

# INFORMATION PACKET



March 2021

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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 stroke survivor's 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 our space. If you bump the chair, please say excuse me. Please don't lean on a wheelchair.
9. Talk to us 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 than 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 and 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 if 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 or 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.

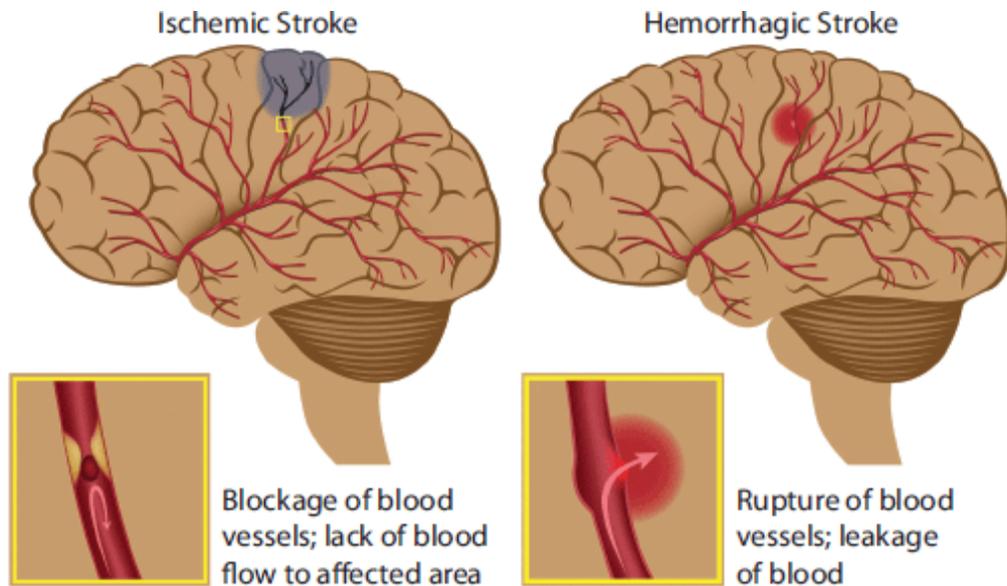
Less common causes of hemorrhagic stroke include a ruptured brain artery aneurysm, an AVM (arteriovenous malformation), bleeding disorders, head injury.

**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 is something 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 a 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 of 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 a 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. Tuesday meetings via Zoom are held in lieu of in-person support groups. Email [info@strokesupportassoc.org](mailto:info@strokesupportassoc.org) by Sunday to receive access instructions on Monday. [www.strokesupportassoc.org](http://www.strokesupportassoc.org).

Long Beach Memorial Medical Center, Stroke Survivors and Caregivers Support Group, held via Zoom. Register by emailing [info@strokesupportassoc.org](mailto:info@strokesupportassoc.org) or call (562) 537-0556. Survivors meet every Tuesday from 10-10:50 a.m. and Caregivers meet every Tuesday from 11-11:50 a.m. [www.memorialcare.org/long-beach-memorial](http://www.memorialcare.org/long-beach-memorial).

### Government Resources

211 LA County. Information and referral source for all health, human & social services in 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](http://www.cms.gov)

Department of Rehabilitation – Provides services and advocacy resulting in employment, independent living and equality for people with disabilities. Phone: (562) 422-8325 or (800) 952-5544. [www.dor.ca.gov](http://www.dor.ca.gov)

EDD/State Disability Insurance – Offers a wide variety of services to Californians. Some offices are closed, or not available for in-person appointment due to the pandemic. Please check the website for specifics. Phone: (800) 480-3287. [www.edd.ca.gov](http://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](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](http://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](http://www.fcscgero.org)

Medi-Cal – California's Medicaid program. A public health insurance program which provides health care services for certain low-income families, the elderly and people

## Resources You May Find Helpful (Continued)

with disabilities. Medi-Cal Helpline: (800) 541-5555 or (916) 636-1980.

[www.medical.ca.gov/www.dhcs.ca.gov](http://www.medical.ca.gov/www.dhcs.ca.gov)

Medicare. [www.medicare.gov](http://www.medicare.gov) Customer Service: (800) 633-4227.

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

Social Security Administration [www.ssa.gov](http://www.ssa.gov) Phone: (800) 772-1213. Local office located at 2005 Long Beach Blvd., Long Beach, CA. 90806. Phone: (888) 256-2631.

SSI / Supplemental Security Income – A program to assist low-income individuals, including those who are disabled, blind or 65 and over. Phone: (800) 772-1213.

[www.ssa.gov/ssi/text-eligibility-ussi.htm](http://www.ssa.gov/ssi/text-eligibility-ussi.htm)

### Local Resources

The California Department of Aging (CDA) administers programs that serve older adults, adults with disabilities, family caregivers, and residents in long-term care facilities throughout the State. The CDA contracts with the network of 33 Area Agencies on Aging, who directly manage a wide array of federal and state-funded services that provide meals, help finding employment; supportive services to assist older individuals as well as younger adults with disabilities to live as independently as possible; promote healthy aging and community involvement; and support family members in their vital care giving role. CDA also contracts with 38 agencies that operate the Multipurpose Senior Services Program through the Medi-Cal home and community-based waiver for the elderly and certifies approximately 242 Adult Day Health Care Centers for participation in the Medi-Cal Community Based Adult Services (CBAS) Program. California Aging and Adult Information Line: Phone: 800-510-2020. [www.aging.ca.gov](http://www.aging.ca.gov)

Center for Health Care Rights (CHCR) is a nonprofit health care advocacy organization. CHCR helps empower elderly and disabled consumers to use Medicare, Medi-Cal and other health benefits as well as to make informed health care choices and take appropriate action to resolve health care problems. Address: 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](http://www.healthcarerights.org)

Cerritos College, 1110 Alondra Blvd., Norwalk, CA. 90650. Disabled Student Programs and Services (DSPS) will become Student Accessibility Services (SAS). Students with limitations due to a disability may receive support services and instruction

## Resources You May Find Helpful (Continued)

from Student Accessibility Services (SAS). Those students with physical, visual, hearing, speech, mental health, learning and intellectual disabilities as well as other health conditions, acquired brain injuries, autism, and ADHD are served. Phone: (562) 860-2451, x 2335. [www.cerritos.edu](http://www.cerritos.edu)

Disabled Resource Center, 2750 E. Spring Street, Ste. #100, Long Beach, CA. 90806. Note: all business is currently being conducted via phone, on-line or by mail. Provides 18 services to people in Artesia, Avalon, Cypress, Hawaiian Gardens, Lakewood, La Palma, Long Beach, Seal Beach and Signal Hill. The agency mission is “to empower people with disabilities to live independently in the community, to make their own decisions about their lives and to advocate on their own behalf.” Phone: (562) 427-1000. [www.drcinc.org](http://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 for resources, respite planning and community education. Phone: (800) 543-8313 / (714) 446-5030. [www.caregiveroc.org](http://www.caregiveroc.org)

Home Delivered Meals – Meals on Wheels of Long Beach delivers cold lunches and hot dinners to isolated elderly, disabled and chronically ill residents, regardless of age, who lack the ability to shop for and prepare their own meals. Long Beach Home Delivered Meals: Phone (562) 420-9660. [www.mealsonwheelsoflongbeach.org](http://www.mealsonwheelsoflongbeach.org)  
Lakewood Meals on Wheels is a nonprofit, volunteer-based organization that provides food to homebound residents living in Lakewood, California and portions of Long Beach and Hawaiian Gardens. Each recipient receives a hot meal for lunch and a sack meal for dinner. Lakewood Home Delivered Meals: Phone: (562) 925-8747.  
[www.lakewoodcity.org/services/human/meals.asp](http://www.lakewoodcity.org/services/human/meals.asp)

Long Beach City College, 4901 E. Carson St., Long Beach, CA. 90808. Disabled Students Programs and Services, coordinates campus-wide academic adjustments for students with qualifying disabilities. LAC Campus - Phone: (562) 938-4558. PCC Campus – Phone: (562) 938-3921. [www.lbcc.edu/disabled-student-services](http://www.lbcc.edu/disabled-student-services)

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](http://www.memorialcare.org/long-beach-memorial)

## Physical Therapy

**Ability First**, Provides a variety of programs designed to help people with disabilities achieve their personal best throughout their lives. There are several locations. The Long Beach Center is located at: 3770 E. Willow, Long Beach, CA. 90815. Phone: (562) 426-6161. [www.abilityfirst.org](http://www.abilityfirst.org)

**California State University, Long Beach**, LifeFit Center located in the Kinesiology Building, is a fee-based program to support active older adults. Learn more about the LifeFit Center at [www.csulb.edu/colleges/chhs/lifefit/index.htm](http://www.csulb.edu/colleges/chhs/lifefit/index.htm) or call (562) 985-2015.

**Long Beach Memorial Medical Center**, 2801 Atlantic Ave., Long Beach, CA. 90806. [www.memorialcare.org/long-beach-memorial](http://www.memorialcare.org/long-beach-memorial). Offers a continuum of rehabilitation services including physical therapy, occupational therapy, speech therapy. Phone: (562) 933-2000.

**Pools of Hope**, 6801 Long Beach Blvd., Long Beach, CA. 90805. Phone: (310) 537-2224. Provides rehabilitation and wellness to children with developmental disabilities, veterans, seniors, and people with disabilities. [www.caaquatictherapy.com](http://www.caaquatictherapy.com)

**St. Jude Medical Center**, 2767 E. Imperial Hwy., Brea, CA. 92821. Rehabilitation (outpatient). Phone: (714) 578-8720 [www.stjudemedicalcenter.org](http://www.stjudemedicalcenter.org)

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

**Veterans Affairs Long Beach Healthcare System**, 5901 E. 7<sup>th</sup> Street, Long Beach, CA. 90822. Phone: (562) 826-8000 or (888) 769-8387.

## Speech Therapy

**Coastline Community College**, 11460 Warner Ave., Fountain Valley, CA. 92708. Phone: (714) 546-7600. [www.coastline.edu](http://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 at Newport Beach Campus, 1515 Monrovia Ave., Newport Beach, CA. 92663.

**Long Beach Memorial Medical Center**, 2801 Atlantic Ave., Long Beach, CA. 90806. Rehabilitation Services – Speech and Language Therapy. Phone: (562) 933-2000. [www.memorialcare.org/long-beach-memorial](http://www.memorialcare.org/long-beach-memorial)

**St. Jude Medical Center**, 2767 E. Imperial Hwy., Brea, CA. 92821. Speech and Swallow Therapy – Phone: (714) 578-8720, ext. 3587. [www.stjudemedicalcenter.org](http://www.stjudemedicalcenter.org)

## Speech Therapy (Continued)

**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](http://www.dignityhealth.org/stmarymedical)

**Veterans Affairs Long Beach Healthcare System**, 5901 E. 7<sup>th</sup> Street, Long Beach, CA. 90822. Speech Pathology - Phone: (562) 826-5415. [www.longbeach.va.gov](http://www.longbeach.va.gov)

## Physical Fitness/Gyms

**Goodwill Fitness Center**, 1601 East St. Andrew Place, Santa Ana, CA. 92705. Phone: (714) 361-6180. [www.ocgoodwill.org](http://www.ocgoodwill.org) "... designed specifically for people living with physical disabilities or chronic illness." TEMPORARILY CLOSED.

**Nifty After Fifty**, Several locations in Northern and Southern California – check website for location nearest you. Phone: (855) 235-4389. [www.niftyafterfifty.com](http://www.niftyafterfifty.com)  
"...a clinically supervised full-body training program for mature adults, created by physicians. Classes being held via Zoom.

## 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, Cityride Dial-A-Ride services and free DASH bus rides." [www.ladottransit.com/cityride](http://www.ladottransit.com/cityride)

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". Phone: (800) 827-0829.

[www.accessla.org](http://www.accessla.org)

### **Orange County Transportation Authority (OCTA) – ACCESS**

"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 Phone: (877) 628-2232. [www.octa.net](http://www.octa.net)

## Driving Evaluations

**Casa Colina Hospital and Centers for Healthcare**, 255. E. Bonita Ave., CA. 91767. Adaptive Driving Program. Phone: (909) 596-7733, ext. 3500. To participate in the Adaptive Driving Program you must have a physician prescription for “Driver Evaluation and Training” and a valid driver’s license or permit. [www.casacolina.org](http://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.” Fax: (310) 423-9222. [www.cedars-sinai.edu](http://www.cedars-sinai.edu)

**Department of Rehabilitation – Mobility Evaluation Program (MEP)**, The Mobility Evaluation Program (MEP) is a part of the Department of Rehabilitation that determines the adaptive driving equipment, vehicle, vehicle modification and training an individual needs to be a safe, independent driver. MEP Office: 5140 Florence Ave., Suite C, Bell, CA. 90201. Phone: (323) 562-1308. [www.dor.ca.gov](http://www.dor.ca.gov)

**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 Comprehensive Driving Evaluation. Phone: (562) 268-5314. <http://www.drivingfitnessvaluations.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](http://www.memorialcare.org/long-beach-memorial)

**Northridge Hospital Medical Center**, 18300 Roscoe Blvd., Northridge, CA. 91325. Center for Rehabilitation Medicine – Driver Preparation Program. Physician referral and valid driver’s license or training permit are required. Phone: (818) 885-5460. [www.dignityhealth.org/northridgehospital](http://www.dignityhealth.org/northridgehospital)

**Rancho Los Amigos Medical Center**, 7601 Imperial Highway, Downey, CA. 90242. Phone: (562) 401-7022. Occupational Therapy Driver Rehabilitation and Training Program. Phone: (562) 385-7081. <https://dhs.lacounty.gov/rancho/patient-programs-and-services/driver-rehabilitation-and-training-program/>

## Driving Evaluations (Continued)

**St. Jude Medical Center**, 2767 E. Imperial Hwy., Brea, CA. 92821. Driver Assessment Program. Physician prescription is required to participate. Phone: (714) 578-8720, ext. 3587. [www.stjudemedicalcenter.org](http://www.stjudemedicalcenter.org).

## Catalogs/Publications/Website Resources

American Stroke Association - [www.strokeassociation.org](http://www.strokeassociation.org) Customer Service: (800) 242-8721.

Constant Therapy – “Speech therapy app designed to help people cope with aphasia, dementia and other speech, language and cognitive disorders caused by stroke or traumatic brain injuries.” [www.constantherapy.com](http://www.constantherapy.com) (iPad apps). Phone: (888) 233-1399.

“Emotions” (EnableMe, Stroke Foundation Australia).

<https://enableme.org.au/resources/emotions>

EnableMe, owned and operated by the Stroke Foundation, Australia, and created specifically for the Australian stroke community. “Enableme is a place to talk to, and seek support from other people who have ‘been there’. It is a place to ask questions, to find the answers that you need and to set recovery goals.” <https://enableme.org.au>

First Street – “Innovative products for seniors and their caregivers”.

[www.firststreetonline.com](http://www.firststreetonline.com) Phone: (800) 704-1209.

“Let’s Talk About Emotional Changes After Stroke (American Stroke Association).

[https://www.stroke.org/-/media/stroke-files/lets-talk-about-stroke/life-after-stroke/ltas\\_emotional-changes-after-stroke.pdf?la=en](https://www.stroke.org/-/media/stroke-files/lets-talk-about-stroke/life-after-stroke/ltas_emotional-changes-after-stroke.pdf?la=en)

Lingraphica – Helps people with speech and language impairments. Phone: (888) 965-6005 or (866) 570-8775. [www.aphasia.com](http://www.aphasia.com)

Live Strong - Health, fitness, and recipe tips. [www.livestrong.com](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. <https://www.mobulstore.com>

National Aphasia Association - [www.aphasia.org](http://www.aphasia.org)

National Caregivers Library – Extensive website library for caregivers. Articles, forms, checklists, links to other resources. [www.caregiverslibrary.org](http://www.caregiverslibrary.org)

## Catalogs/Publications/Website Resources (Continued)

National Center on Health, Physical Activity and Disability – “... a public health practice and resource center on health promotion for people with disability”. Phone: (800) 900-8080. [www.nchpad.org](http://www.nchpad.org)

Performance Health – Rehabilitation and sports medicine related products. Phone: (800) 323-5547. [www.performancehealth.com](http://www.performancehealth.com)

Personal Assistance Services Council (PASC) – “the public authority for In-Home Supportive Services (IHSS) in Los Angeles County”. “Provides services to eligible people over the age of 65, the blind and/or disabled”. Contact number: (877) 565-4477. [www.pascla.org](http://www.pascla.org)

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

Stroke Connection e-news - Monthly publication delivering news, resources and stories for stroke survivors and their caregivers. Exclusively a digital publication. [www.strokeassociation.org](http://www.strokeassociation.org)

The Stroke Foundation – Provides guidance and support for all aspects of recovery to stroke survivors and caregivers. Run entirely by volunteers. [www.thestrokefoundation.org](http://www.thestrokefoundation.org)

Stroke Engine Family – Canadian. “...provides the most current information about intervention and assessment tools used in stroke rehabilitation”. [www.strokingengine.ca](http://www.strokingengine.ca)

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

Stroke Rehab - Website about “stroke rehab., treatment and recovery”. [www.stroke-rehab.com](http://www.stroke-rehab.com)

Today’s Caregiver – “...national magazine dedicated to caregivers...” [www.caregiver.com](http://www.caregiver.com)

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

## Books

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

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.

Daily Comforts for Caregivers, by Pat Samples, 1999.

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

Hope after Stroke for Caregivers and Survivors: The Holistic Guide to Getting Your Life Back, by Tsgoyna Tanzman, 2019.

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, 2<sup>nd</sup> ed., 2008.

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

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

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

# 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](http://www.stroke.org))