Caregivers and Stroke

Taking care of your loved one and yourself
As the primary caregiver for a stroke survivor, you are a very important part of the recovery process. While this role can be very rewarding, it can also be challenging. As you adjust to these life changes, you will have many questions and concerns. This brochure will help you during the recovery journey, with tips on how to improve well-being for both your loved one and you.

Once your loved one leaves the hospital, the primary responsibility for his or her everyday care switches from healthcare professionals to you. It is normal to feel unsure or anxious—developing a new routine and adjusting to the changes brought about by stroke may seem overwhelming.
While the role of a caregiver varies, you may be doing some of the following throughout the recovery process:

- Taking part in informed decision making and treatment planning
- Coordinating appointments with healthcare professionals; helping ensure that medications are refilled and taken properly
- Assisting with walking and transportation
- Helping with everyday tasks such as meal preparation, bathing and toileting
- Monitoring survivor health; being aware of pain, dietary instructions, depression or risk factors that may lead to a second stroke
- Managing financial or legal and end-of-life matters
- Providing encouragement and support for your loved one and family members
- Supporting survivor independence
Encouraging independence is a key part of your role in your loved one’s recovery. The following tips may help survivors maintain their physical and mental health and regain control over their lives.

- **Get support.** Family and friends can help survivors adjust to everyday living, helping with tasks such as meal preparation, correspondence or transportation. A survivor support group provides an outlet to share stories and vent frustrations and is also a way for survivors to remain social.

- **Set measurable goals.** Survivors should set both long- and short-term goals based on their current capabilities. Take pictures/video as reference for improvement. By assessing what they can reasonably accomplish, survivors will be better able to make decisions in their recovery process.
Communicate. Speech and language may be affected when a person suffers a stroke. Survivors should be encouraged to have conversations using fewer words and more gestures as necessary. Communication aids (e.g., cue cards) are also an option depending on the severity of the impairment.

Get dressed. Getting dressed is a way to be independent and maintain self-image. To make it easier, purchase comfortable, loose clothing; replace buttons and zippers with Velcro™ and lay out clothes before wearing.

Stay active. Movement and exercise not only improve health, but may prevent a serious fall and injury if balance has been affected. For those who need a wheelchair, getting outside of the house should be encouraged for general well-being.
Plan meals ahead. Eating healthy and in accordance with medication instructions is an essential part of stroke recovery but may take planning. Purchasing prewashed, precut fruits and vegetables and preparing meals that can be frozen will help keep things simple. Programs like Meals On Wheels can also help.

Pursue interests. Doing things that one enjoys creates balance and alleviates stress. Recreational activities can also help a survivor be active in the community. Remember, most activities can be modified to meet new needs.

Be aware of stroke risk factors. Stroke survivors should always follow the advice of healthcare professionals and make lifestyle changes that may lessen their risk for a second stroke.
Preventing Another Stroke

Of the 795,000 people in the U.S. who suffer a stroke each year, 185,000 (23 percent) have had a previous stroke. As a caregiver, an important responsibility during the recovery process will be to help identify risk factors to avoid a second stroke.

While there are some risk factors that you and your loved one cannot do anything about—such as gender, age, race and family history—there are others that you do have some control over.

- **High blood pressure.** If blood pressure cannot be lowered by diet and exercise changes, seek advice from a healthcare professional.

- **Atrial fibrillation (Afib).** This irregular heartbeat may lead to blood clots, and people with this condition are five times more likely to have a stroke. Common symptoms are heart palpitations, sudden pounding or “fluttering” in the chest and dizziness.
Preventing Another Stroke (cont.)

- **High cholesterol.** A build-up of cholesterol in the arteries may block blood flow to the brain, causing a stroke. If cholesterol cannot be lowered naturally (through proper nutrition, exercise), certain medications may help.

- **Smoking.** Smoking doubles the risk of stroke. If your loved one is a smoker, help support their efforts to quit.

- **Diabetes.** People with diabetes generally have other health problems that make them up to four times more likely to have a stroke.
Caring for the Caregiver

Caregivers may feel more stress than the general population, are twice as likely to become depressed and frequently experience sleep deprivation. However, they are less likely to seek treatment for these conditions.

Keep this in mind: **Caring for yourself is just as important as caring for your loved one.**

- Stress causes increased blood pressure and heart rate.
- Excessive stress puts you at increased risk of heart disease, sleep problems and depression.
- Depression and sleep deprivation interfere with overall quality of life.

Feeling exceptionally tired, irritable or down in the dumps is not “just part of” caregiving. Notice how you are feeling, get regular check-ups and seek counseling for feelings that are overwhelming or draining. Making the time to care for yourself will benefit both you and your loved one.
Caring for the Caregiver (cont.)

10 Tips for caregivers: How to cope

1. **Accept that you cannot do this alone.** Do not feel guilty enlisting the help of friends and family. Assign them specific tasks if they offer to help.

2. **Educate yourself.** Learn about your loved one’s condition and how to effectively communicate with healthcare professionals.

3. **Allow yourself to grieve.** It takes time to accept the loss of your former lifestyle/relationship, but remember that time will also bring about new goals and dreams for you and your loved one.

4. **Learn to relax.** There are many techniques that you can use, from walking or writing to enrolling in a yoga class or practicing meditation.

5. **Eat well.** A diet rich in fruits and vegetables will keep you healthy and energized.
6. **Stay active.** At least 30 minutes of daily exercise can greatly reduce stress, help you maintain a healthy weight and improve your mood.

7. **Have fun!** Take some time to do activities you enjoy. Maintaining your own identity is crucial and will help “recharge” your energy for better care for your loved one.

8. **Stay social.** Make an effort to interact with people. Meet up—and laugh—with your friends.

9. **Find a caregiver support group.** Being around others who are going through similar experiences provides an outlet for sharing ideas, venting frustrations and supporting each other through hardships.

10. **Take things one day at a time.** The future is uncertain—not just for stroke survivors, but for everyone. Focus on the accomplishments of each day, and don’t get carried away with the “what ifs” of the future.
How caregivers fit into the U.S. healthcare system

As a caregiver, you are a crucial extension of the long-term healthcare system. In a survey of 1,480 caregivers, it was reported that:

- On average, caregivers spend 20 hours per week providing care.
- 13 percent of caregivers spend more than 40 hours a week caring for loved ones.
Help for caregivers
- National Stroke Association
  www.stroke.org
- National Family Caregiver Association
  http://thefamilycaregiver.org
- Patient Advocate Foundation
  www.patientadvocate.org
- Today’s Caregiver
  www.caregiver.com

Online communities
- CarelivingSM
  Includes free Careliving Guide and an online social network designed exclusively for caregivers and family members of stroke survivors.
  www.stroke.org/care
- CarePagesSM
  Online community with support tools and a forum to share stories and encouragement
  www.carepages.org
NOTE THE TIME WHEN ANY SYMPTOMS FIRST APPEAR. If given within three hours of the first symptom, there is an FDA-approved clot-buster medication that may reduce long-term disability for the most common type of stroke.

LEARN ABOUT MORE SUDDEN SIGNS OF STROKE AT www.strokeaware.org.
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Learn about more sudden signs of stroke: Warning Signs of Stroke.
National Stroke Association’s mission is to reduce the incidence and impact of stroke by developing compelling education and programs focused on prevention, treatment, rehabilitation and support for all impacted by stroke.

A stroke is a brain attack that occurs when a blood clot blocks an artery or a blood vessel breaks, interrupting blood flow to an area of the brain. Brain cells begin to die.

CALL 9-1-1 IMMEDIATELY IF YOU SEE ONE OR MORE SIGNS OF A STROKE.

1-800-STROKES (787-6537)
www.stroke.org

Supported by Allergan, Inc.
All publications are reviewed by National Stroke Association’s Publications Committee.

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3/12 BG11