

INFORMATION PACKET



August 2018

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WELCOME!!

We are here to support you!! Our survivors/caregivers groups have met continuously for over 30 years.

We know you are overwhelmed and have lots of questions.

And we are here to HELP!

This packet offers information and ideas to better understand stroke in order to assist those living with stroke to optimize their quality of life.

We meet here every Tuesday morning from 10 – 11:30 a.m., except during the months of April, August, and December.

Stroke Support Association

Meeting Location

3759 Orange Ave.
(California Heights United Methodist Church)
Long Beach, CA 90807

Mailing Address

P.O. Box 8340
Long Beach, CA 90808

Please read in a quiet moment:

Highjacked to Holland

When you're going to have a baby, it's like you're planning a vacation to Italy. You're all excited . . . seeing the Coliseum, the Michelangelo, the gondolas of Venice. You get a whole bunch of guide books, you learn a few phrases in Italian, so you can order in restaurants and get around the town. When it comes time, you excitedly pack your bags, head for the airport and take off . . . for Italy. Only when you land, your stewardess announces, "Welcome to Holland." You look at one another in disbelief and shock, saying "Holland? What are you talking about . . . Holland? I signed up for Italy." But they explain that there's been a change of plans and the plane has landed in Holland, and there you must stay. "But I don't know anything about Holland. I don't want to stay here," you say. "I never wanted to come to Holland. I don't know what you do in Holland, and I don't want to learn." But you do stay, and you go out and you buy some new guide books. You learn some new phrases in a whole new language, and you meet people that you never knew existed. But the important thing is that you are not in a filthy, plague infested slum full of pestilence and famine. You are simply in another place, a different place than you'd planned. It's slower paced than Italy, less flashy than Italy, but after you've been there a little while and you have a chance to catch your breath, you begin to discover that Holland has windmills, Holland has tulips, and Holland even has Rembrandts. But everyone you know is busy coming and going to and from Italy, and they're all bragging about what a great time they had there. And for the rest of your life you will say, "Yes, that's where I was going; that's where I was supposed to go' that's what I had planned." And the pain of that will never, ever go away. And you have to accept that pain, because the loss of that dream, the loss of that plan, is a very, very, significant loss. But if you spend your life mourning the fact that you didn't get to Italy, you will never be free to enjoy the very special, the very lovely things about Holland.

By

Shirle Gottlieb, Caregiver
Long Beach, California

13 Cardinal Caregiver Commandments

1. Don't dwell on the past; live in the present one day at a time. Concentrate on where you are, not where you aren't!
2. Be realistic in your expectations. Turn your back on "if only" or "what might have been." They are killers.
3. Join a support group and be an active participant; benefit from others with similar experiences.
4. Learn everything you can about your loved one's disorder. Ask questions. Knowledge is empowering.
5. Don't be reticent to ask for outside help when you need it.
6. Never allow yourself to become isolated behind closed doors; invite family and friends into your home.
7. Keep family informed and involved in the disabled person's (use stroke survivor's instead?) healing process.
8. Do something personal for yourself every day; get out of the house at least once a week.
9. Take time out for your own personal health (i.e. nutrition, exercise, appearance, and relaxation, intellectual and emotional growth).
10. Never be afraid of anger, frustration or guilt. These are expected responses to catastrophic illness. Accept them as normal and learn how to manage them constructively.
11. Work for quality of life within your new parameters.
12. Don't lose your sense of humor. Laughter works miracles.
13. Live each day to the fullest.

By Shirle Gottlieb, Caregiver
Long Beach, California

Ten Guidelines for Interacting with a Stroke Survivor

1. Treat me the same way as you did before my stroke – I am the same person.
2. Every stroke is different, therefore every stroke survivor is different. Common impairments for stroke survivors are: vision, balance, speech, hearing, and weakness or paralysis on one side.
3. Some stroke survivors have difficulty communicating verbally as well as reading, writing, spelling, and understanding what is being said. This is call **aphasia**. Our brains have been rewired which affects our communication. So, we need you to give us enough time to respond. Talk slowly, offer at times to repeat yourself. Be patient when trying to communicate with us. It is okay to help us find a word when we are having trouble.
4. There are other ways of communication besides words: Gestures, facial expression, body language, pictures, pen and paper.
5. Treat us like adults and not children. Speak directly to us, not our spouse or friend. Don't talk like the stroke survivor isn't there. Laugh with us, not at us.
6. Give the stroke survivor a chance to be independent. Ask before you help them. Follow his/her instructions for initiating the help.
7. Many stroke survivors have problems with balance. A rough pat on my back, shoulder, or arm can easily set us off balance and can hurt me. Be gentle and understand that it can take a lot of concentration to walk, especially on uneven surfaces.
8. Wheelchair and walker are extensions of us. Please respect out space. If you bump the chair, please say excuse me. Please don't lean on a wheelchair.
9. Talk to use at eye level when possible when we are in a wheelchair. You can also back up a few feet to make it easier for a person in a wheelchair to look at you.
10. When we are tired and/or frustrated, ALL of our basic skills (i.e. talking, walking, handwriting, and concentration) diminish. If we are more agitated that usual, we are probably tired or frustrated!

Have patience and encourage us to rest or “take a break” when appropriate.

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Dealing with the Survivor's Doctor

By Art Gottlieb

As a caregiver your life has been turned around in a way you could never have imagined. Understanding stroke and the medical profession can help you through this difficult time. On behalf of the person you care for, one of the most important things to keep in mind is that stroke survivors get better every day so long as they work at adapting to their losses or retraining the brain to correct the damage. Improvement can continue for the life of the injured person.

The initial treating doctors deal with the patient during the acute stage of a stroke, and once the emergency is over, they rarely follow the patient for the many months and years of slow improvement. For most people our doctor is close to God, not to be questioned or doubted about whatever advice is given, whether in prescription form or general health information. But, when it comes to the field of stroke, what many doctors advise must be taken with a huge grain of salt. An exception to this general rule is a relatively new field of medicine: the doctor of therapy called a physiatrist. Physiatrists specialize in rehabilitative therapy and supervise the rehabilitation team.

The most trustworthy stroke advice among medical practitioners usually comes from the therapists: whether occupational, physical, or speech. They are the ones who deal with survivors for many weeks and even years after the doctors have handled the acute stage.

Too many doctors state that after the first six months there will be no further improvement. As stated above this advice is simply NOT TRUE. The greatest amount of improvement occurs during those months, but it doesn't end there.

The best approach to a doctor's advice is to become knowledgeable about the field of stroke medicine. You don't have to become an expert, but in the stroke field there is a great deal of information available in pamphlet form. Of great importance is for you to have enough knowledge so that you can ask questions about whatever the doctor advises. Do not be afraid to ask. As with any professional, there is a duty to the patient or caregiver to clarify any procedure or use of a drug. Just as an example, many doctors automatically prescribe Dilantin for all patients. If that happens to your family member, ask why it is necessary for how long the drug is to be taken.

As valuable as the literature is, what is invaluable is the advice you will receive in a stroke support group. All of the caregiver members have been down this tough road, and problems that seem insurmountable to you may be solved by asking the members and benefiting from their experience.

Three Difficult Periods with Stroke

Coping with the recovery after stroke can be the most demanding experience of one's life. Awareness of different phases in recovery may help to ease the difficulty.

The Acute Period: Immediately after the stroke, many people believe "it will all go away". The patient may not fully appreciate the impact the stroke will have on his or her life. This time is most difficult for the spouse, family member or significant other, the "designated caregiver." The caregiver tends to feel very much alone and overwhelmed with the decisions and sudden changes the stroke has brought about.

Suggestions: Try to focus on one day at a time. The spouse needs to seek out information from the medical and paramedical professionals and to persist until his or her questions are answered. Accompany the stroke survivor to therapies whenever possible to gain understanding of the therapeutic and recovery process. Talk with other spouses/caregivers of stroke patients. Stroke caregiver support groups are usually very helpful in offering support, hope and information.

The Discharge from the Hospital: Whether the discharge is to home or to an extended care facility, the second difficult period begins with the discharge. The recovery is not as complete as that expected by the stroke survivor or the caregiver. More losses may become evident. Symptoms of depression may be evident. Added duties and demands for the caregiver may result in serious fatigue.

Suggestions: The spouse/caregiver should know that depression after stroke is "normal" for the stroke survivor when it is recognized that some of the changes and losses from the stroke may not go away. The spouse needs to encourage (or demand) that the survivor continues daily self-care which was demonstrated during therapies. In the long run, the more independent a person can become, the better the adjustment to life after stroke. It is at this time when unnecessary dependence and/or over-protection can develop which are detrimental to optimum recovery.

This post-discharge period is critical, as it sets the precedent for the future survivor-spouse (- caregiver) relationship. It is helpful to deal with these issues with others living with changes from stroke, such as with a stroke support group.

The Adjustment Period: The third difficult period comes six months to nine months after the stroke (or less depending on the individual's pre-stroke coping skills). Improvement from the stroke continues, however it is very slow (often imperceptible at times). Therapies have discontinued and one comes to more fully appreciate the losses: physical, communicative, vocational, financial and social. The spouse or family member realizes these changes as well as the toll that his or her additional responsibilities are taking on their own energy and on her or his mental and perhaps physical health.

Three Difficult Periods with Stroke (continued)

Suggestions: The stroke survivor needs to know that recovery can continue for a long time. He or she needs to find ways to enjoy life within the limits determined by the stroke. It is time to live again. Ultimately it is the survivor's own responsibility to find ways to make life enjoyable and meaningful again. Stroke groups with peer support can be especially valuable during this adjustment.

The spouse/family member needs to find activities that are personally enjoyable and fulfilling. Too much togetherness after a stroke can be wearing on even the best of relationships. Time spent apart with friends and contacts outside the home can greatly improve the quality of time spent with the stroke survivor.

There is life after and with stroke!

By Marianne Simpson, MA, CCC
Stroke Support Association
Long Beach, California

15 Things Caregivers Should Know After a Loved One Has Had a Stroke

1. **It's better to find out than miss out.** Be aware of the medications that have been prescribed to your loved one and their side effects. Ask of your home should be modified to meet the specific needs of the stroke survivor. Ask a doctor, nurse or therapist to clarify any unanswered questions or to provide written information that explains what occurs after the stroke and during recovery of rehabilitation.
2. **Reduce risks, or stroke may strike again.** Survivors who have had one stroke are at high risk of having another one if the treatment recommendations are not followed. Make sure your loved one eats a healthy diet, exercises (taking walks is great exercise), takes medications as prescribed, and has regular visits with their physician to help prevent a second stroke.
3. **Many factors influence recovery.** Recovery depends on many different factors: where in the brain the stroke occurred, how much of the brain was affected, the patient's motivation, caregiver support, the quantity and quality of rehabilitation, and how healthy the survivor was before the stroke. Because every stroke and stroke survivor is unique, avoid comparisons.
4. **Gains can happen quickly or over time.** The most rapid recovery usually occurs during the first three to four months after a stroke, but some stroke survivors continue to recover well in the first and second year post-stroke.
5. **Some signs point to physical therapy.** Caregivers should consider seeking assistance from a physical or occupational therapist if their loved one has any of these complaints: dizziness; imbalance that results in falls; difficulty walking or moving around in daily life; inability to walk six minutes without stopping to rest; inability to do things that he/she enjoys like recreational activities or outings with family or increased need for help to engage in daily activities.
6. **Don't ignore falls.** Falls after stroke are common. If a fall is serious and results in severe pain, bruising or bleeding, go to the Emergency Department for treatment. If a loved one experiences minor falls (with no injury) that occur more than two times within six months, see your physician or the physical therapist for treatment.
7. **Measuring progress matters.** How much acute rehabilitation therapy your loved one receives depends partly on his/her rate of improvement. Stroke survivors on an acute rehabilitation unit are expected to make measurable functional gains every week as measured by the Functional Independence Measure Score (FIMS). Functional improvements include activities of daily living skills, mobility skills and communication skills. The typical rehabilitation expectation is improving 1 to 2 FIM points per day.

15 Things Caregivers Should Know After a Loved One Has Had a Stroke (continued)

8. **A change in abilities can trigger a change in services.** Medicare coverage for rehabilitation therapies may be available if your loved one's physical function has changed. If there appears to be improvement or a decline in motor skills, speech or self-care since the last time the patient was in therapy, he/she may be eligible for more services.
9. **Monitor changes in attitude and behavior.** Evaluate whether your loved one is showing signs of emotional lability (when a person has difficulty controlling their emotions). Consult a physician to develop a plan of action.
10. **Stop depression before it hinders recovery.** Post-stroke depression is common, with as many as 30-50 percent of stroke survivors developing depression in the early or later phases post-stroke. Post-stroke depression can significantly affect your loved one's recovery and rehabilitation. Consult a physician to develop a plan of action.
11. **Seek out support.** Community resources, such as stroke survivor and caregiver support groups, are available for you and your loved one. Stay in touch with a case manager, social worker or discharge planner who can help you find resources in your community.
12. **Learn ins and outs of insurance coverage.** Be sure to consult with your loved-one's doctor, case manager or social worker to find how much and how long insurance will pay for rehabilitation services. Rehabilitation services can vary substantially from one case to another. Clarify what medical and rehabilitation services are available for hospital and outpatient care. Determine the length of coverage provided from your insurance (private or government supported) and what out-of-pocket expenses you can expect.
13. **Know when to enlist help.** If rehabilitation services are denied due to lack of "medical necessity," ask your loved one's physician to intervene on his or her behalf. Ask the physician to provide records to the insurance carrier and, if needed, follow up yourself by calling the insurance company.
14. **Know your rights.** You have rights to access your loved one's medical and rehabilitation records. You are entitled to copies of the medical records, including written notes and brain imaging films.
15. **Take care of yourself.** Take a break from caregiving by asking another family member, friend or neighbor to help while you take time for yourself. Keep balance in your life by eating right, exercising or walking daily, and getting adequate rest.

American Stroke Foundation. Content reviewed 7/31/2013

Understanding Stroke

Introduction

Stroke is also known as a “**brain attack**”, and it can happen to anyone at any time. A stroke occurs when something cuts off the blood supply to an area of the brain. When blood supply is cut off, the brain cells in that area of the brain are deprived of oxygen and begin to die. When brain cells die, abilities controlled by that area of the brain are lost. This may include such things as memory, speech, muscle movement. How a person is affected by their stroke depends on where the stroke occurs in the brain and how much the brain is damaged. Some people recovery completely, but about 2/3 of stroke survivors suffer some form of disability.

Stroke numbers:

- Each year approximately 800,00 people experience a new or recurrent stroke
- A stroke happens every 40 seconds
- Stroke is the fifth leading cause of death in the U.S.
- Every 4 minutes someone dies from a stroke
- Up to 80% of strokes can be prevented
- Stroke is the leading cause of adult disability in the U.S.
- There are nearly 7 million stroke survivors in the U.S.

Women and stroke:

- Stroke is the third leading cause of death for women
- Each year 55,000 more women have a stroke than men.
- Stroke will have a more negative impact for women than men because in general women live longer than men
- More women will:
 - ✓ Live alone when they have a stroke
 - ✓ Be more likely to live in a long-term health care facility after a stroke
 - ✓ Have a worse recovery after a stroke

(Information is from the National Stroke Association)

If the symptoms last less than 24 hours, the event is called a “**transient ischemic attack**” or **TIA** (transient = temporary, ischemic = inadequate blood supply, attack = sudden onset). They are a warning sign that stroke may happen sometime in the future and should be taken seriously, require prompt medical attention, and not be ignored.

Understanding Stroke (continued)

What interferes with the blood supply to or through the brain?

There are two types of stroke: hemorrhagic and ischemic.

Hemorrhagic strokes account for about 15% of all strokes, though they are responsible for about 40% of stroke deaths.

The most common cause of a hemorrhagic stroke is a ruptured blood vessel within the brain. Blood leaks into surrounding brain tissue (intracerebral hemorrhage) causing brain cells to die. High blood pressure (hypertension) and aging blood vessels are the most common cause.

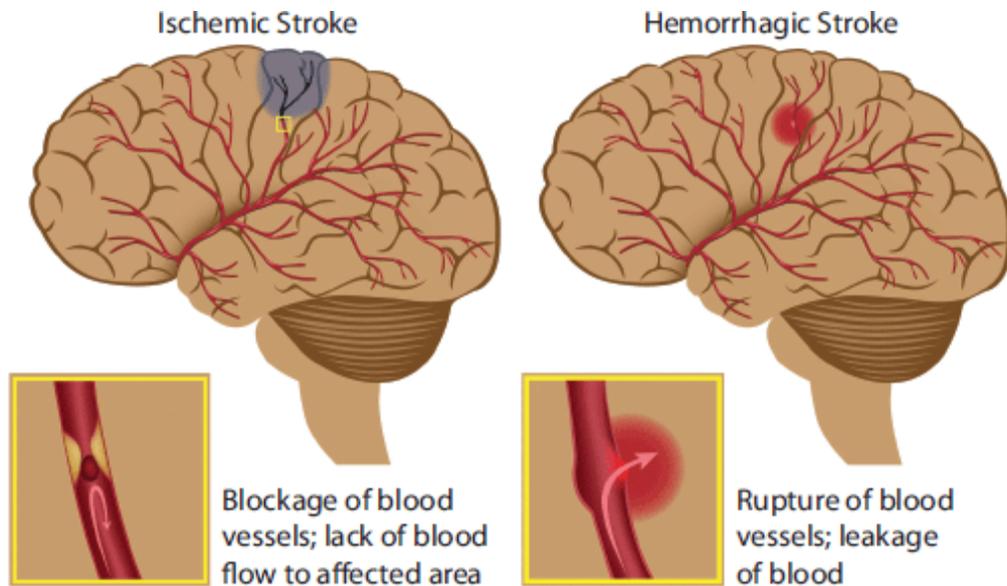
Less common causes of hemorrhagic stroke include a ruptured brain artery aneurysm, an AVM (arteriovenous malformation), bleeding disorders, head injury.

Ischemic strokes account for about 85% of all strokes. They occur in one of two ways:

- a. A blood clot or piece of plaque formed somewhere in the body and traveled to the brain. Once in the brain it traveled until it entered a blood vessel small enough to block its passage. The clot lodged there, blocked blood flow and caused a stroke.

About 15% of these strokes occur in people with a heart arrhythmia called atrial fibrillation (A-fib).

- b. A blood clot formed inside one of the arteries supplying blood to the brain. This clot blocked the passage of blood and caused a stroke. This type is usually seen in people with high cholesterol levels and atherosclerosis.



What is being done about stroke?

Prevention is the most effective treatment for stroke. That is, prevention of the event itself or prevention of an extension of brain damage following stroke. The most meaningful efforts in prevention of stroke are up to us. These include: controlling high blood pressure (hypertension), cessation of smoking, maintaining low cholesterol levels and normal weight through healthy eating habits and regular physical exercise, and treatment of heart disorders, such as atrial fibrillation. The most recent efforts in treatment after stroke has occurred is in administration of a “clot-busting” drug now being offered in many medical centers as well as interventional radiology procedures which “retrieve” or pull the clot out of a blood vessel.

What are the effects of stroke?

Strokes affect a broad spectrum of life including physical capacities, vision, communication abilities including speaking, comprehending, reading and written language, calculation, information processing, social sensitivity, vocation and earning power. A stroke may result in:

- **Lability** – reduced control over emotions such as crying easily
- **Fatigue** – need for more sleep and rest; easily overwhelmed with stimulation such as more than thing to pay attention to. This is often underappreciated by both the stroke survivor and by family members/caregivers
- **Frustration** – impatience with self and losses and changes from stroke that make simple daily activities difficult
- **Anger** – with losses from the stroke and life with stroke. This may appear as short temper, often directed toward those who are closest, or a withdrawal into depression

Understanding Stroke (continued)

- **Depression** – deep sadness, a mourning, in reaction to the changes from the stroke. Professional help may be needed or assistance from others living with stroke in a stroke support group
- **Self-centeredness** – egocentricity, partly due to having experienced a life-threatening illness and concern about one's health. This may be related to pre-stroke personality, and possibly due to brain damage affecting social sensitivity.
- **Seizures** – a seizure disorder may occur following a stroke. This only occurs in approximately 25-30% of people with a stroke. The first seizure usually occurs within 9 months to 2 years after the stroke and, with medication to minimize the occurrence of seizures, usually does not continue beyond 3 years.

Understanding the Effects of Stroke

What are the possible effects of a stroke on the **LEFT** side of the brain?

1. **Right** sided weakness or paralysis
2. **Alteration in feeling** or **sense of touch** on the **right** side of the body
3. **Right** sided blindness
4. **Aphasia**, a disturbance in:
 - ✓ Understanding spoken words
 - ✓ Finding or formulating words for speaking
 - ✓ Reading
 - ✓ Writing
 - ✓ Use of numbers and calculations

What are the possible effects of a stroke on the **RIGHT** side of the brain?

1. **Left** sided weakness or paralysis
2. Reduced awareness or “**neglect**” of the left space and left side one’s own body
3. **Blindness** on the **left** side
4. Other **visual** disturbances such as:
 - ✓ Visual recognition
 - ✓ Difficulty in relating parts of an object or an event one watches
 - ✓ Difficulty in relating clothes to one’s own body for dressing
5. Difficulty remembering the **special layout** (topographical map) of places. May get lost, even in familiar places.
6. **Disturbed ability** to fully or consistently **appreciate the extent** or the implication of **one’s own disabilities**.
7. May **talk too much** or be **self-centered** in topics of conversation. May not be able to anticipate or appreciate the effect of their communication on others - **what** one says or **how** it is said.
8. May not believe what other people tell them because their own **information processing** (what their own brain tells them) is faulty.
9. **Difficulty keeping more than one** aspect of a conversation, situation or sequence of events in mind. Difficulty following or attending to a conversation or story line.
10. May have **difficulty remembering** things (partly due to #9 above).
11. Disturbed ability to judge **passing of time**.
12. Difficulty sizing up a situation or **drawing conclusions** from several facts. May have difficulty **going through several steps** in order to solve a problem.

Stroke and Relationships

How is the spouse or significant other and the relationship affected by the stroke?

The spouse or significant other must deal with changes in:

- Role: in the household and in the relationship
- Responsibility: for the household, healthcare, and caring for the stroke survivor
- Less time for one's self
- Reduced social support and social contacts
- Reduced quality of interpersonal relationships
- Reduced emotional support from others, especially the stroke survivor
- Reduced ability to pursue personally satisfying activities
- Increased physical demands

These, and other changes, over an extended period of time often result in onset of depression and, eventually the stroke caregiver's own health may suffer.

What helps?

- Seek information about stroke to understand the residuals in the stroke survivor
- Attend a stroke family/caregiver support group as soon as possible and for as long as needed
- Talk with others living with a stroke, particularly those that are encouraging and uplifting
- Share your own feelings honestly with the stroke survivor
- It is essential that the family/caregiver take some time to do something that is personally enjoyable and fulfilling. This is difficult to do at first, but must be phased in in increasing amounts of time for the family/caregivers own mental health
- Take care of your own health. Regular check-ups, good nutrition and regular exercise.

Special Needs Fund

The Stroke Support Association maintains a special needs fund which is reserved for the exclusive use of our current and active stroke support group members who have an identified financial need which they are unable to meet on their own.

Special needs may include adaptive medical devices like a leg or arm brace, adaptive devices to enable a disabled person to drive, funding to attend a stroke related workshop or other stroke related expenses.

A recent example of use of this fund occurred when a stroke survivor, whose income was extremely limited due to his stroke, suffered a flood in his house due to a broken water heater. He was unable to afford to clean his carpets which were moldy and created a health hazard. The special needs fund was used to pay for the carpet cleaning.

Current, active Stroke Support Association stroke support group members may apply for special needs assistance by speaking to a group facilitator and requesting a Special Needs Application which must be filled out and returned to the facilitator. The Special Needs Committee will be convened to determine if the request qualifies for funding.

Due to limited funding, the Special Needs Funding are limited to one-time expense and not designed to pay for ongoing expenses of daily living.

Resources You May Find Helpful

Support Groups

Stroke Support Association: Meeting Location - 3759 Orange Ave. (California Heights United Methodist Church), Long Beach, CA. 90807; Mailing Address - P.O. Box 8340, Long Beach, CA. 90808. Support group meets Tuesdays from 10:00-11:30 a.m., except for one month breaks in April, August, and December. www.strokesupportassoc.org

Long Beach Memorial Medical Center, Stroke Survivor Support Group, 2801 Atlantic Ave., Long Beach, CA. 90806. Meets the 1st and 3rd Monday of the month from 4:00-5:00 p.m. Phone: (562) 933-9034. www.memorialcare.org/long-beach-memorial

Government Resources

211 LA County. Information and referral source for all health & human services throughout L.A. County. Phone: 211 or, if outside L.A. County: (800) 339-6993. <https://www.211la.org>

Centers for Medicare and Medicaid Services www.cms.gov

Department of Rehabilitation – An employment and independent living resource for people with disabilities. Phone: (562) 422-8325. www.dor.ca.gov

EDD/State Disability Insurance – Provides partial wage replacement benefits to eligible California workers who are unable to work due to a non-work related illness, injury, or pregnancy. Phone: (800) 480-3287. www.edd.ca.gov

L.A. County Mental Health Dept. – Services include mental health assessment, crisis intervention, case management, medication support, peer support, rehabilitative services, 24 Hour Crisis Hot Line. Phone: (800) 854-7771. http://dmh.lacounty.gov/wps/portal/dmh/our_services

Legal Aid of Los Angeles – Assists low-income individuals with legal advice, advocacy, and legal representation. Phone: (800) 399-4529. www.lafla.org

Los Angeles Caregiver Resource Center – Provides support for caregivers of individuals with neurological conditions with services that help maintain independence. Phone: (855) 872-6060. www.fcscgero.org

Medi-Cal – California program (part of DPSS) to pay for medical care for certain low-income people, families, children, the elderly and people with disabilities. Phone: (877) 597-4777. www.medical.ca.gov/www.dhcs.ca.gov

Medicare. www.medicare.gov Customer Service: (800) 633-4227.

National Institute of Mental Health www.nimh.nih.gov Information Resource Center: (866) 615-6464.

Resources You May Find Helpful (Continued)

Social Security Administration www.ssa.gov Phone: (800) 772-1213. Local office located at 2005 Long Beach Blvd., Long Beach, CA. 90806.

SSI / Supplemental Security Income – A program to assist low-income individuals, including those who are disabled, blind or 65 and over. Benefits are awarded based on need without regard to work history or payroll taxes. Resource limits to be eligible are \$2,000.00 for an individual and \$3,000.00 for couples. Phone: (800) 772-1213.

www.ssa.gov/ssi/text-eligibility-ussi.htm

Local Resources

Center for Health Care Rights “provides free and objective information and counseling about Medicare”, 520 S. Lafayette Park Place, #214, Los Angeles, CA. 90057. Phone: (800) 824-0780 within L.A. County, otherwise phone (800) 434-0222. Local phone: (213) 383-4519. www.healthcarerights.org

Disabled Resource Center, 2750 E. Spring Street, Ste. #100, Long Beach, CA. 90806. Attendant registry, benefits counseling and advocacy, housing information, peer counseling, volunteer services, information and referral. Phone: (562) 427-1000. www.drcinc.org

Family Caregiver Resource Center – Orange County, 130 W. Bastanchury Rd., Fullerton, CA. 92835. Provides individualized, supportive services focusing on caregiver needs. Services include family consultation, assessment, care planning, counseling, referrals, respite planning and community education. Phone: (800) 543-8313 / (714) 446-5030. www.caregiveroc.org

Home Delivered Meals – Recipients must be primarily homebound, often age 65+ Lakewood Home Delivered Meals: Phone: (562) 925-8747. www.lakewoodcity.org
Long Beach Home Delivered Meals: Phone (562) 420-9660. www.mealsonwheelslongbeach.org

Long Beach Memorial Medical Center, 2801 Atlantic Ave., Long Beach, CA. 90806. MemorialCare Senior Plus – “...is a unique program for older adults offered by Long Beach Medical Center making access to health and wellness services, easier. It is a free lifetime membership offering access to a variety of discounts and educational events to older adults who frequently visit the hospital.” Phone: (562) 933-1650. www.memorialcare.org/long-beach-memorial

Multipurpose Senior Services Program (MSSP) “Local MSSP sites provide social and health care management for frail elderly clients who are certifiable for placement in a nursing facility but who wish to remain in the community.” Senior Information Hotline: (800) 510-2020. www.aging.ca.gov/ProgramsProviders/MSSP.

Physical Therapy

Ability First, 3770 E. Willow, Long Beach, CA. 90815. Phone: (562) 426-6161. Offers adult day program, after school program and aquatic programs for children and adults with disabilities. www.abilityfirst.org

California Pools of Hope, 6801 Long Beach Blvd., Long Beach, CA. 90805. Phone: (310) 537-2224. Offers the underserved and underinsured in the community access to wellness programs and nominal-cost warm water exercise and therapeutic activities. www.californiapoolsofhope.org

California State University, Long Beach, Center for Active Aging (formerly Frogs Fitness Wellness Center). Students in the Physical Therapy Department work with those needing assistance in performance of physical exercise. Contact Gloria in the Physical Therapy Dept. for information. Phone: (562) 985-4024. www.csulb.edu

Cerritos College, 1110 Alondra Blvd., Norwalk, CA. 90650. Phone: (562) 860-2451. Disabled Student Programs and Services, including Adaptive Physical Education, offered through the Health, Physical Education and Recreation Division. Courses are designed to offer sedentary or aerobic activities, circuit weight training or swimming for students with disabilities. www.cerritos.edu

Long Beach City College, 4901 E. Carson St., Long Beach, CA. 90808. Disabled Students Programs and Services, including Adaptive Physical Education. Phone: (562) 938-4075 or 4558. www.lbcc.edu

Long Beach Memorial Medical Center, 2801 Atlantic Ave., Long Beach, CA. 90806. www.memorialcare.org/long-beach-memorial Balance and Vestibular Clinic, (562) 933-9001.

St. Jude Medical Center, 101 E. Valencia Mesa Dr., Fullerton, CA. 92835. Phone (714) 871-3280. Rehabilitation, including Physical and Occupational Therapy – Phone: (714) 578-8720 www.stjudemedicalcenter.org

St. Mary Medical Center, 1050 Linden Ave., Long Beach, CA. 90813. Physical Medicine and Rehabilitation Center, including stroke and brain injury. Phone: (562) 491-9000. www.dignityhealth.org/stmarymedical

Veterans Affairs Long Beach Healthcare System, 5901 E. 7th Street, Long Beach, CA. 90822. Phone: (562) 826-8000. www.longbeach.va.gov

Speech Therapy

Cerritos College, 1110 Alondra Blvd., Norwalk, CA. 90650. Phone: (562) 860-2451. Disabled Students Programs and Services, including Adaptive Physical Education, through the Physical Education Dept., ext. 2866. www.cerritos.edu

Coastline Community College, 11460 Warner Ave., Fountain Valley, CA. 92708. Phone: (714) 546-7600. www.coastline.edu Acquired Brain Injury Program is a one-year educational program designed to provide structured cognitive retraining for adults who have sustained a traumatic or non-traumatic brain injury. Classes held in Newport Beach.

Long Beach Memorial Medical Center, 2801 Atlantic Ave., Long Beach, CA. 90806. www.memorialcare.org/long-beach-memorial Rehabilitation Services – Speech and Language Therapy. Phone: (562) 933-9001.

St. Jude Medical Center, 101 E. Valencia Mesa Dr., Fullerton, CA. 92835. Phone (714) 871-3280. Speech and Swallow Therapy – Phone: (714) 578-8706. www.stjudemedicalcenter.org

St. Mary Medical Center, 1050 Linden Ave., Long Beach, CA. 90813. Outpatient rehabilitation offers Speech Therapy as well as OT and PT to those with a wide range of conditions. For more information call: (562) 491-9000. www.dignityhealth.org/stmarymedical

Veterans Affairs Long Beach Healthcare System, 5901 E. 7th Street, Long Beach, CA. 90822. Phone: (562) 826-8000. www.longbeach.va.gov Speech Pathology – dial main number, then extension 5415.

Physical Fitness/Gyms

Goodwill Fitness Center, 1601 East St. Andrew Place, Santa Ana, CA. 92705. Phone: (888) 623-4823 or (714) 361-6180. www.ocgoodwill.org “... designed specifically for people living with physical disabilities or chronic illness.”

Nifty After Fifty, Several locations in Northern and Southern California – check website for location nearest you. Phone: (855) 235-4389. www.niftyafterfifty.com Designed to “... service your fitness and physical therapy needs.”

Transportation Resources for Individuals with Disabilities

CityRide – LADOT Transit “Cityride is a transportation assistance program for individuals age 65 or older and qualified disabled persons in the City of Los Angeles and select areas of Los Angeles County. The program offers Cityride participants reduced costs for the purchase of City of Los Angeles permitted taxi rides and Cityride Dial-A-Ride services.”

From 213, 310, 323 or 818 area codes call: 808-7433.

L.A. County Access Services Access services is the “consolidated Transportation Services Agency (CTSA) for Los Angeles County” www.accessla.org

Reservations (800) 883-295 or

(213) 488-748

Customer Service needs

(800) 827-0829

Orange County Transportation Authority (OCTA) – ACCESS www.octa.net

“OC ACCESS is a shared-ride service that is available to qualified applicants whose physical or cognitive limitations prevent them from utilizing the regular OC Bus fixed-route service.

ACCESS Service

(877) 628-2232

Bus Information

(714) 636-7433

<https://www.ladottransit.com/other/cityride/>

Driving Evaluations

Casa Colina Hospital and Centers for Healthcare, 255. E. Bonita Ave., CA. 91767. Adaptive Driver Program. Phone: (800) 926-5462 or (909) 596-7733, ext. 3500. “Participation in the program is arranged by referral from physicians, hospitals, case coordinators, agencies or vocational counselors. Payment for evaluation and training is on a fee-for-service basis, which may be arranged through Casa Colina.” www.casacolina.org

Cedar-Sinai Medical Center – Outpatient Rehabilitation Services, Driving and Vision Assessment Program, 444 S. San Vicente Blvd., #701, Los Angeles, CA. 90048. “For appointments, a physician's written prescription is needed and may be sent by fax or mail. Prior authorization by the health plan or insurance carrier may also be needed. Following receipt of a prescription by Outpatient Rehabilitation Services, the individual will be contacted to arrange an appointment.” www.cedarsinai.edu

Department of Rehabilitation – Mobility Evaluation Program (MEP), “The Mobility Evaluation Program (MEP) is a section of the Department of Rehabilitation that provides driving evaluations for qualified individuals to help determine their transportation needs.” www.rehab.cahwnet.gov

MEP Office: 5140 Florence Ave., Suite C, Bell, CA. 90201. Phone: (323) 562-1308.

Driving Evaluations (Continued)

Driving Fitness Evaluations (DFE), to schedule an appointment ask your physician for a medical prescription, have the physician fax the prescription and all pertinent medical information including the client's contact information and medical insurance. DFE will setup an appointment for a driving evaluation.

Phone: (562) 268-5314. <http://www.drivingfitnessevaluations.com>

Kanor Driving and Traffic School, 5663 Lincoln Ave., Suite A, Cypress, CA. 90630.
Phone: (714) 821-4578 or (888) 562-6748. <https://kanor.net>

Long Beach Memorial Medical Center, 2801 Atlantic Ave., Long Beach, CA. 90806. Driving Rehabilitation Program. Physician referral required. (562) 933-9084.
www.memorialcare.org/long-beach-memorial

Northridge Hospital Medical Center, 18300 Roscoe Blvd., Northridge, CA. 91325.
Phone: (818) 885-5460. www.dignityhealth.org/northridgehospital

Center for Rehabilitation Medicine – Driver Preparation Program. Physician referral is required. Phone: (818) 885-5460.

Rancho Los Amigos Medical Center, 7601 Imperial Highway, Downey, CA. 90242.
Phone: (562) 401-7022.

Occupational Therapy Driver Rehabilitation Program - Driver Education & Training Program: Phone: (562) 385-7081. www.dhs.lacounty.gov/wps/portal/dhs/rancho

St. Jude Medical Center, 101 E. Valencia Mesa Dr., Fullerton, CA. 92835. Phone (714) 871-3280. www.stjudemedicalcenter.org

St. Jude Centers for Rehabilitation & Wellness – Driving Assessment Program. Physician referral is required. Phone: (714) 578-8706, ext. 2327.

Catalogs/Publications/Website Resources

American Stroke Association www.strokeassociation.org Phone: (888) 478-7653.

Constant Therapy - “highly personalized, continuous therapy tools to patients with traumatic brain injury, stroke, aphasia, and learning disabilities.” <https://www.constantherapy.com> (iPad apps). Phone: (888) 233-1399.

First Street – “innovative products for seniors and their caregivers”
www.firststreetonline.com Phone: (888) 612-7036.

Lingraphica - Provides solutions for those with communication difficulties and disorders due to aphasia, brain injury, and disease. Phone: (888) 274-2742. www.aphasia.com

Catalogs/Publications/Website Resources (Continued)

Live Strong - "helping you live strong every day". Health, fitness, recipe tips.
<http://www.livestrong.com>

Mobul – the home mobility store – medical aids and products. 2153 N. Bellflower Blvd., Long Beach, CA. 90815. Phone: (562) 343-7333 www.mobulstore.com

National Aphasia Association www.aphasia.org

National Caregivers Library – extensive website library for caregivers. Articles, forms, checklists, links to other resources. www.caregiverslibrary.org

National Center on Health, Physical Activity and Disability – "... a public health practice and resource center on health promotion for people with disability" www.nchpad.org

National Stroke Association www.stroke.org Phone: (800) 787-6537.

Performance Health – medical related products. www.performancehealth.com
(800) 323-5547.

Personal Assistance Services Council (PASC) – "the public authority for In-Home Supportive Services (IHSS) in Los Angeles County". ".....the IHSS Program helps pay for services provided to low-income elderly, blind or disabled individuals to hire someone to help them with housework, meal preparation, and personal care."
www.pascla.org Contact number: (877) 565-4477.

Silverts Adaptive Clothing and Footwear www.silverts.com Phone: (800) 387-7088.

Stroke Connection magazine. Subscription free to stroke survivor. Exclusively a digital publication. www.strokeassociation.org

The Stroke Foundation www.thestrokefoundation.com

Stroke Engine Family – Canadian. www.strokeengine.ca

Stroke Family – family assisted speech and recovery. www.strokefamily.org Phone: (855) 585-5350.

Stroke Rehab www.stroke-rehab.com Website about "stroke rehab., treatment and recovery".

Stroke Smart Magazine and eNewsletter www.strokesmart.org Print subscription free to U.S. Residents.

Today's Caregiver – "...national magazine dedicated to caregivers..."
www.caregiver.com

Victory Drugs and Medical Supplies, 16823 Bellflower Blvd., Bellflower, CA. 90706.
Phone: (562) 925-7575 <https://www.victoryhms.com>

Books

Chicken Soup for the Caregiver's Soul: Stories to Inspire Caregivers in the Home, Community and the World, by Jack Canfield, Mark Victor Hansen, and LeAnn Thieman, 2012.

Passages in Caregiving: Turning Chaos into Confidence, by Gail Sheehy, 2011.

Caregiving Wife's Handbook: Caring for Your Seriously Ill Husband, Caring for Yourself, by Diana B. Denholm, 2012.

Stroke Recovery Stories: Humorous and Inspiring Stories Told By Stroke Survivors and the People Who Love Them, by Jeff Kagan, 2015.

The Emotional Survival Guide for Caregivers: Looking After Yourself and Your Family While Helping an Aging Parent, by Barry J. Jacobs, 2006.

Daily Comforts for Caregivers, by Pat Samples, 1999.

The Invaluable Guide to Life After Stroke: An Owner's Manual, by Arthur Josephs, 1992.

Kate's Journey: Triumph over Adversity by Kate Adamson, 2004.

Paralyzed But Not Powerless: Kate's Journey Revisited, 2nd ed., 2008.

Stroke for Dummies, by John R. Marler, MD, 2005.

MY MEDICATION LOG

Your Name: _____

Date: _____

Doctor's Name: _____

Pharmacy Name: _____

Doctor's Phone Number: _____

Pharmacy Phone Number: _____

Medication Name	Why am I taking this medication? Ex.: for my arthritis	How am I taking this medication? Ex.: two pills at lunch	Side effects I am experiencing	Questions for my doctor or pharmacist	When I started taking this medication



POST-STROKE CHECKLIST (PSC):

For Survivors and Caregivers

Many stroke survivors live with problems that could be treated but aren't, because they never tell their doctor about those problems. Fill out this checklist and use it to talk with your doctor about problems you might be having. Read each item and circle the most correct answer.

1. **RECURRENT STROKE PREVENTION** Since your stroke, have you made lifestyle changes to prevent another stroke?

Do you monitor your blood pressure?

Never 1-2 x/Month 1-2 x/Week Always (at least daily)

Do you take medication(s) as prescribed?

Never 1-2 x/Month 1-2 x/Week Always

If overweight, have you lost weight?

No Yes N/A

Do you exercise regularly?

Never 1-2 x/Month 1-2 x/Week Always (at least daily)

Have you stopped smoking?

No Yes N/A

2. **ACTIVITIES OF DAILY LIVING** Since your stroke, is it harder to:

Dress?

Always 1-2 x/Week 1-2 x/Month

Bathe?

Always 1-2 x/Week 1-2 x/Month Never

Eat or prepare meals?

Always 1-2 x/Week 1-2 x/Month Never

Go outside?

Always 1-2 x/Week 1-2 x/Month Never

3. **MOBILITY AND MOVEMENT** Since your stroke, is it harder to:

Walk?

Always 1-2 x/Week 1-2 x/Month Never

Move between bed and chair?

Always 1-2 x/Week 1-2 x/Month Never



Do you fall more easily?

Always	1-2 x/Week	1-2 x/Month	Never
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Get in and out of a car?

Always	1-2 x/Week	1-2 x/Month	Never
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Balance?

Always	1-2 x/Week	1-2 x/Month	Never
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4. **SPASTICITY OR TIGHTNESS** Since your stroke, do you have more stiffness in your:

Arms?

Always	1-2 x/Week	1-2 x/Month	Never
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Hands?

Always	1-2 x/Week	1-2 x/Month	Never
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Legs?

Always	1-2 x/Week	1-2 x/Month	Never
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5. **PAIN** Since your stroke:

Do you have any new pain?

Always	1-2 x/Week	1-2 x/Month	Never
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Do you have pain more often?

Always	1-2 x/Week	1-2 x/Month	Never
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Is your pain more severe?

Always	1-2 x/Week	1-2 x/Month	Never
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6. **INCONTINENCE** Since your stroke, are you having trouble controlling your:

Bowels?

Always	1-2 x/Week	1-2 x/Month	Never
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Bladder?

Always	1-2 x/Week	1-2 x/Month	Never
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7. **COMMUNICATION** Since your stroke, are you having trouble:

Communicating with others?

Always	1-2 x/Week	1-2 x/Month	Never
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Speaking?

Always	1-2 x/Week	1-2 x/Month	Never
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Reading?

Always 1-2 x/Week 1-2 x/Month Never

Using numbers?

Always 1-2 x/Week 1-2 x/Month Never

8. MOOD Since your stroke, are you feeling:

Anxious?

Always 1-2 x/Week 1-2 x/Month Never

Moody or having mismatched and/or unstable emotions?

Always 1-2 x/Week 1-2 x/Month Never

Depressed?

Always 1-2 x/Week 1-2 x/Month Never

Like a different person? Has your behavior changed?

Always 1-2 x/Week 1-2 x/Month Never

9. COGNITION Since your stroke, is it harder to:

Think?

Always 1-2 x/Week 1-2 x/Month Never

Concentrate?

Always 1-2 x/Week 1-2 x/Month Never

Remember things?

Always 1-2 x/Week 1-2 x/Month Never

10. LIFE AFTER STROKE Since your stroke, is it harder to:

Work?

Always 1-2 x/Week 1-2 x/Month Never

Participate in social and leisure activities or hobbies?

Always 1-2 x/Week 1-2 x/Month Never

11. SEXUALITY Since your stroke, are you unhappy with:

Your sexual and intimate relationship?

Always 1-2 x/Week 1-2 x/Month Never

Your sexual functioning?

Always 1-2 x/Week 1-2 x/Month Never



12. RELATIONSHIP WITH FAMILY

Have your relationships with your family or friends become more difficult or stressed since your stroke?

Always

1-2 x/Week

1-2 x/Month

Never

COMPLETED BY: Stroke Survivor Caregiver

(Post-Stroke Checklist was developed by the National Stroke Association and is available on their website: www.stroke.org)