After your stroke

The information here will assist you on your road to recovery following your stroke. Your healthcare provider may recommend that you participate in some form of rehabilitation. It is important to remember that strokes can occur in any area of the brain and may affect different parts of the body. Rehabilitation is tailored to meet your specific needs. In the following pages, you will find more information on:

2 Going home
6 Coping with the emotional impact of stroke
7 Changes in thinking and behavior
8 Relationships and intimacy
After a stroke, you may be apprehensive about being on your own at home. Talk openly with your healthcare provider and family to help ease your concerns.

**After a stroke, you may be anxious about being on your own at home.**

You may display these fears as anger, agitation or tension. Talk openly with your healthcare provider and family to help ease your concerns. With a positive attitude, you can find ways to overcome the difficulties.

**Driving**

Most people consider driving an essential activity of daily life. Driving provides freedom, independence and self-reliance. However, driving is a complicated activity that requires multiple levels of information processing as well as mobility.

About 80 percent of stroke survivors are able to drive again. Whether you are able to drive again depends on the type of damage caused by your stroke. People with perceptual problems are less likely to regain safe driving skills. If you have trouble judging distances, or if you have a visual field cut (hemianopsia), you should not drive. You will endanger yourself and others on the road.

It’s critical that you talk with your healthcare provider before driving. A comprehensive driving evaluation should be done with a healthcare practitioner who has a background in driver training and understands the physical and cognitive issues brought on by stroke. Your practitioner will be able to tell the difference between temporary changes in driving ability and a permanent inability to drive.

**Steps to consider**

If you are receiving rehabilitation services, speak to your occupational therapist about driving. Occupational therapists are involved with providing driver evaluations, treatment, educational resources and guidance to people who want to drive again.

Request a driver’s evaluation by a qualified healthcare professional.

Become familiar with the transportation resources in the community such as public transit, volunteer ride programs and taxi services.

**A driver’s evaluation will usually include:**

- Assessment of functional ability
- Reaction time testing
- Visual testing
- Perceptual testing
- In-car testing

**Regular driving schools are not specialized enough for people who have experienced stroke.** Because instructors do not always know about the medical aspects of a stroke, they are often not prepared to teach stroke survivors. Speak to your healthcare provider about driver’s training programs.

If you require adaptive equipment to drive, you will be connected with a specially trained driving instructor.

**Possible physical problems and solutions for driving:**

If you have use of only one hand, a spinner knob is appropriate. A spinner knob is attached to the steering wheel and allows you to steer the car easily with one hand. If you are unable to use the right arm and leg, a left gas pedal and spinner knob can be installed in your car.

If you have use of only one leg, an automatic transmission will be easier than a standard transmission.

If you have trouble reading or understanding what is read, training to read the road sign symbols rather than words can be helpful. However, this problem requires careful evaluation.

If you are unable to use the left extremities, a directional signal extender may be helpful.

**Driver’s training may include:**

- In-class instruction
- Classroom driving simulation
- Transfer training
- In-car, on-the-road training
- Wheelchair-loading instruction
Easing back into life

Stroke does not have to rob you of doing the things you enjoy. Involvement in recreation and leisure activities promotes health by helping you cope with stress and can help lift your mood. Activities can shift your attention away from what you can’t do and toward what you can do. These activities can also be useful for improving perception, coordination and strength.

Ways to adapt leisure activities:

If you like to cook, you can peel and slice vegetables, put frosting on a cake, roll out pastry or assemble salads from a stable position.

If you like gardening, tend to potted plants on a window sill and start new plants from cuttings.

If you enjoy needlework, use a special clamp and embroidery hoop to hold the fabric steady.

If you are a reader with a visual impairment, locate reading materials in large type or audio formats.

Social activities keep you connected to your community. Community centers, senior centers, churches, municipalities and other organizations offer social opportunities. Eating at a local restaurant, visiting the library or walking in the park will help you feel connected.

Some leisure activities can help you build skills that you can use for volunteering, continuing education or employment. Your social worker or case manager can suggest resources in your community to assist with these transitions.

Setting goals

Stroke recovery begins in the hospital, but continues at home. To maximize your recovery, you and your caregiver will develop a plan of action to help restore not only your physical function but also your capacity to make decisions and execute choices.

In the months that follow a stroke, the rate of recovery slows. When this happens, you can become discouraged and overlook the progress you’ve made. Setting goals can help you deal with that discouragement by giving you concrete improvements for which to strive.

A crucial part of setting goals is examining what you can reasonably accomplish.

First, you and your caregiver need to examine what you can reasonably accomplish, and then break that down into short- and long-term goals. This process may require you to consider new interests, strengths and abilities to replace or modify activities you enjoyed before your stroke. Goals may relate to physical improvement, such as increasing your ability to care for yourself, or you might have personal goals such as relearning to drive or developing a deeper relationship with children or grandchildren.

Stroke recovery takes time, dedication and effort. But with a positive attitude and the support of your caregiver, you can return to a joyful and fulfilling life.
Coping with the emotional impact of stroke

The grieving process
After surviving a stroke, you and your family may feel like you’re on an emotional roller coaster. This is normal. Shortly after the stroke, survivors and families begin to comprehend their personal losses and go through a grieving process, much like those who have experienced death or divorce. Recognizing common stages of grief can help you better cope with the emotional changes that go along with it. Friends can gain insight into the grieving process as well, so they can better understand your thoughts, feelings and actions. You may not go through every stage or each stage “in order.” One stage doesn’t abruptly stop so the next can begin. Rather, grieving is a gradual healing process that takes time and work. Each person moves through the process in his or her own way.

Stage 1: Shock
Shock usually occurs during the early phase of hospitalization or rehabilitation. A feeling of helplessness may accompany the shock. During this time, the support of family and friends is extremely important.

Stage 2: Denial
Denial involves not wanting to accept that something bad has happened. This is a coping mechanism. Being in denial gives you time to adjust to a negative situation. During this stage, it is important to focus on the here and now. What do you need to do to get well? What is necessary today?

Stage 3: Reaction
This stage begins when you and your family start to realize the full impact of the situation. The most common reactions are anger, bargaining (with God or others), depression and a mourning of losses and changes. If these reactions interfere with rehabilitation or usual activities, it is important to be evaluated, and if necessary, treated by a mental health professional.

Stage 4: Mobilization
This is the stage when you may say, “OK, I want to live... show me how.” You might become more eager to learn during this stage. When family members reach this stage, they begin to show more interest in learning how to help you. This is often a good time to try short trips or outings.

Stage 5: Acceptance
Acceptance is the final stage of the grieving process. This is when you and your family learn to live with the effects of the stroke. One stroke survivor said, “The way I look at it, you have two choices. You may say to yourself, ‘Oh, to heck with it. I’ll just be a cripple for the rest of my life.’ Or you can say, ‘I’m going to do as much as I can, and when I reach my limit, then I’m going to see how much I can do within that limit.’” Acceptance doesn’t mean you won’t sometimes have strong feelings about the changes, losses or problems that remain. Rather, it means those feelings no longer keep you from feeling hopeful and grateful to be alive.

Changes in thinking and behavior

Stroke can affect your thinking and behavior in various ways. It’s important to understand these potential changes and talk to your physician if you experience any of them.

Depression
Depression can result from either emotional reactions or physical injury to the brain resulting from the stroke. Depression can be overwhelming, affecting the spirit and confidence of everyone in your life. Low self-regard, harsh self-criticism and the desire to isolate yourself can prevent you from engaging in activities that can help increase your self-esteem. This creates a dangerous cycle of isolation and despair. Depression is a normal part of the grieving process, but if it doesn’t go away, seek professional help.

To help combat depression:
- Attend a stroke support group
- Pursue treatment with therapy, counseling or medication
- Be as physically active as possible
- Set goals and structure a way to measure accomplishments
- Schedule daily activities to provide structure and purpose
- Participate in social activities to provide stimulation, enhance language recovery and improve self-esteem

Apathy
Strokes can affect the parts of the brain that motivate, stimulate interest and drive desire for activity and involvement. Post-stroke apathy is different from depression (although it may look very much like it) and may require an evaluation by a neuropsychologist to sort it out. Treatment may be different from that for depression.

Memory loss
You may need reminders or prompts to finish a sentence or certain tasks. Doing things in a more highly structured manner may help.

Perception/concentration problems
These issues are common after stroke. Social situations can be especially difficult for people with these problems. Choose to attend small, quiet, slow-paced gatherings.

One-sided neglect
Damage to the right side of the brain may cause you to neglect half—usually the left half—of your world. You may ignore the left side of the face when washing or may not eat food on the left side of the plate. If you move your head to the left, neglected objects usually become noticed.

Emotional liability
(involuntary emotional expression disorder or IEED)
Sudden laughing or crying for no reason and difficulty controlling emotional responses are common after stroke. Oddly, there may be no real mood changes involved, and the emotional display may end very quickly. This response frequently lessens over time and may go away on its own. Medicine may be prescribed to help the problem.
Relationships and intimacy

Stroke can change your body and how you feel, which can affect sexuality. Stroke survivors often report a decrease in sexual desire and how often they have sexual relations. But part of getting back into a normal routine involves resuming a healthy sex life. Loving and being loved, and having the physical and mental release that sex provides, are important.

However, having sex after stroke can present problems or concerns for you and your partner. Women may have a strong decrease in vaginal lubrication and the ability to have an orgasm. Men often have weak or failed erections and ejaculations.

If you experience any of these symptoms, please discuss with your physician or healthcare provider.

Factors affecting sexuality

Fear of further damage — Check with your physician before resuming sexual activity. Most stroke survivors can resume a happy and healthy sex life.

Personality changes — Personality changes can impact a person’s desire and ability to engage in sexual activity. After a stroke, some worry that sex is now wrong or off-limits. Fears of hurting a partner during sex are common and can hinder sexual intimacy. Reassurance, warmth and time can often ease these concerns. Resuming sexual activity can help strengthen the relationship and provide pleasure and enhanced self-esteem to both partners. If personality changes or a psychological issue continue to stand in the way of your sexual relationship, talk to a psychologist or mental health professional.

Clinical depression — Depression can affect sexual function and result in a lack of desire or impotence. If you or your partner is experiencing depression, discuss it with your doctor. Medicines and/or counseling can be helpful.

Paralysis and sensory loss — It is helpful to be aware of any sensory loss. In the case of paralysis, experimenting with different positions for sexual intercourse is advisable.

Difficulty with speech — Sexuality is a special form of communication that is not dependent on speech. Everyone is receptive to touch, and seduction can be accomplished without words.

Impotence caused by medicines — In the male stroke survivor, if there is no morning erection, impotence may be caused by medications. Some blood pressure or heart drugs, diuretics, antidepressants, tranquilizers and sedatives are known to cause decreased sex drive. If this has happened, it is important to let your physician know. Often your medications can be adjusted to fix the problem.

External collecting device or internal Foley catheter — A catheter does not need to be a barrier to sexual enjoyment. In males, the external collection device can be removed. If you have a catheter, you may remove it, clamp it off or keep it in. If you keep the catheter in, disconnect it from the leg bag. Fold the catheter back along the penis and apply a condom. In females, the catheter can stay in place. Disconnect it from the leg bag and clamp it. Or you can remove and reinset it later.

If impotence or sexual difficulties do not resolve, there are many treatments available, and there are physicians and psychologists who specialize in this area. Your psychologist, physician or the social worker at a rehabilitation hospital should be able to refer you.

It’s important to remember that sexuality is more than the act of sexual intercourse. It involves the whole process of relating to another person. Tenderness, the desire to give and receive caresses, holding, cuddling, touching, intimacy, reciprocal concerns, tolerance and love—all are a part of sexual communication that goes beyond words. After the separations and loss caused by a stroke, sexual intimacy can help a couple reclaim a closeness that is unique to them.

Returning to sexual intimacy

Talk to your physician before having sex again.

Ask your physician about changes to expect when having sex and for advice on how to deal with them.

Focus on being loving, gentle and caring with each other.

Speak honestly with your partner about your sexual changes. Together you can often work out the best solution.

Join a stroke support group. Other survivors will understand, validate your issues and offer encouragement and ideas.

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