyone learns to patiently interact at the same pace.
11. Lower energy and stamina are common after stroke. Survivors may do less, but they can choose activities that mean the most, that interest and stimulate, that expand capabilities and enrich their lives. Personal passions add meaning and purpose to life.

12. Caregivers often become overwhelmed while providing hours of support, taking care of the household, meeting personal and work responsibilities. Experienced caregivers in a support group can provide strategies, suggestions and resources for respite and calm.

13. Stroke affects family roles. Caregivers may be stressed over extra responsibilities. Survivors may be upset over loss of status or decisions that are made without their input. Solutions can be found through education and shared experience in support groups.

14. Both survivors and caregivers yearn for independence. Since capabilities can gradually change in recovery without being noticed, periodic reevaluation identifies what survivors can now do on their own and the responsibilities that caregivers can safely release.

15. There are often behaviors that are not recognized as effects of stroke, including changes in mood, emotions, thinking, memory, motivation and energy. Education and support help survivors and families understand and manage the complexities of stroke.

16. Sometimes, survivors don’t look like they have had a stroke. Survivors, families and friends need to understand internal effects of stroke that aren’t obvious, so they can be realistic and patient in their expectations of self and others.

17. Stroke affects every area of life, including financial and residential stability. Recovery programs help survivors and families connect with community resources.

18. Because recovery is gradual, survivors and families learn to accept their limitations and capabilities, and play with the cards they have been dealt with patience and determination.

19. When can less be more? For some, the losses in stroke lead to deeper experience of life. In recovery, anger and bitterness can be replaced with gratitude and loss with love.

20. Fortunately, for individual survivors and families, only some of these issues arise, and at different times over the span of recovery, and when they do occur, stroke recovery groups and experienced survivors and families are there to support them.

21. Here are general guidelines for resolution of psychological and social challenges of stroke in a group: connect with others for mutual support, encouragement and inspiration; learn about visible and hidden effects and impact of stroke; identify and discuss the effects of your stroke and methods of coping; formulate strategies to address concerns; share experience with others; seek individual psychotherapy and medication when needed.
The Stroke Recovery Group
Connection, education, guidance, example, empowerment, practice, self-care

1. “I’ve lost control of my body and life and I feel powerless, afraid and alone.” These are common feelings after stroke. Humans cope with such distressful circumstance and emotion by banding together to create connection, relationships, love, caring, belonging, identity, support, example, encouragement and safety.

2. The stroke recovery group is similarly protective, like the nurturing family that we had or needed. The group meets weekly because regular interaction with survivors and families creates connection, trust, healing and empowerment, and because it helps to learn the many skills of recovery sooner, with help, rather than later, by trial and error.

3. In group, individual survivors and caregivers share their personal experiences, feelings and concerns in a safe environment. Others listen with empathy and give feedback on how they felt and acted in similar circumstances.

4. Participants are encouraged to speak from personal experience and point of view to increase self-awareness and to connect with and support others. The most helpful communication and response is in the first person.

5. An atmosphere of trust is created by authentic interaction and commitment to confidentiality. What is shared in the group stays in the group.

6. As universal concerns are uncovered, each participant discusses how he or she has been affected by or relates to the issue at hand. Facilitators focus on and educate about significant topics that arise, and guide discussion to deeper awareness and understanding.

7. Ideally, support groups begin during rehabilitation and continue for as long as needed (at least the first year) so participants learn and practice the many steps and skills of recovery and learn to enjoy life, even as they recover.

8. Significantly, those who participate in interpersonal connection, education, guidance, support, example, practice of recovery skills, psychosocial and social healing, personal empowerment and self-care make more progress in physical recovery, have fewer subsequent strokes and better quality of life than those who do not.

No one should face stroke alone
SASC Stroke Recovery Groups and Community Resources
Contents

The New Stroke Paradigm – Page 3

The Power of Community – Page 7

Prevention through Wellness – Page 13

Call 911 - Every Minute Counts – Page 21

Empowerment after Stroke – Page 25

Psychological and Social Recovery – Page 37

SASC Stroke Recovery Groups and Community Resources – Page 43

Stroke Services in Your Community – Page 53

Author – Page 57
The Stroke Recovery Group at UCLA Westwood

There have been major advances in stroke treatment and what survivors and families can do to get better.

The weekly group educates, supports, inspires and empowers participants to achieve optimal physical, functional, psychological and social recovery.

In the group, survivors and families:

1. Are empowered to restore functioning, independence, quality of life.
2. Know that recovery can be continuous with commitment and effort
3. Select impaired functions they want restore and practice them daily
4. Connect with others and share courage, hope, optimism and progress
5. Move from powerlessness to empowerment, disability to capability
6. Gradually restore functioning, capabilities, independence, self-identity
7. Proactively seek medical care and follow directions to protect health
8. Practice self-care; make changes in lifestyle; manage stroke risk factors
9. Use community resources to support and enrich our recovery and lives
10. Enjoy life and the portion of the glass that is filled

Mondays, 2:00 PM – 3:30 PM
UCLA Medical Plaza, 300 Building
Leif Conference Room, 3rd Floor

Please call to confirm meeting time and location
(310) 575-1699 • recovery@strokesocal.org
Acquired Brain Injury Program Overview

Santa Monica College

- **Assessment course** offered twice per year; designed to provide feedback on academic readiness and cognitive skills as well as physical access to classes and associated materials
  - “For Credit” classes
    - Students enroll in fee-based class to earn academic credit towards a degree/certificate or for continued personal development
    - Ongoing assistance and problem solving through individual and/or group sessions
    - Guidance provided in educational planning to meet academic/personal goals
  - “Non-Credit” classes (free)
    - ABI Connections – to promote community and lifestyle skills, as well as provide instruction for personal development
    - Adult Education classes in development

Emeritus College

- Free education classes designed for adults over age 50
- **Pathfinders Program** for individuals who have had an acquired brain injury and completed a course of rehabilitative therapy (ages 18+)
  - **Exercise class** – to promote wellness and physical fitness
  - **Communication class** – to support speech and language skills with group interaction and computer-based activity
  - **Cognitive class in development**
  - Classes are offered year-round & taught by rehabilitation professionals

How to Enroll

- Complete department application & meet with the ABI specialist
- Provide medical documentation to verify non-progressive, acquired brain injury sustained after age 13
- Demonstrate sufficient self-help skills to manage within the college environment
- Return application and medical verification to:

  **Stephanie Lewis, ABI Specialist/Faculty**
  **Disabled Student Program and Services**
  **1900 Pico Blvd., Santa Monica, CA 90405**
  **Phone (310) 434-4442, Fax (310) 434-4272**
  **lewis_stephanie@smc.edu**
The Stroke Recovery Groups at Rancho
Empowerment after Stroke

Stroke can affect every aspect of life. The stroke groups at the wellness center empower survivors and families to restore their functioning, speech, thinking, emotions, relationships; energy and motivation; interests; purpose and meaning; and quality of life.

There are two separate stroke groups, so patients who have therapy in the morning can attend the afternoon group, and those who have therapy in the afternoon can attend the morning group.

The stroke recovery groups and the many resources of Rancho Los Amigos enable survivors and family members to attain optimal physical, psychological and social recovery.

Don Knabe Wellness Center, Room #110
Wednesdays, 11 am to Noon, 1 pm to 2 pm
Rancho Los Amigos National Rehabilitation Center
7601 Imperial Highway, Downey, CA 90242
(310) 575-1699 • recovery@strokesocal.org
The Don Knabe Wellness Center
Empowerment after Stroke

After inpatient and outpatient rehabilitation, recovery from stroke can be continue with frequent practice and support. Stroke survivors and families participate in wellness activities at the Don Knabe Wellness Center to restore functioning and quality of life.

Adaptive classes at the wellness center include a gym, a pool, trainers; movement, dance, yoga, Tai Chi; art, performance; activities to improve cognition, communication, social connection; meditation, relaxation, recreation; assistance with benefits, finances, housing, caregiving; volunteer opportunities; and stroke recovery groups.

The Don Knabe Wellness Center
Monday – Friday, 7:00 am – 6:00 pm
Rancho Los Amigos National Rehabilitation Center
7601 Imperial Highway, Downey, CA 90242
(562) 385-6600 ● RLAWellness@dhs.lacounty.gov
The Stroke Recovery Group at the South Pasadena Senior Center

There have been major advances in stroke treatment and what survivors and families can do to get better.

The weekly stroke group educates, supports, inspires and empowers participants to achieve optimal physical, psychological, social and functional recovery.

In the group, survivors and families:

1. Are empowered to restore functioning, independence, quality of life.
2. Know that recovery can be continuous with commitment and effort
3. Select impaired functions they want restore and practice them daily
4. Connect with others and share courage, hope, optimism and progress
5. Move from powerlessness to empowerment, disability to capability
6. Gradually restore functioning, capabilities, independence, self-identity
7. Proactively seek medical care and follow directions to protect health
8. Practice self-care; make changes in lifestyle; manage stroke risk factors
9. Use community resources to support and enrich our recovery and lives
10. Enjoy life and the portion of the glass that is filled

**Location:**
South Pasadena Senior Center
1102 Oxley Street
South Pasadena, CA 91030

**Time:**
Tues. from 11 AM to 12:30 PM.
On the 2nd Tues. of the month, we meet at Huntington Hospital

(310) 575-1699 ● recovery@strokesocal.org
Valuable Community Resources Empower Stroke Survivors and Families

Enjoy Wellness with Lineage
Parkinson’s Disease Stroke TBI MS

∞ Dance for Joy  Wednesday at 2pm - Saturday at Noon - FREE
A specialized dance class for adults with neurological challenges designed to focus your mind and body to move with purpose, creativity, musicality & grace. Classes provide a joyful experience that enhances one’s balance, while simultaneously developing control and freedom of the participant’s movement.

∞ Out Loud  Wednesday at 1pm $5 Donation suggested
Breathe, Talk, and then Sing! This class focuses on the fundamentals of each while improving pulmonary function, projection, and articulation.

∞ Foundations/Tackling Everyday Movement  Tues & Thurs at 1pm- FREE
The Foundations Class lays a base for people who face movement challenges. This class will be spent rigorously practicing specific exercises that target foundational motor skills like walking, sidestepping, turning, and reaching.

<table>
<thead>
<tr>
<th>Sunday</th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
<th>Saturday</th>
</tr>
</thead>
<tbody>
<tr>
<td>1pm</td>
<td>Out Loud</td>
<td>1pm</td>
<td>Foundations</td>
<td>2pm</td>
<td>Foundations</td>
<td>Noon</td>
</tr>
<tr>
<td>Foundations</td>
<td>Tackling Everyday Movement Joy</td>
<td>Dance for Joy</td>
<td>Tackling Everyday Movement</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

All Classes Are Open to All Abilities – Work Seated or Standing
For more information email amybuilds@gmail.com

Lineage is dedicated to making the arts accessible to all, regardless of age, ability or background. We are a non-profit 501c3 and this programming is supported in part by the Tournament of Roses Foundation.

If you appreciate this programming and would like to support its future, click the "Donate to Lineage" button at the bottom of this page.

Lineage / 89 S. Fair Oaks Ave. / Pasadena, CA 91105 / 626-844-7008

Through funds raised by Moving Day Los Angeles, A Walk for Parkinson’s, Dance For Joy classes are free to the public! Lineage is grateful to the Parkinson’s Foundation for their support!

Parkinson’s Foundation

626-844-7008
Fair Oaks Ave. / Pasadena, CA 91105

DONATE TO LINEAGE
follow us:  Facebook  Twitter  Instagram
Online Posting of Stroke Groups and Services in Southern California

The Stroke Association wants survivors and families to know about your groups and services. Please use this fillable form to update changes. Also, survivors, families and stroke professionals are invited to identify groups and services they found to be helpful.

<table>
<thead>
<tr>
<th>County</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>City/Zip</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Region (For example: “San Fernando Valley”)</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Group or Provider Name:</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Description of group or services:</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Street Address:</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Location (building, room):</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Day and Time</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Contact Name:</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Contact Phone Number:</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Contact Email Address:</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Additional Information:</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Date of Update:</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

Thank you for this information. This is an effective and efficient way identify groups and services. Please complete and send the form to our website at strokesocal.org or email the form as an attachment to recovery@strokesocal.org. Also, update the form as needed.
Stroke Services in Your Community
Contents

The New Stroke Paradigm – Page 3
The Power of Community – Page 7
Prevention through Wellness – Page 13
Call 911 - Every Minute Counts – Page 21
Empowerment after Stroke – Page 25
Psychological and Social Recovery – Page 37
SASC Stroke Recovery Groups and Community Resources – Page 43
Stroke Services in Your Community – Page 53
Author – Page 57
Stroke Services in Your Community

This is an invitation to support and participate in universal wellness, stroke prevention, treatment, rehabilitation and recovery in your community.

The National Institutes of Health and other research agencies, the American and National Stroke Associations, accredited stroke centers and rehabilitation facilities all provide crucial stroke services, yet research, medicine, therapy and media can only do so much. For optimal outcomes, participation of individuals, families and communities is essential.

Emergency medical care can now restore blood flow to the brain and stop, reduce or reverse the injuries of stroke, but success in treatment depends on immediate recognition of signs and symptoms, a call to 911 and specialized care at a stroke center.

After acute and subacute treatment, continued progress in stroke recovery depends on what survivors and families do for themselves and how services in the community educate, guide and support them.

The Stroke Association of Southern California has created an innovative model to support universal wellness, illness prevention, stroke treatment and recovery. (Please read “The New Stroke Paradigm.”) This modality can only succeed with the enthusiastic participation of individuals, families and communities.

1. Individuals and families practice self-care to protect themselves from stroke and other illness and promptly call 911 in case of medical emergencies.

2. Experienced survivors and families serve as guides and advocates, and provide support, example and inspiration in the hospital, home and community.

3. Health professionals and facilities contribute their expertise to universal wellness and prevention, stroke treatment and recovery in the community.

4. Concerned civic, educational, business and religious organizations contribute their administrative, financial and marketing expertise, skills and resources.

5. Individuals and families who are professionally, socially and financially willing and able to do so use their connections and resources to sustain specific projects.

The Stroke Association of Southern California needs your support and participation to help individuals, families and communities protect their health and recover from stroke.

Your support and participation will make a difference

The New Stroke Paradigm ● Page 55
(310) 575-1699 ● strokesocal.org
What we can do together

The services of the Stroke Association (SASC) could be expanded to more communities with your support. We ask concerned individuals and families; healthcare professionals, providers and payers; local government, civic minded agencies and businesses, education and religious organizations to support stroke services in your community.

1. The Stroke Association enlists people and organizations in the community to support universal wellness, stroke prevention, treatment and recovery.

2. SASC creates and presents focused education modules for the public, professionals, hospitals, inpatients, outpatient survivors and families.

3. Experienced survivors, families and stroke groups inform the public about stroke and its role and responsibilities in wellness, prevention, treatment and recovery.

4. To prevent stroke, participants in wellness classes learn to practice self-care, healthy lifestyle, risk factor management and to access proactive medical services.

5. In case of stroke, class participants learn to recognize stroke signs and symptoms, to immediately call 911 and go to a stroke center to restore brain circulation.

6. After stroke onset, stroke survivors and families are formally educated about stroke and prepared for their role and responsibilities in each stage of recovery.

7. After acute and subacute care, recovery continues with periodic rehabilitation, weekly functional exercise classes and daily practice of targeted functions.

8. Weekly recovery groups educate, support and inspire participants as they progress in physical, psychological and social recovery.

9. To assure continuity of care, professionals and facilities prepare survivors and families for transition from one stage of recovery to the next.

10. In a thorough review, progress and outcomes are regularly evaluated, and survivors and families are guided to optimal recovery and health.

The modest cost of these services could be sustained by contributions of concerned individuals, families, businesses and agencies within a community. Services could also be supported by the equivalent of co-payments from participants who are able to pay.

It is also in the interest of providers and insurers to support these low-cost services, for as they improve health, they also reduce subsequent illness and expense. The medical cost savings of one participant could pay the annual program costs of one community.

Millions are spent on research and treatment during the first six months of stroke. Can we also invest in the first years of stroke since we now know that recovery is continuous?
Author
Contents

The New Stroke Paradigm – Page 3
The Power of Community – Page 7
Prevention through Wellness – Page 13
Call 911 - Every Minute Counts – Page 21
Empowerment after Stroke – Page 25
Psychological and Social Recovery – Page 37
SASC Stroke Recovery Groups
and Community Resources – Page 43
Stroke Services in Your Community – Page 53
Author – Page 57
About Reams Freedman
Director

In 1998, I had a severe stroke that was difficult because I knew nothing about stroke and I was afraid my life was over. Fortunately, I joined the weekly stroke group at UCLA that provided vital education and support. It was very helpful to connect with other stroke survivors and their families.

As I learned and grew, I eventually became facilitator of stroke groups at UCLA and at Rancho Los Amigos National Rehabilitation Center. In 2006, I became director of the Stroke Association of Southern California.

Here is information about my personal and professional experience and credentials. For over thirty years, I worked in various jobs in the healthcare industry, as a paramedic, health educator, family therapist, clinical supervisor and hospital manager, in public and private, inpatient and outpatient, profit and non-profit, provider and payer settings.

My degrees are a B.A. in Health and Safety Studies and an M.A. in Human Development. My professional credentials are as a Licensed Marriage and Family Therapist and as a California Community Colleges Instructor in Health and Physical Care Services.

I learned about healthcare through my education and profession. I learned something about life from illness and recovery. After life-changing strokes, others and I formed the UCLA Stroke Groups. Together, we discovered we have choices in how to respond to illness. While we may have limited control during the acute phase of illness, we do have significant control over our subsequent progress, daily life and ultimate outcome.

As we passed through stages of uncertainty, challenge, and healing, we each found within us courage, patience, determination, adaptability, love for others and life, and will to live and thrive. We discovered we are stronger than we thought.

In 1998, I was unprepared for stroke. I now know that stroke can be prevented, successfully treated, and that a satisfying and meaningful life is possible for both survivors and their families, and that prevention, rehabilitation and recovery are more enjoyable and productive when done with others.

At the Stroke Association, no one faces stroke alone
Lessons from Stroke
Reduction and Recovery

One way to describe stroke is as a process of reduction. The injury of stroke reduces life to something less than it was. We are unable to function and live as we once did. There are feelings of loss and we may feel that our fate is sealed. In my case, after a severe stroke, I believed my life was over and I was very depressed.

What I’ve learned since is that, paradoxically, stroke can also reduce our lives to something more. In the culinary arts, the process of reduction brings out full flavor and enjoyment of food. It may seem improbable but the same thing can happen after stroke. In recovery, life can be distilled or refined to its most precious qualities and experiences.

“Shakespeare in Love”

I knew little about stroke when I had one. I now know that recovery is a process of gradually moving from powerlessness to empowerment, disability to capability, hopelessness to hopefulness, pessimism to optimism, loneliness to connection, loss to love, fear to courage, anger to gratitude, depression to passion, and to satisfying and meaningful life.

And this transformation takes place through continuous education, guidance, interpersonal connection, support, encouragement, example, human spirit, courage, determination and practice,

I am now able to enjoy life daily, even as I recover. I don’t have to wait for future events or accomplishments. Each day, I focus on my capabilities and opportunities, with little thought of limitations, and even when I am confronted by disabilities, my life has improved quality and deeper meaning than before the stroke.

Illness and recovery lead me to richer experience of life.