

# After a Stroke

A Guide for Caregivers





## Being a caregiver

Taking care of a loved one at home after a stroke can be stressful at first. It is important to take things slowly. Keep activities as simple as possible in the beginning. Recovery is a lifelong journey. Information in these pages can help guide you along the way.

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# New responsibilities

As the caregiver of a person who has had a stroke, you are taking on new responsibilities and facing new situations. 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 does not want to take part in an activity, do not insist. Many stroke survivors feel more energetic during a certain part of the day. Consider scheduling activities during those periods. Offer choices so that your loved one still feels in control. For example, you could ask, "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.

Offering choices can help your loved one feel in control.

You will notice several changes in your loved one during recovery. The changes may be physical, mental 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.

## Communication difficulties

Communication problems are among the most frightening after-effects of stroke for both the survivor and the family. Some stroke survivors have problems controlling their face and mouth muscles. This means they are unable to pronounce certain sounds properly.

If the stroke damaged the language center in the brain, your loved one may have trouble expressing themselves or understanding others. This condition is known as **aphasia**.

- They may have trouble finding the right words.
- They may barely be able to speak at all.
- They may have trouble reading or writing.

A speech and language therapist can help you and your loved one learn to communicate more effectively. This can reduce frustration for both of you. Getting involved in therapy can help you learn the best ways to communicate with your loved one.

Aphasia therapy can help your loved one:

- Use remaining communication abilities
- Restore language abilities as much as possible
- Learn how to communicate in different ways

Treatment may be offered in individual or group settings. Individual therapy focuses on specific needs. Group therapy gives your loved one a chance to practice new skills in a comfortable setting.

Stroke clubs are available in most major cities. These clubs offer another setting to try new communication skills. Stroke clubs can also help you and your family adjust to the life changes due to stroke and aphasia.

If your loved one has aphasia, try to:	
Simplify language by using short, simple sentences	Repeat words or write them down to help your loved one understand
Speak naturally as you would to any adult	Minimize distractions, such as a blaring radio, whenever possible
Include your loved one in conversations	Ask for and value your loved one's opinion, especially regarding family matters
Encourage any type of communication: speaking, hand signals, pointing or drawing	Avoid correcting your loved one's speech
Allow your loved one plenty of time to talk	Help your loved one become involved outside the home
Seek out support groups, such as stroke clubs	Seek help from a speech and language therapist

The Northwestern Medicine Aphasia Center at Marianjoy Rehabilitation Hospital, part of Northwestern Medicine, is designed for anyone who is experiencing aphasia and would like to improve their communication skills. Small group sessions are led by a therapist who specializes in language disorders. Participants meet in a comfortable and supportive environment to practice skills through real-life activities.

If you would like to register for the Northwestern Medicine Aphasia Center at Marianjoy, or have questions regarding the program, individual treatment sessions or aphasia research studies, please call 630.909.8562 (TTY: 711).

# 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 hard for caregivers and family members to cope with. Seek professional help when necessary.

## Depression

Depression can look different in each person. Know the warning signs and get help when you see them.

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A person with depression may:

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- Stop taking their medication
  - Stop doing exercises that improve mobility
  - Stop eating or sleeping
  - Be short-tempered
  - Lack emotion or motivation
  - Express feelings of hopelessness or helplessness
  - No longer enjoy their favorite activities
  - Feel sluggish
  - Move and speak more slowly
  - Have distressing or even suicidal thoughts
  - Blame themselves unreasonably for anything that goes wrong
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It is important to know the warning signs of depression so that you can get help.

If your loved one is depressed, you and your family may lose the desire to help. This can make the depression even worse.

Depression may get better as your loved one recovers from stroke. But it can also become serious enough to make stroke recovery more difficult.

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

If you or a loved one is feeling depressed, please talk to their physician.

## Cognitive impairments

Depending on the location in the brain, stroke can impact the mind's ability to process thoughts.

### Memory loss

You may not notice some changes in behavior, such as memory loss, at first. Your loved one may be nervous and cautious. They may need a reminder to finish a sentence or to know what to do next. Some people have difficulty with numbers and math. They can no longer handle money or balance a checkbook. You may need to keep things in the same place, do things in the same order and tell your loved one in advance what is going to happen. You may even have to take over some responsibilities. Memory loss can be hard to accept. It can be frustrating for you and your loved one.

### Poor judgment

Your loved one may display poor judgment, and lack of insight or self-awareness. If so, they should not drive a car or operate any machinery (including small appliances). They should not go outside or near stairways alone. They may become impulsive, making decisions without careful thought. You should guide them when making important decisions. Discuss these problems 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 is being said by whom. It also allows time to think and respond. Your loved one may have trouble recognizing people or remembering names of friends or family members. If so, make a habit of offering a prompt of the person's name such as, "Bob was just telling me about his new car."

### Sensory function

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

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You can stimulate senses in a variety of ways:

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

You and your family may experience stages of grief following your loved one's stroke. Stages one and two—shock and denial—will affect each family differently. Continue to support your loved one and your family. Offer positive feedback and encouragement.

Three more stages of grief are reaction, mobilization and acceptance. If you experience any of these feelings, try not to feel guilty. They are an important part of grieving.

### 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 has not died. Yet, stroke changes a person. 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 dying would have been better than living with a disability. Eventually, you will begin to understand who your loved one has become. As you grow more comfortable, you will develop a new relationship with them.

For survivors, the transition can be hard because they have to learn who they have become. Allow your loved one to openly express their feelings. They may also be grieving the loss of their old self.

You and your loved one may feel frustrated and angry. Your loved one may feel that nobody can do anything right. You may be mad at the survivor

for suffering a stroke. The only way to get beyond these feelings is to experience them. Gradually, healing takes place.

### Mobilization

Mobilization is a willingness to try to find a new normal. This is a time when you and your loved one start to return to the community. You may feel frustrated and anxious. You might find that you move back and forth between reaction and mobilization. This is a time of transition. People around you may be insensitive and unaware of how much progress you and your loved one have made.

### Acceptance

Acceptance may come at different times for different people. Grief is a personal experience. Compromise and patience will help you and your loved one 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. Married couples commonly feel a great sense of loss when one partner suffers a stroke. For many people, marriage is the central and longest-lasting 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 typically share household responsibilities and the joys of social activities. After a stroke, they may not be able to do all of the same things you used to do. Previously shared responsibilities may fall entirely on one spouse. This can be physically and emotionally difficult. Combine that with the physical, emotional and cognitive changes in the stroke survivor, and the relationship may feel strained. Additionally, the couple may be physically separated due to hospitalization and rehabilitation. This can make them feel emotionally disconnected, too.

Rebuilding physical intimacy in the relationship is very important. 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. 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 their children have many responsibilities at work, with their own children and in the community. These adult children become caught between the demands of their own lives and the needs of their parents. The role reversal of becoming a parent to one's own parent can be hard. The grieving process is important for coping to begin.

### Siblings

Sometimes, the family member responsible for the care of the stroke survivor is a brother or sister. That person is often at the stage in life when they are planning for or enjoying retirement, free for the first time from family responsibilities. This new and unexpected role can cause anger, friction and stress. Some siblings may also 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, you can overcome these issues.

## Caring for the caregiver

You may be so focused on caring for your loved one that you forget to take care of your own needs. Your loved one may have become depressed and demanding after suffering a stroke. It is 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 their participation in leisure activities, and then find some fun activities for yourself.

If you can give yourself a break from caregiving, you will help yourself and your loved one. Ask for help. Find relatives, friends, neighbors or community volunteers who can take over caregiving a few hours a 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 are not sure whether you can leave your loved one alone, ask their clinician or therapist. Strive to create a rhythm to daily life 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: 711).





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Winfield, Illinois 60190  
630.933.1600

**Northwestern Medicine Delnor Hospital**

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Geneva, Illinois 60134  
630.208.3000

**Northwestern Medicine Kishwaukee Hospital**

1 Kish Hospital Drive  
DeKalb, Illinois 60115  
815.756.1521

**Northwestern Medicine Palos Hospital**

12251 South 80th Avenue  
Palos Heights, Illinois 60463  
708.923.4000

**Northwestern Medicine Valley West Hospital**

1302 North Main Street  
Sandwich, Illinois 60548  
815.786.8484

**Marianjoy Rehabilitation Hospital,  
part of Northwestern Medicine**

26w171 Roosevelt Road  
Wheaton, Illinois 60187  
630.909.8000

TTY for those who are deaf or hard of hearing: 711

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