

Going Home

A Guide for Patients After Stroke





After your stroke

The information here will help you recover from your stroke. Your care team may recommend some form of rehabilitation. Remember that a stroke can occur in any area of the brain. It may affect different parts of the body. Your care team will design your rehabilitation plan to meet your needs. In the following pages, you will find more information on:

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Going home

After a stroke, you may be nervous about going home. Here are some common fears:

A stroke might happen again

You cannot accept your disabilities

You might be placed in a nursing home

Your loved ones may not be prepared to care for you

Friends and family will abandon you

After a stroke, you may be scared to be on your own at home. Talk about these fears with your healthcare team and family.

Worry can also make you angry, irritated or tense. Talk about your feelings with your healthcare team and family. With a positive attitude, you can find ways to overcome problems.

Driving

Driving is an important freedom for most people. Driving provides independence and self-reliance. However, driving requires you to be able to process information quickly and accurately. It also requires certain physical abilities.

About 80% of people who have had a stroke are able to drive again. Whether you are able to drive again depends on the type of damage caused by your stroke. For example, if you have trouble judging distances, or if your stroke affected your ability to see well, you should not drive. It will be dangerous to you and others on the road.

Be sure to talk with your physician before driving. You should have a driving evaluation with a healthcare professional who has a background in driver training and understands the possible effects of stroke. They will be able to tell if you can drive now, if you will be able to drive again in the future, or if you should not drive again.

For information about Marianjoy Rehabilitation Hospital's Driver Rehabilitation Program, call 630.909.6080 or visit marianjoy.org.

A driver's evaluation will usually include:

Functional ability testing

Reaction time testing

Visual testing

Perceptual testing

In-car testing

Regular driving schools are not specialized enough to help drivers after stroke. Instructors do not always know about the medical aspects of stroke. A specially-trained instructor can help you learn to drive again. They can help you use special equipment to drive if you need it. Ask your healthcare team about driver's training programs.

Driver's training may include:

In-class instruction

Classroom driving simulation

Transfer training

In-car, on-the-road training

Wheelchair-loading instruction

Possible physical problems and solutions for driving

If you have use of only one hand, a spinner knob can help. A spinner knob is attached to the steering wheel and allows you to steer the car easily with one hand. If you cannot use your right arm and leg, a left gas pedal and spinner knob can be installed in your car.

If you can only use one leg, an automatic transmission will be easier than a manual transmission ("stick shift").

If you have trouble reading or understanding what you read, you can learn to read the road sign symbols rather than words. However, be sure to discuss this problem with your care team.

If you are unable to use the left arm and leg, an extension can be added to turn on your turn signal.

Steps to consider

If you are in rehabilitation, talk to your occupational therapist about driving. They can often help with driver evaluations, treatment, educational resources and guidance for people who want to drive again.

Request a driver's evaluation from a qualified healthcare professional.

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

Easing back into life

Stroke does not have to rob you of doing the things you enjoy. These activities promote health by helping you cope with stress and lifting your mood. Activities can shift your attention away from what you cannot do and toward what you can do. They can also be useful for improving vision, 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 and your vision has been affected by stroke, find reading materials in large type or audio formats.

Social activities keep you connected to your community. Community centers, senior centers, churches, park districts 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. If you want to be more involved in the community, your social worker or case manager can suggest helpful resources.

Setting goals

Stroke recovery begins in the hospital, but continues at home. To help you recover, you and your caregiver will develop a plan of action. This plan can help restore your physical and mental abilities.

In the months that follow a stroke, the rate of recovery slows. When this happens, you can become discouraged. Do not overlook the progress you have made. Setting goals can help you deal with discouragement by keeping you focused on making concrete improvements.

A key part of setting goals is looking at what is actually possible.

First, you and your caregiver need to talk about what you will be able to achieve. Then, break that down into short- and long-term goals. You may need 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 driving again, or developing a deeper relationship with children or grandchildren.

Stroke recovery takes time, dedication and effort. With a positive attitude and support from loved ones, you can return to a joyful and fulfilling life.



The emotional impact of stroke

The grieving process

After a stroke, you and your family may feel like you are on an emotional roller coaster. This is normal. Shortly after the stroke, survivors and families begin to understand what they have lost. They often go through a grieving process, much like those who have experienced death or divorce. Recognizing common stages of grief can help you cope with your emotions. Friends can gain insight into the grieving process as well, so they can better understand what you are going through.

You may not go through every stage, or go through each stage "in order." One stage does not stop so the next can begin. Rather, grieving is a gradual healing process. It takes time and work. Each person moves through the process in their own way.

Recognizing common stages of grief can help you cope with your emotions.

Stage 1: Shock

Shock usually occurs during the early phase of hospitalization or rehabilitation. You may feel helpless. During this time, the support of family and friends is very 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, 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 your stroke. The most common reactions are anger, bargaining (with God or others), depression and mourning what has been lost. If these reactions interfere with rehabilitation or usual activities, talk to your care team. You may benefit from mental health care.

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. This does not mean you will not sometimes have strong feelings about your situation. It means that even with the changes in your life, you feel hopeful and grateful to be alive. Instead of focusing on what you cannot do, you are able to concentrate on learning, and enjoying, what you can do.

Changes in thinking and behavior

Stroke can affect your thinking and behavior in many ways. You should understand these 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 after stroke. Depression can be overwhelming. It can affect the spirit and confidence of everyone in your life. You may have low self-regard, and want to isolate yourself. This can prevent you from doing 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 does not go away, talk to your care team.

To help combat depression:

Attend a stroke support group

Find treatment with therapy, counseling or medication

Be as physically active as possible

Set goals and measure your accomplishments

Schedule daily activities to provide structure and purpose

Participate in social activities to provide stimulation, enhance language recovery and improve self-esteem

Apathy

Stroke can affect the parts of the brain that motivate, stimulate interest, and drive desire for activity and involvement. Post-stroke apathy may look like depression, but it is different. You may need to see a neuropsychologist to help determine if you have apathy or depression. Your treatment may be different depending on your diagnosis. This will help ensure you get the right kind of treatment.

Memory loss

You may need to be reminded to finish a task or even complete a sentence. Structure and routine may help.

Perception/concentration problems

These issues are common after stroke. Social situations can be especially hard 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 lability

Sudden laughing or crying for no reason and difficulty controlling emotional responses are common after stroke. This is called involuntary emotional expression disorder, or IEED. Your mood may not change at all, and the emotional display may end very quickly. IEED often gets better over time and may go away on its own. Medication may help.

Relationships and intimacy

Stroke can change your body and how you feel. This 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 have any of these symptoms, please discuss them with your care team.

Remember that sexuality is more than the act of sexual intercourse. It involves the whole process of relating to another person.

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 people worry that sex is now wrong or off-limits. Fears of hurting a partner during sex are common and can get in the way of 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 psychological issues 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. It can result in a lack of desire and impotence, or the inability to have an erection. If you or your partner is experiencing depression, discuss it with your physician. Medication and/or counseling can help.

Paralysis and sensory loss

Be aware of any sensory loss. In the case of paralysis, try different positions for sexual intercourse until you find what works best for you and your partner.

Difficulty with speech

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

Impotence caused by medication

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

External collecting device or internal Foley catheter

You can enjoy sex even if you have a catheter. 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 reinsert it later.

If impotence or sexual difficulties do not get better, treatment is available. Some physicians and psychologists specialize in this area. Your psychologist, your physician or the social worker at a rehabilitation hospital should be able to refer you.

Remember 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 separation 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 what you are going through. They can offer encouragement and ideas.



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