After a Stroke

A Guide for Caregivers
Being a Caregiver

Being at home on your own with the new responsibility as “caregiver” can be stressful at first. It is important to take things slowly and keep activities as simple as possible in the beginning. Recovery is a lifelong journey, and information in these pages can help guide you along the way.

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If a survivor has aphasia, family members are encouraged to:

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<th>Action</th>
<th>Reason</th>
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<td>Simplify language by using short, uncomplicated sentences</td>
<td>Repeat the content words or write down key words to clarify meaning as needed</td>
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<td>Maintain a natural conversational manner appropriate for an adult</td>
<td>Minimize distractions, such as a blaring radio, whenever possible</td>
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<tr>
<td>Include the person with aphasia in conversations</td>
<td>Ask for and value the opinion of the person with aphasia, especially regarding family matters</td>
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<tr>
<td>Encourage any type of communication, whether it is speech, gesture, pointing or drawing</td>
<td>Avoid correcting the individual’s speech</td>
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<td>Allow the individual plenty of time to talk</td>
<td>Help the individual become involved outside the home</td>
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<tr>
<td>Seek out support groups such as stroke clubs</td>
<td>Seek help from a speech and language therapist</td>
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New responsibilities

As the caregiver of a person who has had a stroke, you are assuming a new set of responsibilities and facing situations you likely never experienced before. Be patient with yourself and with your loved one. In time, you will both learn to adjust to a “new normal.”

If your loved one doesn’t want to take part in an activity, be sensitive and don’t insist. Many stroke survivors feel better and more energetic during a certain part of the day, so consider scheduling activities during those periods. Offer choices so that your loved one still feels in control, such as asking, “Do you want to do your exercises at 2:00 or 3:00?” instead of saying, “You have to do your exercises now.” During times of tension, a smile or caress can often change the mood.

Communication difficulties

Communication problems are among the most frightening after-effects of stroke for both the survivor and the family. Some stroke survivors are unable to pronounce certain sounds properly because of weakness or problems controlling their face and mouth muscles. If the stroke damaged the language center in the brain, your loved one may have trouble expressing himself or herself or understanding others, a condition known as aphasia. He or she may not make sense when talking, have trouble finding the right words or barely be able to speak at all. He or she may also have trouble reading or writing. Assistance from a speech and language therapist can help you and your loved one learn to communicate more effectively to reduce frustration.

Aphasia therapy strives to improve an individual’s ability to communicate by helping the person to use remaining abilities, to restore language abilities as much as possible, to compensate for language problems and to learn other methods of communicating. Treatment may be offered in individual or group settings. Individual therapy focuses on the specific needs of the person. Group therapy offers the opportunity to use new communication skills in a comfortable setting. Stroke clubs, which are regional support groups formed by individuals who have had a stroke, are available in most major cities. These clubs offer the opportunity for individuals with aphasia to try new communication skills. In addition, stroke clubs can help the individual and his or her family adjust to the life changes that accompany stroke and aphasia.

Family involvement is often a crucial component of aphasia treatment so that family members can learn the best way to communicate with their loved one.

You will notice several changes in your loved one as you both move through the recovery process. The changes may be physical, cognitive or emotional, or may be a combination of these. Strive to be compassionate, patient, tolerant and respectful. This may not be easy. You may need professional help to learn how to manage difficult situations.

Offering choices can help your loved one feel “in control.”

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Behavior changes resulting from stroke

You may notice some behavior changes in your loved one after a stroke. Those changes can result from depression or from the brain damage that occurred during the stroke. Both conditions can be trying for caregivers and family members. You’re encouraged to seek professional help when necessary.

Depression
Depression can surface in many ways. A depressed person may refuse or neglect to take medicine, may not be motivated to perform exercises that will improve mobility, may not eat or sleep, or may be irritable with others. Apathy is a related condition that can show itself in decreased or flattened emotions and motivation.

Depression may dampen the family’s enthusiasm for helping with recovery or drive away others who want to help. This creates a vicious cycle by depriving the stroke survivor of social contacts, which could help dispel the depression. It is sometimes the case that as a person improves from stroke, depression may lift by itself. However, depression can become serious enough to impair functioning.

Caregivers and family members of stroke survivors are also at risk of depression, so keep an eye on yourself and others in the family who may be having trouble adjusting to a new reality.

It is important to know the warning signs of depression so that you can get help.

Cognitive impairments
Depending on the location in the brain, stroke can cause a variety of cognitive impairments.

Memory loss
Some changes in behavior, such as memory loss, can be so subtle you may not recognize them at first. The stroke survivor may be anxious and cautious, needing a reminder to finish a sentence or to know what to do next. Some people have difficulty with numbers and calculating. They can no longer handle money or balance a checkbook. Family and friends may need to learn to keep things in the same place, do things in the same sequence and tell the person in advance what is going to happen. You may even have to take over some responsibilities. Memory loss can be hard to accept and frustrating for both the stroke survivor and for the family.

Poor judgment
Some survivors display poor judgment and lack of insight or self-awareness. These individuals should not drive a car or operate any machinery (including small appliances), and should be accompanied when walking outdoors or near stairways. They also should be guided when making important decisions. Impulsivity can appear, as well as other significant issues that should be discussed with a neuropsychologist.

Concentration
Problems with concentration are common after stroke. Social situations can be especially difficult for people with these problems. As a caregiver, you can help by choosing or arranging small, quiet, slow-paced gatherings. This type of setting allows time to sort out what’s being said by whom. It also allows time to think and make an appropriate response. If your loved one now has trouble recognizing acquaintances or remembering names of long-time friends or family members, be ready to offer a prompt of the unknown name such as, “Bob was just telling me about his new car.”

Sensory function
Some stroke survivors appear not to be responsive because their sensory functions (sight, hearing, smell, touch or taste) have been impaired.

Provide stimulation in a variety of ways:

- Pleasant music
- Flowers or plants
- Bright colors
- Books and magazines with pictures
- New clothes
- Colorful foods with strong flavors

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If you or a loved one is experiencing feelings of depression, please discuss with your physician or healthcare provider.
Coping with grief

The following are details of the final three stages of grief that may affect you and your family as caregivers. Stages one and two—shock and denial—will affect each family differently. It is important for you to remain supportive, offering positive feedback and encouragement on the road to recovery. If you should experience any of the following feelings, try not to feel guilty. They are essential parts of the grieving process.

Reaction
A funeral formally recognizes a death and encourages support for a bereaved family. But there is no socially acceptable way to grieve for the loss of a person who hasn’t died. Yet, stroke changes a person, and you may be struggling to say goodbye to your loved one’s former self.

It is normal for both the survivor and the family to sometimes feel that death would be preferable to survival with a disability. Eventually, families develop new relationships with the survivor as they grow comfortable and begin to understand who the survivor has become.

For survivors, the transition can be difficult because they must develop a new sense of self. It’s important to allow your loved one to openly express feelings and allow him or her to grieve the loss of the old self.

Frustration and anger go along with the experience of loss. The survivor may feel that nobody can do anything right. A spouse may feel resentful toward the survivor for suffering a stroke. The only way to get beyond these feelings of anger, guilt or sadness is to experiment with them.

Gradually, healing takes place.

Mobilization
The mobilization stage is characterized by a willingness to try to find a new normal and begin to return to the community environment. Frustration and anxiety can arise, and people often fluctuate between reaction and mobilization. This is a time of transition, and a time when people around you may be insensitive and unaware of how much progress you and your loved one have made.

Acceptance
It is impossible to say how long it will take any given individual or family to enter the acceptance stage. Grief is a personal experience. Compromise and patience will help a family and a survivor get through tough times.

Relationships and intimacy

Spouse
The closeness that a couple shares before a stroke will affect how their relationship evolves after a stroke. It’s normal for married couples to experience a profound sense of loss when one partner suffers a stroke. For many people, marriage is the central and most enduring relationship of their lives. Married couples share a common history of joys and sorrows as well as hopes and dreams for the future. They depend upon each other for companionship, understanding, support and sexual fulfillment.

Spouses are accustomed to sharing the responsibilities of the household and the joys of social activities. When a partner suffers a stroke, he or she may not be able to offer the same level of participation in the relationship as before. Previously shared responsibility may fall entirely on one spouse, who may feel a deep physical and emotional burden. Combine that with the physical, emotional and cognitive changes in the stroke survivor, and the relationship may feel strained.

Additionally, the couple may face prolonged separation during hospitalization and rehabilitation, putting further distance between them.

That is why it is especially important to rebuild physical intimacy in the relationship. Once the survivor’s physician approves a return to sexual intimacy, the couple can discover new ways of giving and receiving sexual satisfaction. Whatever is comfortable and acceptable between partners is normal sexual behavior, and while it may take time to rediscover sexual intimacy, it is an important step in building a new life together.

Children
Often a parent’s stroke comes at a time when children are carrying significant work, family and community responsibilities. These adult children become caught between the demands of their own families and the needs of their parents. The role reversal of becoming a parent to one’s own parent is a difficult one for many people. Once again, the grieving process must occur in order for coping to begin.

Siblings
Sometimes, the family member responsible for care of the stroke survivor is a brother or sister. That person is often at the stage in life when he or she is planning for or enjoying retirement, free for the first time from family responsibilities. This new and unexpected role can cause anger, friction and stress. Additionally, siblings may have unresolved feelings from their childhood relationship that can resurface during this time; adult siblings may find themselves playing out the same old power struggles. With time, patience and communication, these issues can be resolved.
Caring for the caregiver

You may become so preoccupied with caring for your loved one that you forget to take care of your own needs. Your loving, sensitive spouse may have become depressed and demanding after suffering a stroke. It’s important to find ways to cope with the changes and help with the recovery process.

As a caregiver, try to encourage as much independence as possible. Allow your loved one to make decisions. Support his or her participation in leisure activities, and then try to find some fun activities for yourself.

If you can give yourself a break from caregiving, you’ll be helping both yourself and your loved one. Don’t be shy about enlisting the occasional help of other relatives, friends, neighbors or community volunteers who may be able to give you a break for a few hours each week. A paid helper may be available to offer you time away. Additionally, you may benefit from a support group.

Not every stroke survivor requires around-the-clock care. If you’re not sure whether it’s safe to leave your loved one alone, ask your loved one’s healthcare provider or therapist. Strive to create a rhythm to daily life—a rhythm that respects the needs of everyone in your life, including yourself.

With time, patience and dedication, you and your loved one will return to joyful, fulfilling lives.

For more information on support groups, please call 630.933.3278. TTY for the hearing impaired 630.933.4833.