



American  
Stroke  
Association.  
*A division of the  
American Heart Association.*

# PREVENTION SELF-ADVOCACY RECOVERY **HOPE:**

## The Stroke Recovery Guide



# RELATIONSHIPS MOVEMENT RESOURCES EXERCISE

[stroke.org](https://stroke.org)

# HOPE: THE STROKE RECOVERY GUIDE

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### Dear Friend,

Thank you for entrusting us to provide **HOPE: The Stroke Recovery Guide** as you and your family navigate your stroke recovery.

No matter where you are in your recovery journey, there's hope. While we recognize that each person's stroke and recovery is unique, you can beat stroke with the right care, support and a lot of hard work. And we're here to provide resources to support you and your family and caregivers.

**HOPE: The Stroke Recovery Guide** provides valuable information in four sections:

- **Helpful Information** addresses important post-stroke issues and offers suggestions on how to address your concerns.
- **Self-Advocacy** shows you how to be an active participant in your recovery and helps you set short- and long-term goals.
- **Preventing Another Stroke** includes lifesaving information about stroke awareness, symptoms, recognition and how to decrease your chances of having another stroke.
- **Movement and Exercise** provides two illustrated exercise programs to help you gain strength and range of motion.

The American Stroke Association's mission is *to be a relentless force for a world of longer, healthier lives and fewer strokes*. We team with millions of volunteers to prevent, treat and beat stroke by funding innovative research, fighting for stronger public health policies, and providing lifesaving tools and information. Please contact us at **1-888-4-STROKE (1-888-478-7653)** or visit **stroke.org** for further information and support.

We look forward to teaming with you on your stroke recovery journey.

Sincerely,

Your American Stroke Association Team

The American Stroke Association sincerely thanks the following people for their careful review and assistance with **HOPE: The Stroke Recovery Guide**.

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# CHAPTER ONE

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## **BEGINNING THE RECOVERY PROCESS THROUGH REHABILITATION**

The goal of stroke rehabilitation is to restore as much independence as possible by improving physical, mental and emotional functions. This must be done in a way that preserves your dignity and motivates you to re-learn basic skills that stroke may have affected, such as eating, dressing and walking.

Rehabilitation should start in the hospital as soon as possible. If you're medically stable, rehabilitation may begin within one day after your stroke and should be continued after release from the hospital, if needed. For others, rehabilitation can take place months or years later as your condition improves, or in some cases, worsens.

Stroke rehabilitation options will depend on several factors, including:

- Ability to tolerate the intensity of rehabilitation (hours/stamina)
- Degree of disability
- Available funding
- Insurance coverage
- Your geographic area

### **Making Rehabilitation Decisions**

More than 7 million stroke survivors live in the United States, but not all strokes are the same. More than two-thirds of stroke survivors receive rehabilitation services after leaving the hospital. Effective rehabilitation is an essential part of stroke care.

Stroke rehabilitation requires a sustainable and coordinated effort from a team with the patient and the patient's goals at the center. In addition to the patient, the team includes family and friends, other caregivers, physicians, nurses, physical and occupational

therapists, speech/language pathologists, recreation therapists, psychologists, nutritionists, social workers and others.

Rehabilitation is meant to care for you, increase your independence, help you reintegrate into your community and rejoin your family at home.

When considering the different types of rehabilitation settings, together with your family, ask:

1. Is the hospital certified to care for patients following a stroke?
2. What medical care professionals are available to care for a patient following a stroke?
3. Do staff members participate in special certifications or trainings that make them more qualified?
4. How often will my doctor see me?
5. What is the maximum amount of therapy offered in my rehabilitation setting?

**Stroke rehabilitation care options include:**

Programs	Services	Setting	Frequency of Rehabilitation	Likely Candidates
<b>Inpatient rehabilitation facilities</b>	24-hour medical care and a full range of rehabilitation services	Hospital or special rehabilitation unit of a hospital	Several hours each day (most demanding)	Survivors who have many medical issues and may develop problems without continued medical treatment
<b>Skilled nursing facilities</b>	Provide daily nursing care and a wide range of rehabilitation services	Rehabilitation center, rehabilitation unit of a hospital, skilled nursing facility (short-term nursing care) or skilled nursing home (long-term), skilled nursing unit in a hospital	Less demanding program, but continues for longer periods	Survivors who have serious disabilities and are unable to handle the demands of acute programs in a hospital
<b>Long-term care facilities</b>	One or more treatment areas	Nursing home, skilled nursing facility	2–3 days per week	Survivors who have medical problems under control but still need 24-hour nursing care
<b>Outpatient clinics</b>	One or more treatment areas	Doctor’s office, hospital-based outpatient center, other outpatient centers and some adult day centers	2–3 days per week	Survivors who have medical problems under control enough to live in their homes and can travel to get treatment
<b>Home health agencies</b>	Rehabilitation services in one or more treatment areas	In the home	As needed	Survivors who live at home but are unable to travel to get their treatment

## Rehabilitation Health Care Team

During all phases of your rehabilitation, you’ll most likely partner with professionals from different specialties. It’s important that you know your health care team and feel comfortable addressing recovery issues with them. See the table on the following page for detailed descriptions of the rehabilitation team.

Services delivered during rehabilitation may include physical, occupational, speech and language therapies, therapeutic recreation and specialty medical or psychological services.

### Physical Therapy

Physical therapy (PT) helps restore physical functioning and skills such as walking and range of motion, and addresses issues such as partial or one-sided paralysis, faulty balance and foot drop. See **Chapter 7** for exercise examples.

### Occupational Therapy

Occupational therapy (OT) involves re-learning skills for everyday living, including eating, using the bathroom and dressing.

### Speech Therapy

Speech and language therapy (SLT or ST) reduce and compensate for problems such as communicating, thinking or swallowing.

Dysarthria and aphasia can cause speech problems among stroke survivors. With dysarthria, a person can’t pronounce speech sound properly because of weakness or trouble controlling the face and mouth muscles. With aphasia (see details in **Chapter 3**), a person thinks clearly but can’t process language to talk or understand others. Speech and language therapy can teach you and your family ways to cope with these communication challenges. If your communication difficulties are severe, a therapist may suggest alternative ways to communicate, such as using gestures or pictures.

Speech and language therapists also help with memory loss and other “thinking” problems caused by stroke

For help in locating a private speech and language therapist, contact the American Speech-Language-Hearing Association at **1-800-638-8255** or visit **asha.org**. You may also consider the social work or speech and hearing department at your local hospital or rehabilitation facility.

### Recreational Therapy

Therapeutic recreation reintroduces leisure and social activities to your life. Activities might include swimming, going to museums, plays and libraries, or taking music and art lessons. An important factor with this therapy is getting you back into the community and developing social skills again. A therapeutic recreation specialist may be available through your hospital, in community-based programs/organizations (for example, YMCA or senior centers) and in adult day programs.

Rehabilitation Team	
<b>Physiatrist</b>	A doctor who specializes in rehabilitation following injuries, accidents or illness
<b>Neurologist</b>	A doctor who specializes in preventing, diagnosing and treating stroke and other diseases of the brain and spinal cord
<b>Rehabilitation Nurse</b>	Specializes in helping people with disabilities; helps survivors manage health problems that affect stroke (for example, diabetes, high blood pressure) and adjust to life after stroke
<b>Physical Therapist (PT)</b>	Helps stroke survivors with problems in moving and balance; suggests exercises to strengthen muscles for walking, standing and other activities
<b>Occupational Therapist (OT)</b>	Helps stroke survivors learn strategies to manage daily activities such as eating, bathing, dressing, writing or cooking
<b>Speech-Language Pathologist (SLP)</b>	Helps stroke survivors re-learn language skills (talking, reading and writing); shares strategies to help with swallowing problems
<b>Dietitian</b>	Teaches survivors about healthy eating and special diets (for example, low salt, low fat, low calorie)
<b>Social Worker</b>	Helps survivors make decisions about rehabilitation programs, living arrangements, insurance, and support services in the home
<b>Neuropsychologist</b>	Diagnoses and treats survivors facing changes in thinking, memory, behavior or depression
<b>Case Manager</b>	Helps survivors facilitate follow-up, coordinate care from multiple providers and link to local services
<b>Recreation Therapist</b>	Helps stroke survivors learn strategies to improve thinking and movement skills by using recreational activities

## Health Insurance

Rehabilitation programs can be costly. So it's important to know what part of the bill your health insurance pays and what you pay. It's also good to know if you can choose any doctor you want. Stroke recovery may require extensive rehabilitation. This may include many services in different settings. Check with your health insurance company to find out under what settings you're covered.

If you worked prior to your stroke, apply for disability benefits that provide income supplements to people who aren't employed due to a disability (usually physical).

Several types of disability benefits may apply to you, including private disability insurance or government disability benefits. Private disability insurance benefits are provided by an employer or through a disability insurance plan you purchased.

The Social Security Administration (SSA) has two programs that provide money to people who are disabled and unable to work:

- **Social Security Disability Insurance (SSDI)** is a payroll tax-funded, federal insurance program that provides income supplements to people who are physically restricted in their ability to be employed because of a notable disability, usually a physical disability.
- **Supplemental Security Income (SSI)** is a federal income supplement program funded by general tax revenues and provides cash assistance to people who are either 65 or older, blind or disabled.

Because of the time to process the paperwork, be sure to contact the SSA as soon as possible. Apply for benefits even if you plan to go back to work. Also, keep copies of all documents you send to them and letters they have sent to you. Keep track of the names of the people you talked to, dates and what they told you. If you're denied, find out about the appeal process and challenge your denial. Learn more at Social Security Administration at **1-800-772-1213** or visit **ssa.gov**.

Every health insurance plan has coverage limitations. But you may have options for rehabilitation services:

- Contact your insurance company or your employer's benefits administrator for information on your private health insurance plan.
- Contact the "exceptions" department of your health plan.
- Ask to work with a case manager for chronic or catastrophic illness.
- File an appeal if you're denied payment or medical service to which you're entitled.
- Ask the social worker or discharge planner at your rehabilitation hospital for contacts. If you need help talking to your insurance company about your health care and recovery, contact resources in your community, including vocational rehabilitation services, aging agencies, disability law/elder law projects and the Social Security Administration Office of Disability (**ssa.gov/disability**).
- Call **1-800-MEDICARE** or visit **medicare.gov** for more information on Medicare coverage for stroke rehabilitation.
- Trade inpatient rehabilitation days for outpatient days. Some plans have short inpatient coverage but longer home care/outpatient coverage.

## Discharge Planning

Discharge planning prepares you to live independently. It helps maintain the benefits of rehabilitation after you have been released from the program. It begins early during rehabilitation and involves you, your family and the stroke rehabilitation team. You should be discharged from rehabilitation soon after your goals have been reached.

### Discharge planning can include:

- Having a safe place to live after discharge.
- Having access to prescription medications for your health conditions.
- Deciding what care, assistance or special equipment you'll need.
- Arranging for more rehabilitation services or other services in the home.
- Choosing the health care professional who will monitor your health and medical needs.
- Determining the caregivers who will provide daily care, supervision and assistance at home.
- Determining which community services may be helpful now or after some time. Examples include meal delivery, volunteer rides to the rehabilitation center, visitor programs and caregiver relief programs.

## Social Support

Socializing with family and friends can be an important part of recovery.

### Support Group

A support group allows you to interact with other stroke survivors who know what you're going through. People in a support group can:

- Help you find ways to solve problems related to your stroke.
- Share information about products that may help your recovery.
- Encourage you to try new things.
- Listen to your concerns and frustrations.
- Give you a chance to get out of the house.
- Provide an opportunity to share your story.
- Become your new friends.

## Family and Friends

Family and friends can:

- Involve you in their activities.
- Encourage you to join community recreation programs or support groups.
- Arrange for you to attend social gatherings and fun activities.
- List all the phone numbers of the people you care about, allowing you easy access to them.
- Help you buy and write cards or letters to send to people.
- Give you rides to social events.

To find a support group near you, contact the American Stroke Association at **1-888-4-STROKE** or visit **stroke.org**. From the homepage, select the Help and Support tab at the top of the screen, then select Stroke Support Group Finder from the menu.

## GOING BACK HOME

After a stroke, you may be apprehensive about being on your own at home. Common fears you may have include:

- A stroke might happen again.
- You may realize the extent of your disabilities and be unable to accept them.
- You might eventually be placed in an assisted living facility or skilled nursing facility.
- Your loved ones may not be able or prepared to care for you.
- Friends and family will abandon you.

You may display these fears as anger, agitation or tension. Talk openly with your doctor and family to help ease your concerns. With a positive attitude, it will be much easier to find ways to overcome the difficulties.

## Home Modifications

### Renovating the Structure

Your home may need to be modified so that narrow doorways, stairs and bathtubs don't interfere with your ability to manage personal needs. Expenses of remodeling must be considered, as some families can't afford to pay for extensive structural changes or move to more accessible living quarters.

## Renovating the Environment

The alternative to costly renovations is to remove barriers and add assistive devices such as ramps and grab bars. A local rehabilitation hospital can usually give suggestions on assistive devices.

**Safety** is an important consideration when making adaptations to a home. Many areas of the home can be made safer by removing throw rugs and furniture that may cause an accident. It might be helpful to ask for assistance when in the bathroom or kitchen — depending on your strength, ability and judgment.

**Assistive devices** such as grab bars can help you use the toilet, tub or shower and can be installed at strategic spots in the bathroom. A raised toilet seat and a tub bench may be helpful. A handheld showerhead can be attached to the bath or shower faucet so you can take a shower while seated. Plastic strips that adhere to the bottom of the tub can help guard against falls. Long-handled brushes, washing mitts with pockets for soap or soap-on-a-rope aid in bathing. Electric toothbrushes, razors and hair dryers can also be useful.

## Daily Living Modifications

### Meal Preparation

Meal preparation is easier with small electric appliances such as food processors, mixers, blenders, toaster ovens, can openers and juicers. “Lazy Susans” placed on kitchen countertops and in low cupboards make spices and utensils more accessible. Dishes and pot lids can be stored vertically. If the countertop is too high, a substitute workspace can be made by opening a drawer at the desired height and placing a cutting board or breadboard over it, or by using a wheelchair lapboard. To reduce the time you spend on meal preparation, consider using Meals on Wheels, a program that will deliver one meal daily. Check with your local social services department to find out about this and other programs. Seniors can often get healthy, low-cost meals at senior centers. Check your local newspaper or the Internet for locations, times and menus.

### Eating and Nutrition

Eating healthier after a stroke is important to your recovery. Choosing healthier foods can help your energy level for therapy, exercise and favorite activities. Be sure to plan and keep things as simple as possible.

Maintaining a healthy body weight is important for everyone, including stroke survivors. You can work with your health care team to create a plan that can keep you at a healthy body weight. Carrying extra body weight can make it harder for someone with a stroke-related disability to move around and exercise.

- Eat a healthy diet that includes a variety of fruits and vegetables, whole grains, low-fat dairy products, skinless poultry and fish, nuts, legumes and non-tropical vegetable oils.
- Limit saturated fat, trans fat, sodium, red meat, sweets and sugar-sweetened beverages.
- Choose pre-washed, pre-cut fruits and vegetables from the grocery store.
- Ask friends or family members to make healthy meals that can be stored in the refrigerator or freezer.

### Nutrition Resources

You can get nutritional charts, recipes and other suggestions for restricted diets from many sources, including your state health department, the local Office on Aging, public libraries or stroke support groups and other self-help groups.

- Check out healthy recipes at [recipes.heart.org](http://recipes.heart.org).

### Special Utensils

Special utensils can help if your arms and hands are impaired. These include flatware with bigger handles that are easier to grasp, rocker knives for cutting food with one hand and attachable rings that keep food from being pushed off the plate. Rubberized pads under the plate help keep it from sliding. These devices are available online or through medical supply stores.

### Swallowing

Difficulty or discomfort in swallowing (dysphagia) is common after stroke. Dysphagia can lead to malnutrition, dehydration, weight loss and overall decreased quality of life. Identifying this condition early and implementing appropriate interventions (swallowing exercises, therapies, environmental and dietary modifications) will help with its management.

If you have trouble swallowing, you may need to be observed while eating so that you don't choke. Choose soft foods. Tougher foods should be cut into small pieces or pureed. Your beverages may need to be thickened to keep them from going down the wrong

way. Natural thickeners include tapioca, flour, instant potato flakes, oats and matzo meal. Consult with a speech and language therapist for additional help with swallowing problems. If you can't obtain adequate nutrition by mouth, a dietitian can suggest dietary supplements or alternative means of food preparation and eating.

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## Diet Concern for Stroke Survivors with Diabetes

A stroke can change the severity of your diabetes or eating problems can interfere with your previous diabetic diet. If you require insulin treatment for your diabetes, it's particularly important that you consult with a registered dietitian. Also, some stroke survivors with diabetes who previously gave themselves daily injections of insulin will need training by a nurse or occupational therapist on how to do this with one hand. This training should be done before leaving the hospital. These resources can provide you with additional information:

- American Diabetes Association: **1-800-DIABETES (1-800-342-2383)**, [diabetes.org](http://diabetes.org)
- Know Diabetes by Heart: [knowdiabetesbyheart.org](http://knowdiabetesbyheart.org)

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## Dressing and Grooming

Dressing yourself is a form of independence and can enhance your self-image. If you're able, it's good to try to change from nightclothes and robes into comfortable day wear.

You can minimize the difficulties of getting dressed in several ways:

- Avoid tight-fitting sleeves, arm holes, pant legs and waistlines, as well as clothes that must be put on over the head.
- Wear clothes that fasten in front.
- Replace buttons and zippers with Velcro fasteners.
- Substitute a cape for a coat and Velcro closures on shoes for laces.
- Avoid shoes that stick to the floor that could possibly cause a fall.

Certain devices can aid in dressing and grooming, including a mirror that hangs around your neck, a long-handled shoehorn or a device to help pull on stockings. These and similar items can be found online or in medical supply stores.

A systematic approach can make it easier to get dressed. You or a caregiver can lay out your clothing for the day. Safely seat yourself to the extent possible and allow enough time for dressing.

If you work with an occupational therapist, he or she may visit your home and recommend adaptations.

## Oral Hygiene

Oral hygiene care is important for maintaining good health and reducing the risk of serious illnesses. Keep your mouth thoroughly clean, including the tongue, roof of the mouth and dentures. Clean your mouth after every meal. Talk to your dentist if you have dry mouth or decayed teeth. He or she may help you deal with these conditions.

## Bowel or Bladder Control

Loss of bowel or bladder control is a common condition for stroke survivors that can be distressing. Trouble urinating may also be a problem. Talk to your caregivers or health care team about your bowel and bladder control. You may need to use a small, flexible tube called a catheter to urinate. It's important to rule out urinary tract infections. Medications may treat or prevent these conditions and you may need to consult a urologist.

Constipation and involuntary release of stool can also be a problem. These may result from:

- Reduced fluid intake
- What you eat
- Not moving around enough
- Side effects from prescription drugs
- Being unaware that you need to use the bathroom
- Weakness in the muscle that holds stool until you reach a bathroom
- Being unable or reluctant to ask for help

These ideas might help make these conditions easier to manage:

- Set up a regular toileting schedule, perhaps every two hours throughout the day. Also, try to use the bathroom immediately after meals.
- In the bathroom, use a raised toilet seat.
- Install grab bars in the bathroom to make it easier to get on and off the toilet.
- Stool softeners, mild laxatives, suppositories or small enemas (available in drug stores), as well as diet, can aid in bowel function and help to avoid constipation or impaction. Talk to your health care professional or a pharmacist before taking any medications or supplements to be sure that they won't interact with your other treatments.
- Use disposable or washable bed pads and underclothing, which are commonly available online or in drug stores and medical supply stores.

If getting to the bathroom during the night is a problem, it may help to:

- Limit fluids for two or three hours before bedtime.
- Use a bedside commode or urinal.
- Place your walker or cane near the bed for easy access.
- Leave a light on at night.
- Place a bell on the night table that can awaken a caregiver if needed.

## Medications

You, your family, your doctor and your pharmacist can work as a team to ensure that medications produce the desired benefits, particularly if they're taken for more than one condition. Before your stroke, you may have already been taking medications for high blood pressure, diabetes and other conditions. Your doctor or pharmacist can make sure that the combination of medications are safe and won't counteract each other or produce undesirable side effects.

Make a list of every medication, vitamin or dietary supplement you're taking or place all the bottles in a plastic bag and take them to the appointment. Be sure to include all your prescriptions (even those from the dentist) and over-the-counter drugs such as aspirin, laxatives, cough medications and pain relief pills. Include herbal remedies because they might interact with other medications. If you regularly drink wine, beer or liquor, the doctor needs to know that, too.

**Interactions** between medications may cause confusion, memory loss, insomnia, nervousness, hallucinations or depression. If medications are causing problems, the doctor may alter dosage or substitute other drugs.

Medications should be taken in the **prescribed dose** at the scheduled time, including weekends and holidays.

Unless directed by your health care professional, medication shouldn't be stopped because you feel better, nor should you take more than what's prescribed.

To help keep track of your medication schedule, you can use a medication dispenser, set reminders on your smartphone or use a medication tracker/reminder app. You can also ask a relative or close friend to give you a daily reminder. Ask your doctor for other suggestions and communicate any problems you may experience.

If you take medications for chronic illness, carry medical identification with you in case of an accident or other emergency. This makes doctors who treat you aware of your current illness and prescriptions. A wallet-sized card can usually be obtained from your local pharmacy. Drug stores and medical supply stores carry identification bracelets and necklaces that serve the same purpose.

## Pain Management

### Common Causes of Pain

Pain may be caused by many factors, including weakness of the muscles that support the shoulder, inflammation or improperly fitted braces, slings or special shoes. The source of pain is often nerve damage, bedsores or an immobilized joint. Lying or sitting in one position for too long causes the body and joints to stiffen and ache.

Sometimes damage to the brain following a stroke can make even normal touch feel painful. You may have one or several types of pain. The key is to figure out what's causing the pain.

### Types of Pain

Pain after stroke can be:

- Mild, moderate or severe
- Constant or on and off
- In one part or all of the side of your body affected by the stroke
- Felt in your face, arm, leg or torso (trunk)
- Aching, burning, sharp, stabbing or itching

### Ways to Manage Pain

Report pain to your doctor so that the cause can be determined and steps can be taken to ease it. Here are a few simple pain solutions you can try at home:

- Weakened or paralyzed arms or legs can be positioned or splinted to reduce discomfort.
- Heat packs or simple exercises may also help.
- Pain in the shoulder resulting from the weight of a paralyzed arm can be alleviated by supporting the arm on a lapboard or an elevated armrest, or with a pillow while lying in bed.

Ask your doctor about pain relievers compatible with your drug program.

## Driving Again

Most people consider driving an essential activity of daily life. Driving provides us with an easy way to get around, independence and self-assurance.

Driving is complicated, requiring multiple levels of information processing and mobility. The majority of survivors return to driving within a year after stroke. But people with perceptual problems are much less likely to regain safe driving skills.

The key to finding out if you're able to drive again is to participate in specialized training and evaluation by a health care practitioner. This person knows the physical and cognitive issues caused by stroke, as well as the difference between temporary changes in driving ability and a permanent inability to drive.

### Driver's Evaluation

A driver's evaluation usually includes:

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

### Driver's Training

Driver's training may include:

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

Instructors at most regular driving schools aren't prepared to teach stroke survivors, particularly those who have other hidden problems in addition to paralysis.

### Physical Problems and Solutions for Driving

- If you have use of only one hand, a spinner knob may be appropriate. A spinner knob is attached to the steering wheel and allows you to steer the car easily with one hand. If you're 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 reading or comprehension issues, learning the road sign symbols rather than words can be helpful.
- If you have trouble judging distances or have a visual field cut (hemianopsia), you shouldn't drive. You may endanger yourself and others on the road.
- If you're unable to use left extremities, a directional signal extender may be helpful.

### Steps to Consider

- If you're receiving rehabilitation services, speak to your occupational therapist about driving. Occupational therapists can provide driver evaluations, treatment, educational resources and guidance to people who want to drive again.
- Become familiar with the resources in the community such as public transportation services, volunteer ride programs, taxis, etc.

### Finding Driver Evaluations and Training

To locate a qualified driver education and training program in your area, you can:

- Ask your doctor or the physical or occupational therapist at the hospital where you were treated.
- Contact the state office of vocational rehabilitation or your local Department of Motor Vehicles.
- Go to [aota.org/olderdriver](http://aota.org/olderdriver) for extensive information on driver rehabilitation. It also includes a searchable database of national driving rehabilitation programs.

### Easing Back Into Life

The things you enjoyed before your stroke can be adapted for almost every situation. Pleasurable pursuits can help shift attention from disability to your abilities and can enhance your self-esteem and confidence. Leisure and recreation activities can also improve perception and coordination and strengthen muscles.

For example:

- If you like to cook, you may be able to peel and slice vegetables, put frosting on a cake, roll out pastry dough or assemble salads from a stable position in a wheelchair, seated or supported standing stance.
- If you like gardening, you might be able to tend to potted plants on the window sill and start new plants from cuttings.
- If you enjoy needlework, you may be able to continue with your hobby using a special clamp and embroidery hoop to hold the fabric steady.
- If you like to read but are visually impaired, braille, large-type books and "read aloud books" are available.
- Leisure activities can be done individually or as a group. Social leisure activities are at community centers, senior centers, churches, municipalities and other organizations offering recreation programs.

Recreation and leisure activities can promote health by providing a buffer for stress and can create a sense of balance. Similarly, pleasurable activities such as watching an entertaining movie can enhance your mood. Recreation may be central to feeling a part

of your community and having a good quality of life. This is especially true of activities that help you feel involved in the neighborhood, such as eating in a restaurant, visiting a library or walking in a park.

Some leisure activities can help you build skills and transition to volunteer opportunities, continued education and a return to work. The social worker or case manager who worked with you can suggest resources in your community to assist with this transition.

### Setting Goals

Recovering from a stroke begins with the hospital but continues at home. To achieve as much progress as possible, you and your caregiver need a plan.

Many stroke survivors feel that they have lost control of their lives. Developing a plan can help restore the capacity to make decisions and execute choices. In the months following a stroke, the rate of recovery inevitably slows. Because the gains are no longer as large and dramatic, it's easy to become discouraged and overlook the progress you've made.

In everyday life, we rely on our work, family and community activities, as well as our hobbies and interests, to give us a sense of structure, purpose and self-worth. After your stroke, you may find that physical changes require you to develop new interests and involvement so that you can continue to feel positive about life under changed conditions.

Developing these new interests, strengths and abilities can be made easier by setting long- and short-term goals. Setting goals can help you deal with the discouragement that comes during the recovery period. A crucial part of setting goals is examining what you can reasonably accomplish. This must consider what you would like to do given your current abilities. Goals may be for physical improvement or personal growth. Physical improvements might result in your ability to independently care for yourself. Personal goals might focus on relearning a skill such as driving or developing a more rewarding relationship with your family and friends. For more information on how to set goals, see **Chapter 4**.

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# CHAPTER TWO

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## CHANGES IN BEHAVIOR, EMOTIONS AND THINKING FOLLOWING STROKE

A stroke can cause many bewildering changes in a person's emotions and behavior. Stroke survivors' brains have been injured and the behaviors and emotions they may display can be a reflection of that injury. Understanding and dealing with such changes are just as important as the physical issues dealt with in rehabilitation.

### Depression

As the survivor and family members come to grips with the stroke and its resulting disabilities, depression can be a natural reaction. However, depression can sometimes become serious enough to impair functioning and inhibit the survivor's recovery. It's important to identify warning signs. Depressed people:

- Frequently express feelings of worthlessness, low-self-regard, and harsh self-criticism
- Have the desire to hide or isolate themselves — these emotions can prevent you from engaging in activities that might help increase your self-esteem
- Exhibit changes in appetite and weight
- May attempt or talk about suicide

This can be a dangerous cycle, as depression results in increasing isolation and despair. Depressed feelings are a normal part of grief, but when they seem to go on and on, it is necessary to seek professional help from a social worker, psychologist or other trained mental health professional.

## What to Do About Depression

Family members can help by trying to stimulate your interest in other people, encourage leisure activities and nudging you to participate in spiritual activities that fit your values and lifestyle. You might consider attending a stroke support group to help with depression. For a list of groups in your area, contact the American Stroke Association at **1-888-4STROKE** or visit **stroke.org**. Or connect with others sharing similar journeys with stroke by joining our Support Network at **stroke.org/supportnetwork**.

Depression may be treated with a combination of individual or group therapy and/or antidepressant drugs.

**Counseling** is extremely helpful in treating depression. It can also be very helpful to deal with the painful and self-defeating emotions of depression by developing new perspectives and ways of experiencing yourself as strong, valuable and whole again. At first glance, it may seem backward to try to change how you feel by changing how you act.

### Take these steps to combat depression:

- Be as physically active as possible.
- Schedule daily activities to provide structure and a sense of purpose.
- Enjoy social activities that stimulate and help enhance language recovery and self-esteem.
- Set goals to measure your accomplishments. Start with mini goals and applaud yourself every step of the way.

## Anger

Feelings of anger and resentment are also common for survivors following their stroke. Such feelings may be expressed verbally or physically, or by withdrawing from others. Some stroke survivors may express their anger more openly by being overly critical of other people. In some cases, the survivor may not be angry with others, but with the stroke itself.

When a survivor becomes upset, he or she may take anger out on others. When this happens, the caregiver should keep her or his own emotions under good control. It may be necessary to leave the survivor's presence for a while until his or her control is regained. In a firm but understanding manner, make a positive supportive comment such as, "I know this must make you really angry, let's see if we can work through it together." It's important for caregivers to devise a plan to react and deal more effectively with the anger that may result from stroke.

## Emotional Lability *(also called pseudobulbar affect, or PBA)*

Emotional lability is a physical brain condition that causes spontaneous, uncontrolled, emotional reactions. For example, the stroke survivor may burst into tears or laughter for no apparent reason. The frequency of emotional lability is greatest in the first few months after the stroke and most often slowly fades away over time.

The best approach for dealing with emotional lability is to accept the behavior in a matter-of-fact manner. If the survivor is known to be labile, the caregiver should continue the conversation or activity and ignore the display of emotion. If the stroke survivor apologizes, the caregiver should remind the survivor that the symptom is due to the stroke to diminish embarrassment and continue the current activity or discussion.

Medication may be prescribed to help the problem, though it frequently lessens and may go away on its own over time.

## Left-Brain Injury

Along with some right-side paralysis and communication problems, left-brain survivors may experience personality changes. In contrast to those with right-brain injuries, survivors with left-brain damage tend to behave in a cautious, compulsive or disorganized way and are easily frustrated. These behaviors and emotional responses may be related to speech and language problems in which the survivor is slow to respond to questions or to take action.

Mood and behavior changes associated with a left-brain injury can be frustrating to the survivor and caregiver. To help the survivor perform as normally as possible:

- Develop strategies that will allow the survivor to function at a comfortable pace. Be sure to organize daily routines and schedules.
- Recognize and deal with fatigue — a major barrier to recovery. Encourage the person to ask for help or to pass on duties to someone else that will allow wiggle room in returning to his or her life and ease guilt about frustrating limitations.
- Be patient. Give survivors time to respond to your questions or comments. Don't rush them or respond for them.
- Give immediate and frequent feedback — verbally, with gestures or both.
- Keep questions and comments simple. Questions should be stated so that the survivor can give a yes or no answer.
- Speak in a normal voice unless you know the person has a hearing problem.

For those around people with aphasia daily, developing strategies that allow them to function at a comfortable pace will help them to accept themselves. This initially involves constant reflection and planning.

## Right-Brain Injury

Behavioral changes can vary depending on the severity of the stroke and what part of the brain has been affected. The right hemisphere in most people typically heavily influences emotions, nonverbal communication and spatial orientation (sense of body position). Among an array of emotional and behavioral problems, an impulsive style can be dangerous to the individual. Right-brain stroke survivors may be unaware of their impairment and be certain that they can perform the same tasks as before the stroke. They may also experience emotional lability, short attention span, short-term memory loss and poor judgment.

The spatial-perceptual difficulties of stroke survivors with right-brain injuries are often overlooked. When they have difficulties performing simple activities, they may be seen as uncooperative, overly dependent, confused or unmotivated. Once the limitations of right-brain injury are realized, you can better deal with these problems by:

- Keeping the environment safe. Potentially dangerous items such as sharp objects, cleaning agents and poisons may need to be kept out of reach of the right-brain survivor.
- Monitoring the person's activities. If left unattended, the stroke survivor may become confused or injured.
- Being sensitive to the visual and sensory problems of stroke survivors. For example, if people can't perceive things on their left side, place items they may need on their right.
- Encouraging them to acknowledge the affected half of their body as part of them.
- Frequently reminding them of the affected side by touching or rubbing it or asking the survivor to massage it.
- Encouraging them to scan (turn their heads from side to side) to see what they usually ignore on the affected side.
- Minimizing distractions and clutter in the stroke survivor's environment. Too much auditory and visual stimulation can add to his or her confusion and may be dangerous. A quiet, calm environment can help the person focus on the task at hand.
- Preventing injuries caused by the survivor's inability to determine the depth and distance by clearly marking pointed edges on furniture, doorways and other items.

Although stroke survivors with right-brain injuries don't have aphasia (see **Chapter 3**), they frequently have other kinds of speech and communication problems. Many have difficulty pronouncing speech sounds properly due to weakness or problems controlling their mouth and face muscles. They may also have trouble interacting normally as a result of problems with their "thinking" skills. A speech and language pathologist can help the right-brain stroke survivor and family members address these kinds of communication problems.

Left Brain	Right Brain
<p>If the stroke occurs in the left side of the brain, the right side of the body will be affected, producing some or all of the following:</p> <ul style="list-style-type: none"><li>• Paralysis on the right side of the body</li><li>• Speech/language problems</li><li>• Slow, cautious behavioral style</li><li>• Memory loss</li></ul>	<p>If the stroke occurs in the right side of the brain, the left side of the body will be affected, producing some or all of the following:</p> <ul style="list-style-type: none"><li>• Paralysis on the left side of the body</li><li>• Vision problems</li><li>• Quick, inquisitive behavioral style</li><li>• Memory loss</li></ul>

## Apathy

Strokes can affect the parts of the brain that get us going, stimulate our interest in things and drive us to want to be active and stay involved in the world. Post-stroke apathy is different from depression (although it may look like it) and may require an evaluation by a neuropsychologist. Treatment may be different from that for depression.

## Memory Loss

You may need reminders or prompts to finish a sentence or certain tasks. Try these tips for managing memory loss:

- Have a place for everything and put things away where they belong.
- Have a routine.
- Post both daily activities and special events on a calendar.
- Keep a notebook of important information handy.
- Use memory cues by connecting a task or piece of information to something meaningful, such as an image, familiar name or song.
- Break tasks down into easy steps.

## Perception and Concentration Problems

These are common after stroke. Social situations can be especially difficult for people with these problems. Attend small, quiet, slow-paced gatherings. Physical activity or cognitive rehabilitation may help improve attention and executive function.

## One-Sided Neglect

Damage to the right side of the brain can cause you to neglect literally half — usually the left side — 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.

## The Grieving Process

Shortly after a stroke, survivors and families begin to comprehend their losses and go through a grieving process, much like those who have experienced death or divorce. You and your family may feel as if you're on an emotional roller coaster. This is normal.

Recognizing common stages of grief can help you cope with the emotional changes that go along with a stroke. It can also help friends and family members better understand your thoughts, feelings and actions.

Grieving is a gradual healing process that takes time and work. Each person moves at his or her own rate. You may not go through every stage or each stage in order. One stage doesn't abruptly stop so the next can begin.

### Stage 1: Shock

Shock usually occurs during the initial phase of hospitalization or rehabilitation. A feeling of helplessness may accompany the shock. During this step, the support of family and friends is extremely important.

### Stage 2: Denial

An inability to believe that something terrible has happened after a crisis or a great loss is normal. Denial lets you and your family escape the overwhelming aspects of the disability. You may be more motivated to work toward recovery than to learn to function with a disability. The focus should be on the "here and now" and the new realities you must face.

### Stage 3: Reaction

This stage begins when you and your family start to realize the full impact of the disability. The most common psychological reactions are anger, bargaining (with God or others), depression and mourning of losses and changes. If these reactions interfere with rehabilitation or usual activities, it's important to talk to 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. Family members start 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 disability stroke has caused. 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 isn't a one-time thing, and it doesn't mean a person won't sometimes have strong feelings about changes, losses or problems. But it means those feelings won't keep you from feeling hopeful and grateful about being alive.

## RELATIONSHIPS AND INTIMACY

Part of getting back into a normal routine involves resuming a healthy sex life. The need for love and to be loved, and to have the physical and mental release sex provides, is important. However, having sex after stroke can present problems or concerns for you and your partner. Consult with a psychologist if this is a problem after your stroke.

Stroke can change your body and how you feel. Both can affect sexuality. Stroke survivors often report a decrease in sexual desire. Women report a strong decrease in vaginal lubrication and the ability to have an orgasm. Men often have weak or failed erections and ejaculations.

## Factors Affecting Sexuality

### 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. Medications and/or counseling can be effective.

### Fear of Further Damage

Most stroke survivors can resume a happy and healthy sexual life. However, check with your doctor before resuming sexual activity.

### Personality Changes and Impotence

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 help with 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 hinder your sexual relationship, discuss this with a psychologist or mental health care professional.

## Common Physical Obstacles

### Paralysis and Sensory Loss

If there is sensory loss, it's helpful to be aware of this. If there's paralysis, experimenting with different positions for sexual intercourse is advisable.

### Difficulty with Speech

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

## Impotence Caused by Medications

In the male stroke survivor, if there is no morning erection, impotence may be a result of medications. Some blood pressure or heart drugs, diuretics, anti-depressants, tranquilizers, sedatives and alcohol may decrease sex drive. If this has happened, it's important to let your doctor know, as medications may be altered to resolve the problem.

## External Collecting Device or Internal Foley Catheter

A catheter does not need to be a barrier to sexual enjoyment. With men, simply remove the external collection device. 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 it back along the penis and apply a condom. With women, the catheter can stay in place. Disconnect it from the leg bag and clamp it or remove and reinsert the catheter later.

If impotence or sexual difficulties don't resolve, treatments for dysfunction may help. These problems are not always permanent. Some doctors and psychologists specialize in this area. Your psychologist, doctor or 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 are all a part of sexual communication that goes beyond words. After the separations and loss caused by a stroke, a couple can reclaim a closeness that's unique to them.

## What Can Help

- Ask your doctor about changes to expect when having sex and for advice on how to deal with them.
- Be sure to discuss when it's safe to have sex again.
- Focus on being loving, gentle and caring with each other.
- Speak honestly with your partner about your sexual changes to work out the best solution.
- Get more information on sexuality from the American Stroke Association.
- Join a stroke support group. Often survivors will understand, validate your issues and offer encouragement and ideas.

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# CHAPTER THREE

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## APHASIA

Simply defined, aphasia is the loss of ability to communicate normally resulting from damage to the left side of the brain, the center of communication. It may affect a person's ability to express himself through spoken language and to understand what others say, as well as the ability to read, write or deal with numbers. Intelligence is not lowered, although the inability to communicate may leave the impression that the person with aphasia is less intelligent than he or she actually is.

No two people with aphasia are affected in exactly the same way. The extent and range of deficits depend on the location and severity of the brain injury.

## Types of Communication Problems Resulting from Aphasia

### Speaking

Problems with spoken expression vary greatly among people with aphasia. Some people are able to speak at a normal rate. Others speak slowly, with pauses and great difficulty. Some can produce only a few words or phrases but may be capable of uttering obscenities when angry. Less commonly, a stroke survivor may be unable to speak at all. Most people with aphasia need extra time to express their ideas and respond to questions. The language of people with aphasia often contains errors. For example, they may say "dog" instead of "horse" or "may" instead of "hey." Some people speak at a normal rate but their language makes little or no sense. Some use nonsense words. Some are aware of their errors while others are not.

People with "word-finding" problems may frequently pause during a conversation, use nonspecific words (like "thing" or "it") and make word errors. They may struggle and become frustrated while trying to find the right word. Attempting to get their message across in other ways, such as describing the object or using gestures, can often help them communicate more effectively.

## Understanding Others' Speech

Many people with aphasia have trouble understanding others. Comprehension problems may be mild, occurring only when others use lengthy and complex sentences. Still, some will have trouble understanding simple sentences or even single words. Using simple language, short sentences and familiar words, and repeating when necessary, often helps people with aphasia understand better. Gestures and visual information (such as objects or demonstrations) can also be helpful.

## Reading and Writing

People with aphasia often have trouble reading aloud or understanding what they are reading. They also may have difficulty writing and spelling. Their problems with reading and writing are often similar to their difficulties with speaking and understanding speech.

## Types of Aphasia

There are several types of aphasia, depending on what parts of the brain are impacted by the stroke. In general, aphasia may be classified as "fluent" or "nonfluent." A speech-language pathologist or a neurologist can help determine the type of aphasia.

### Nonfluent Aphasia

Speech is produced slowly and with difficulty. It may consist of only single words or short sentences with missing words. In an attempt to communicate, the person with aphasia often uses hand and face gestures. Common types of nonfluent aphasias include global aphasia and Broca's aphasia.

#### Global Aphasia

This is the most severe form of aphasia. As the term indicates, there is great difficulty with all language functions — comprehension or understanding, reading, talking, or even repeating what is heard. Sometimes, the only thing that the person with aphasia can say is the same sound or word over and over again.

#### Broca's Aphasia (Expressive Aphasia)

For people with this type of aphasia, understanding is better than their ability to express themselves. They often understand most everyday conversations. Language output is slow and hesitant, with frequent pauses. Sometimes, the person may not be able to produce any words. Other times, he or she can say words or put a few words together to make partial sentences.

### Fluent Aphasia

Though speech may be normal or rapid, incorrect words or sounds are substituted. The person may say "dog" when he or she means "horse," or "may" instead of "hey."

Sometimes the person with aphasia may not realize these errors even after the words are spoken. Common types of fluent aphasias include Wernicke's aphasia, anomic aphasia and conduction aphasia.

#### Wernicke's Aphasia (Receptive Aphasia)

People with this type of aphasia hear sounds and words but do not understand what they mean. Their speech is fluent with frequent sound and word substitutions so that it does not always make sense. People with Wernicke's aphasia are not aware of this and do not monitor their own speech.

#### Anomic Aphasia

Understanding is good. The major difficulty is in naming even common objects or places. Because of the difficulty finding words, they may frequently pause during conversation, use nonspecific words (such as "thing" or "it") and make word errors.

#### Conduction Aphasia

Understanding is quite good. Speech remains somewhat normal but trouble occurs in repeating anything said by another person. Also, it's hard to find the right words or express ideas.

## Dealing With Aphasia

The thinking skills of those with aphasia are generally unimpaired; therefore, it is essential to treat the person as an intelligent adult. The brain is like a muscle; unless it is exercised, it eventually loses its abilities. With this in mind, stimulation from outside the home is critical. Although the tendency of many persons with aphasia is to avoid social situations, they need to take an active role in their recovery, explaining to others that they have a language problem due to stroke. Most listeners will be patient and even generous in helping the person re-establish his or her place in society.

Stroke-related aphasia typically improves in the first weeks, with **improvements in speech and language** continuing for months and even years. Some stroke survivors become increasingly able to benefit from therapy once they have had time to adjust to the major life changes caused by the stroke. If the involvement of health care professionals is needed, an individualized team approach is preferable. Since emotional responses such as anger, distress, depression, anxiety, low self-esteem and dependency are common, counseling is sometimes advised.

### For More Information

- National Aphasia Association (NAA): [aphasia.org](http://aphasia.org)
- American Speech-Language-Hearing Association (ASHA): **1-800-638-8255**; [asha.org](http://asha.org)
- National Academy of Neuropsychology (NAN): **303-691-3694**; [nanonline.org](http://nanonline.org)



## CONNECT WITH A **STROKE SUPPORT GROUP**



A stroke changes a survivor's life – and their loved ones' lives – in an instant.

Stroke support groups enable you to connect with others to share experiences, learn helpful information and help ease the depression and isolation that is so common after stroke.

Find a stroke support group in your area today.

**[stroke.org/SupportGroup](https://stroke.org/SupportGroup)**

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# CHAPTER FOUR

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## **SELF-ADVOCACY**

Recovery after a stroke almost always takes more time and effort than anticipated. But you can do things to make the journey easier. This chapter provides a map for your stroke recovery journey.

It's essential to recognize that you're not a victim — you're a survivor. Taking a positive approach to your recovery is the single most important step you can take. Different people — including family or members of your health care team — may tell you not to get your hopes up, or to only expect a certain amount of progress. While a significant portion of recovery is done within the first six months to a year after a stroke, progress can be made years later. Remember, recovery is a lifelong journey. Stay positive. Stay the course.

**Advocacy** means “active support,” especially the act of pleading or arguing for something. **Self-advocacy** is being a supporter, believer, encourager and activist of and for yourself. It's standing up for your needs in a clear, specific and firm way. It's being unafraid to ask for help.

### **Why is Self-Advocacy Important?**

Having a stroke can be overwhelming — taking away your control over your physical and mental health and well-being. Self-advocacy empowers you to take responsibility in making the most of your recovery from stroke. You have a say in what you want and need and can directly impact your quality of life.

### **Self-Advocacy Steps**

#### **Prevent another stroke**

Do what your doctor prescribes to prevent another stroke. This includes monitoring your blood pressure, finding out your cholesterol numbers and controlling them, quitting smoking, etc. (See **Chapter 5**.)

## Educate yourself

Gather information to help you understand what has happened to you and what to do next. Learn about stroke, your disabilities and treatment options. Find out what resources are available to you. You can:

- Read books, pamphlets and fact sheets.
- Watch informational videos or DVDs or listen to podcasts.
- Browse the web or have a friend or family member do it for you.
- Attend a workshop or seminar.
- Join or visit a stroke support group.
- Talk to a social worker, case manager or community resource specialist.
- Contact the American Stroke Association at [stroke.org](http://stroke.org) or 1-888-4STROKE.
- Connect with others who have also had an experience with stroke by joining the American Stroke Association's Support Network at [stroke.org/supportnetwork](http://stroke.org/supportnetwork).

## Ask questions

Seek out and listen to people who are familiar with or specialize in stroke and rehabilitation. This includes members of your health care team, stroke experts in the community and other stroke survivors. If you're uncertain or not satisfied with what they're telling you, seek a second opinion.

## Determining Wants and Needs

Many considerations go into planning your care after hospitalization. Your needs and resources are key. Many families have found it helpful to consider several alternative plans. Your social worker and therapists are the best sources of accurate, reliable information on options that fit your values and resources. Together with your family, take a realistic inventory of your strengths and weaknesses when addressing the following areas and questions:

### Physical

- Can you transfer from a wheelchair to a bed independently?
- Can you move independently while walking or in a wheelchair?
- Can you control bowel and bladder functions during the day and night?
- Can you carry out basic independent daily activities (dressing, personal hygiene, etc.)?
- What are your communication limitations? Can you call for help?
- To what degree are visual and perceptual problems present?

- Do you have special care needs such as a catheter, diabetes, etc.?
- What is the physical layout of the place of residence?

### Emotional

- Do you or others think that you behave appropriately?
- Have you experienced emotional difficulties in the past or present, such as severe depression? If so, what kind of special care is needed?
- Do you thrive on social activity or is there a strong need for privacy?
- How do you feel about not living at home?

### Anticipated Improvement

- What is your potential to improve in each of these areas?
- To achieve your goals, do you require follow-up services such as outpatient or home-based occupational therapy, physical therapy, speech therapy, psychotherapy, etc.?

### Financial

- What are your financial resources, including insurance to cover needed services?
- Are you eligible for assistance through government programs such as Medicare, Medicaid, Social Security Disability, etc.?

### Caregiver Needs and Limitations

- What are other responsibilities for the potential caregiver? (Include family, work, community and recreational commitments.)
- Is the caregiver emotionally and physically healthy?
- What are the family's financial resources?
- How does your family feel about caring for you?
- What were relationships like before the stroke?
- How has the stroke affected those relationships?
- How does the potential caregiver feel about the changes in you?
- Is time spent together rewarding for all involved?
- Is guilt or external pressure involved in their decision to help care for you?

It's best to address these questions before discharge from the hospital or before your care. Remember, decisions should be based on your situation — not on a family member or what you think is expected of you.

## Goal Setting

### Developing Goals

Developing goals or a plan can help you make decisions. In the months following a stroke, the rate of recovery predictably slows. Don't get discouraged. Most hospital rehabilitation programs are in a highly structured environment where you follow a daily schedule of therapies. You'll be around supportive and understanding people. Isolation and inactivity are rarely a problem.

Upon returning home, you can feel overwhelmed by all the spare time. In everyday life, we rely on work, family, community activities, hobbies and interests for a sense of purpose and self-worth. After your stroke, physical changes may require you to develop new interests to feel good about life.

Developing new interests, strengths and abilities is easier when you set short- and long-term goals. So plan daily activities.

Setting goals can help you deal with discouragement during recovery. A crucial part of setting goals is examining what you can reasonably accomplish with your abilities and disabilities. Be realistic and flexible. Set a time to complete your goals. And consider four main areas:

- Physical rehabilitation
- Recreational/social
- Family/community
- Personal

In each area, certain activities are necessary to reach goals. Breaking each step into smaller parts can help your family and you see progress. Place your goals in the category that seems most sensible to you.

### Achieving Goals

You must be able to tell when you've accomplished goals by measuring tangible results. "Doing a better job at my leg exercises" isn't specific enough. "Walking around the block with my cane" is measurable.

### Setting Long-Term Goals

To begin, write down your long-term goals in each of the areas described earlier — physical rehabilitation, recreational/social, family/community and personal. Take your time during quiet moments to think carefully and learn more about yourself.

## Setting Short-Term Goals

Short-term goals are measurable and may be necessary to accomplish long-term ones. They can also be independent activities. For example, if your long-term goal is to join a stroke club, your short-term goal might be to find clubs in your area.

## Problem Solving

When you encounter unusual periods of stress, problem-solving methods that worked in the past may break down. Sometimes stress makes even small problems seem overwhelming. You can't anticipate all problems your family and you may encounter upon leaving the hospital or rehabilitation program. But techniques such as the ones listed below can help solve them. Keep in mind that problems need to be solved one at a time.

- Identify the problem clearly.
- Acknowledge the problem.
- Write down your thoughts and responses to the problem.
- Identify possible causes.
- Decide what you want to accomplish.
- Brainstorm solutions.
- Review your solution list.
- List things you'll do to solve the problem.
- Seek help from an expert about possible solutions.

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# CHAPTER FIVE

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## PREVENTING ANOTHER STROKE

Having a stroke increases the risk for a recurrent stroke. Up to 80% of second strokes may be prevented through lifestyle changes and medical interventions. Here are the facts:

- About 1 in every 4 survivors will have another stroke.
- Of the nearly 800,000 strokes in America each year, about 185,000 are recurrent.

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**Preventing another stroke starts with knowing the underlying cause of the first one. Talk to your doctor about whether further testing may help determine it. Once you know the cause of your stroke, work with your doctor to develop a plan for preventing another one.**

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## Your Lifestyle Choices

You can't control some stroke risk factors. You can control others.

### Stroke risk factors you can't change include:

- Age (the older you are, the higher your risk)
- Gender (females have a higher lifetime risk of stroke than males)
- Being African American, Hispanic or Latino
- Family history of stroke

Having one or more of these factors doesn't mean you'll have a stroke.

Simple lifestyle changes can reduce the risk of a first or recurrent stroke:

- Monitor your blood pressure; if it's high, get it treated.
- Find out if you have atrial fibrillation, an irregular heartbeat that allows blood to pool in the heart and cause blood clots.
- Quit smoking.
- Limit alcohol.

- Check your cholesterol levels and control bad cholesterol.
- Manage your diabetes.
- Exercise regularly.
- Eat foods low in sodium (salt) and saturated or trans fats.
- Monitor circulation problems with the help of your doctor.

## Monitor Your Blood Pressure

High blood pressure is an important and controllable stroke risk factor.

Blood pressure is two numbers. An example is "120/80". The first number is systolic, the force your blood exerts on blood vessel walls as your heart pumps. The second is diastolic, the force your blood exerts on blood vessel walls when your heart is at rest between beats.

For people over age 18, normal blood pressure is less than 120/80 millimeters of mercury. A reading of 120-129/80 or higher is considered elevated. If yours is in this range, you're more likely to develop high blood pressure. A reading of 130 or higher and 80 or higher is called hypertension.

Have your blood pressure checked at least once each year. If you have high blood pressure, have had a heart attack or stroke, have diabetes, kidney disease, high cholesterol or are overweight, have your blood pressure checked more frequently, maybe as often as once a month, until you respond to treatment. If you're at risk for high blood pressure, ask your doctor how to manage it more aggressively.

Sometimes blood pressure can be controlled through diet and exercise. Even light exercise, such as a brisk walk, bicycle ride or swim can make a difference. Adults should get at least 150 minutes per week of moderate-intensity aerobic activity. Before you start an exercise program, check with your doctor.

## If Your Blood Pressure is High

If you still have high blood pressure after eating healthy and exercising, talk to your doctor. Common classes of blood pressure medication include:

- Diuretics
- Beta-blockers
- ACE inhibitors
- Angiotensin II receptor blockers
- Calcium channel blockers
- Alpha blockers
- Alpha-2 receptor agonists
- Combined alpha and beta-blockers
- Central agonists
- Peripheral adrenergic inhibitors
- Vasodilators

Try not to be discouraged if some medication adjustments are made to determine your treatment. That's common. Once you find a drug that works, take it as prescribed, even when you feel fine.

## Medications

Drugs may also help reduce stroke risk by controlling high cholesterol, treating heart disease and affecting the blood's tendency to form potential stroke-causing blood clots.

## Heart Disease

Atrial fibrillation, or AFib, is an irregular heartbeat that may cause blood clots that travel to the brain. AFib is associated with a 5-time greater risk of stroke. People with AFib are treated with anticoagulants and antiplatelets and should be regularly monitored by a health care professional.

## High Cholesterol

High levels of a waxy substance called cholesterol may increase stroke risk by not letting blood move freely through the arteries. Cholesterol buildup can break off, causing a clot to form or a stroke to occur. Several drugs, including a class of drugs called statins, may help lower cholesterol. The risk of having another stroke can be lowered by taking a statin.

## Blood Clotting

Anticoagulants and antiplatelets are two types of drugs to prevent clotting and reduce stroke risk.

## Surgical Options

For those whose first stroke was caused by a blockage in the carotid arteries (vessels that carry blood from the heart to the brain), surgery known as carotid endarterectomy may help reduce risk of a recurrent stroke. During surgery, blockages and buildup in the arteries are removed to restore the free flow of blood. Your doctor is the best source to decide if this is a good option for you.

## Adherence is Critical

The key to preventing recurrent stroke is simple: Follow your doctor's recommendations about diet, exercise and weight loss, and take medication as directed. Your doctor will decide what's best for you based on your general health and medical history. By understanding the basis for these decisions, you'll be better able to follow the suggestions and make informed choices that will help reduce your risk of stroke.

## TRANSIENT ISCHEMIC ATTACKS (TIAS): A WARNING SIGN FOR STROKE

Stroke prevention is also crucial for those who have had transient ischemic attacks (TIAs), also known as "warning" strokes. TIAs are brief episodes of stroke-like symptoms that last from a few minutes to 24 hours. TIAs don't cause permanent disability, but they can be serious warning signs of an impending stroke. Up to one-third of people who have a TIA are expected to have a stroke, and most of these will occur in the first few days to weeks after the TIA. Just like a first stroke, many recurrent strokes and TIAs can be prevented through lifestyle changes, surgery, medication or a mix of all three.

## Symptoms of TIA (and Stroke)

The symptoms of TIAs are the same as for stroke. They vary depending on which part of the brain is affected:

- Sudden numbness or weakness of face, arm or leg, especially on one side of the body
- Sudden confusion, trouble speaking or understanding
- Sudden severe headache with no known cause

B.E. F.A.S.T. is an easy way to remember how to recognize a stroke and what to do.

# B.E. F.A.S.T.

Balance  
Loss

Eye (Vision)  
Changes

Face  
Drooping

Arm  
Weakness

Speech  
Difficulty

Time to  
Call 911

If you have any of these symptoms, even for a moment, or notice them in someone else, seek medical attention immediately. Don't wait for the symptoms to go away, because you can't tell whether you're having a stroke or TIA. If you're having a TIA, a doctor can evaluate, treat the causes and set up a plan to prevent a stroke.

## Different Causes of TIAs

Three factors generally cause TIAs:

- Low blood flow at a narrowing in a major artery to the brain
- A blood clot in another part of the body breaking off and temporarily lodging itself in a brain blood vessel
- Narrowing in one of the smaller blood vessels in the brain, stopping blood flow temporarily

Unfortunately, most people who have TIAs don't seek treatment, either because the symptoms come and go quickly and are painless, or because they think their symptoms are caused by old age, fatigue, etc. Once you've had a TIA, you're at high risk for another TIA or a full stroke, if not treated.

## Managing TIAs

The goal of TIA management is to prevent a stroke. Treatment depends on the causes of the TIA. In addition to lifestyle changes such as diet and exercise, your doctor may recommend drugs to treat high blood pressure, high cholesterol or heart disease. These changes may reduce your risk of further TIA or stroke.

Medications can help prevent blood clots from forming, reducing the risk of a full-blown stroke. Statins and blood pressure control may also reduce stroke risk.

## BETTER NUTRITION FOR STROKE PREVENTION

Eating healthy will help you manage your weight and blood pressure. Both are crucial to prevent another stroke and stay healthy. Ask your doctor to arrange a visit with a licensed dietitian who can teach you how to plan meals and snacks to improve your health.

- Eat a variety of foods each day, including whole grains, lean meats, legumes, nuts, skinless poultry, low-fat or fat-free dairy.
- Eat at least five servings of fruits and vegetables per day.
- Choose foods low in saturated and trans fats.
- Your doctor may suggest a special diet to help you lose weight. Or, you may need to eat foods with less salt or fat.

## Eat Foods with Adequate Starch and Fiber

Complex carbohydrates are better than simple carbohydrates, such as sugars, because they contain essential nutrients and fiber. These foods include beans, peas, nuts, fruits, vegetables, whole-grain breads and cereals.

## Avoid Excess Sugar

Added sugars provide only empty calories to the body. So it's best to:

- Use less of all sugars, including white, brown and raw, and honey and syrups.
- Eat less of foods containing large amounts of sugar, such as candy, soft drinks, cakes, ice cream and cookies.
- Consume fresh fruit or fruit canned in water or its own juice.
- Watch for hidden sugar. Read labels. If sucrose, glucose, maltose, dextrose, lactose, fructose or syrups are listed first among the ingredients, the product has a lot of sugar.

## Avoid Excess Fat

The intake of fat, particularly saturated animal fat, trans fat and cholesterol, is a contributing factor in developing atherosclerosis, which is associated with stroke and heart disease. To avoid excess bad fat in your diet:

- Eat lean meat, fish, poultry, dried beans and peas as your protein source. Cut back on red meat.
- Trim excess fat off meats before cooking.
- Minimize use of eggs (no more than three a week) and organ meats (for example, liver).
- Use only low-fat dairy products.
- Broil, bake or boil rather than fry foods. A spray vegetable oil coating may be used.
- Read labels to determine the amount of fat contained in foods.

## Avoid Excess Sodium

Excess salt in your diet increases the risk of high blood pressure, which is a major factor in heart disease and stroke. Table salt is the primary source of dietary sodium. To limit sodium in your diet:

- Avoid salt in cooking and at the table. Learn to enjoy the natural unsalted flavor of foods.
- Limit your use of foods that have a high salt or sodium content such as cured meats, potato chips, pretzels, salted nuts, cheese, prepackaged dinners, baked desserts and dried fruits. Watch for hidden salt. Di-sodium phosphate, monosodium glutamate, sodium nitrate and other sodium compounds in the list of ingredients indicate a high sodium content.

- Avoid the use of spices and condiments containing sodium such as bouillon cubes, catsup, chili sauce, celery salt, garlic salt, onion salt, meat tenderizers, pickles, relishes, Worcestershire and soy sauce. Some of these are now being made in low-sodium versions.
- Some over-the-counter drugs, especially antacids and headache remedies, have a high sodium content.
- Be sure to check with your doctor before using a salt substitute.

## Limit Alcohol

Alcoholic beverages are high in calories and low in nutrients. Heavy drinking may lead to serious physical and mental deterioration and increase the risk of high blood pressure, obesity and stroke. Drink only in moderation. This means an average of one to two drinks per day for men and one drink per day for women. (A drink is one 12 oz. beer, 4 oz. of wine, 1.5 oz. of 80-proof spirits, or 1 oz. of 100-proof spirits).

## Maintain Ideal Weight

Being overweight increases the risk of numerous diseases, including high blood pressure, coronary atherosclerosis and diabetes. All of these problems increase the risk of stroke or heart attack. Excess weight will decrease mobility and interfere with daily activities. To lose weight, you must decrease calories without sacrificing essential nutrients and maintain an exercise program.

## Tips for Eating Healthier

- Instead of frying, bake, broil, steam or grill. If sautéing, use nonstick cookware and a nonstick spray.
- Make it your goal to try a new vegetable each time you visit the grocery store.
- To help keep blood pressure under control, exchange high-sodium ingredients such as soy sauce for low-sodium, high-flavor alternatives such as herbs or orange juice.
- Instead of a cookie, grab a handful of walnuts for a snack.
- Look for pre-washed, pre-cut fruits and vegetables at the grocery store. Most places offer apple slices, baby carrots, broccoli florets, celery sticks, mixed vegetables, salad greens and spinach.
- Make healthy meals that you can store in the refrigerator or freezer to eat on days you're too tired to cook.



GIVE US A CALL

**Talk with someone who cares.**



Need to talk to someone who can answer your questions about stroke?  
Call our Stroke Family Warmline and connect with our trained specialists to:

- Receive support.
- Get helpful information.
- Help you better understand your condition.
- Connect you with local services.
- Just be a listening ear.

Call us 8:30 a.m.–5 p.m. CT Monday–Friday at  
**1-888-4-STROKE (1-888-478-7653)** or visit [stroke.org/SpeakWithUs](https://stroke.org/SpeakWithUs).

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# CHAPTER SIX

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## FAMILY CAREGIVERS

Shock, helplessness and worry are common emotions for caregivers, as well as stroke survivors. Immediately after a stroke, it's not unusual to feel overwhelmed, fearful and uncertain about your new role as a caregiver. These emotions may be a result of your loved one's severely limited physical functioning and personality changes. You may also fear that he/she will have another stroke and that it's your duty to help prevent it. Your relationship with your loved one has also been altered. In addition to your previous responsibilities, you may have to take on more household chores and other tasks that your loved one handled. This chapter includes information on issues you might encounter as a primary caregiver. It's a supplement to the previous sections for stroke survivors.

### Dealing with New Responsibilities at Home

Being at home, on your own, can be a trying time for you and your loved one. Often, moments of friction can be avoided by simplifying activities. It's important to take things slowly and realize the road to recovery is a lifelong journey. When your loved one doesn't want to take part in an activity, be sensitive to their needs and wishes and don't insist. Stroke survivors may feel better and more energetic during one part of the day, so schedule activities then. A smile or caress can often change the mood. By giving the stroke survivor choices, you allow them to feel "in control." An example would be: "Do you want to do your exercises at 2 o'clock or 3 o'clock?" instead of "You have to do your exercises now."

### Changes in Your Loved One

You will likely 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. Following are some brief descriptions of the issues that commonly accompany stroke.

## Communication Difficulties

Stroke can cause a variety of communication problems. Some stroke survivors are unable to pronounce speech 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 themselves or understanding others, a condition known as aphasia. (See **Chapter 3**). They may not make sense when talking, have trouble finding the right words or barely be able to speak at all. They may also have trouble reading or writing.

Communication problems are among the most frightening after-effects of stroke for the survivor and the family. A speech and language therapist can help you and your loved one learn to communicate more effectively to reduce frustration.

Finally, the behavior of the family should be considered. Strive to be compassionate, patient, positive, tolerant and respectful. This may not be easy. You may need professional help to learn how to manage difficult situations.

## Loss of Bowel or Bladder Control

Loss of bladder and bowel control is a common condition for stroke survivors. Reassure your loved one and encourage him or her not to be embarrassed, and to talk to you and your family doctor about it.

### These simple suggestions may help make this condition easier to manage:

Watch for signs indicating a need for toileting.

- Facial expressions, sudden agitation or an aimless pulling at clothes may mean the person needs help.
- A regular toileting schedule may help create predictability and control for you both.
- Discuss persistent difficulties with bowel and bladder function with a doctor.

## Pain Recognition

Some people may not be able to feel pain accurately in parts of the body where sensation has been lost. They might not be aware of a cut or a broken bone, or if a bedsore has begun to form or a heat application is too hot. Those who are unable to speak can't always tell you that they're in pain.

It's important to pay attention and react to changes in the skin such as swelling, bleeding or any other sign that something is wrong. Restlessness, moaning or anguished facial expressions may be signals of pain.

## Effects of Pain

Pain can have a debilitating effect. Someone in pain may lack the motivation to make the extra physical effort required to get out of a wheelchair or bed. For example, unrelieved pain may interfere with the use of a limb or cause resistance to the exercise

program that improves mobility. Immobility can cause joints to “freeze,” and subsequent attempts to move will be even more painful. The disability may advance, making the stroke survivor more and more dependent. It’s important that stroke survivors not let pain keep them from being active. Encourage some movement or exercise daily.

## Nutrition

Proper nutrition is an important part of stroke recovery and stroke prevention. You and your family should work together to make sure your loved one has the willingness and the tools to maintain a healthy diet. Some people may have little appetite. Ill-fitting dentures or a reduced sense of taste or smell can make food unappealing. Those who live alone might even skip meals because of the effort involved in buying groceries and preparing food. Soft foods and foods with stronger flavors may tempt those who are not eating enough. Nutrition programs, such as Meals on Wheels or hot lunches offered through community centers, serve the elderly and chronically ill. If you’re worried about the eating habits of a stroke survivor who lives apart from you, seek help from these sources or a dietitian or nutritionist.

## Skin Care

For those who are in stationary positions most of the time, decubitus ulcers (bedsores) can be a serious problem. The sores usually appear on the elbows, buttocks, heels or shoulder blades and can occur within days if not properly monitored. Check the skin daily for any changes. Reddened spots are the first warning signs of pressure areas.

To prevent bedsores, make sure your loved one doesn’t sit or lie in the same position for long periods. The bedfast person should be turned frequently to lie first on one side and then the other. Use pillows to support the weak arm or leg. Pillows can be put under the knees to prop them so that the soles of the feet rest flat on the bed. A therapist can instruct you on more positioning techniques. Try to keep the bedding smooth and wrinkle-free. Special mattresses or cushions can reduce pressure and help prevent bedsores.

A person sitting in a wheelchair can relieve pressure on the skin of the buttocks by getting out of the chair periodically or by leaning forward or to one side. A physical or occupational therapist can teach this technique. Rough, abrasive clothing should be avoided. An air cushion might also help relieve pressure and increase comfort.

A mild cream can be applied to points of roughness, redness or inflammation. Gentle massaging of the reddened area will help restore circulation. Take special care when the stroke survivor has memory or language problems. He or she may have lost sensation and not be able to feel the pain that signals the beginning of bedsores, so the caregiver needs to be on the alert. Notify the doctor if an irritated spot doesn’t clear up or seems to be spreading, or if red or white areas don’t fade in 15 to 20 minutes after pressure is relieved. A history of bedsores or being at risk for skin breakdown may qualify Medicare beneficiaries for a pressure relief mattress and/or cushion.

## Behavior Changes Resulting from Stroke *(See Chapter 2)*

Behavior changes in your loved one can result from depression or brain damage that occurred during the stroke. Both conditions can be trying for caregivers and family. 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 medication, may not be motivated to perform exercises that 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 family and friends’ enthusiasm for helping with recovery. This creates a vicious cycle by depriving the stroke survivor of social contacts, which could help dispel the depression. As a person improves from stroke, depression may lift by itself.

However, sometimes depression can become serious enough to impair functioning. This can occur in the emotional life of the survivor, caregiver or family member and can occur regardless of the living situation of the survivor.

It’s important to identify the warning signs of depression and seek professional help and treatment. People who are depressed frequently express feelings of hopelessness, helplessness and a lack of pleasure in usually enjoyed activities. They may feel sluggish in their body movements and speech patterns. They may think distressing thoughts, such as “I am worthless,” or even suicidal thoughts. They may blame themselves unreasonably for anything that goes wrong.

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

### One-Sided Neglect

One-sided neglect occurs when the stroke survivor is unable to pay attention to one side so that they are missing literally half of the world around them.

Simple methods to help them deal with this condition include:

- Putting clothes on the recognized side of the dresser drawer and closet.
- Placing a sign on the mirror with a reminder to turn the head while shaving or putting on makeup.
- Gently reminding him or her when you notice neglect.

### Memory Loss and Cognitive Changes

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 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, tell the person in advance what's going to happen and possibly take over some responsibilities. Memory loss can be hard to accept and frustrating for the stroke survivor and family, and can be partial, severe or affect only certain kinds of information and material (for example, visual or verbal).

### **Poor Judgment and Insight**

Some survivors display poor judgment and insight. They shouldn't drive a car, operate machinery (including small appliances) and should be accompanied when walking outdoors or near stairs. They also should be guided when making important decisions. Impulsivity and other significant issues can occur and should be discussed with a neuropsychologist.

### **The Confused, Cautious Survivor**

The confused, cautious survivor might be helped by an ordered environment where fewer choices have to be made. Those experiencing poor judgment must be guided when making important decisions. At times, they may be apathetic, which can worsen if the environment is too quiet and simple. If you notice problems in your loved one's behavior, try to identify the cause and make it easier for both of you. (See **Chapter 2**.)

### **Concentration**

Problems with concentration are common after stroke. Social situations can be especially difficult. As a caregiver, you can help by choosing or arranging small, quiet, slow-paced gatherings. This type of setting allows slower expression of thoughts and a limited number of people with whom to interact. A slower pace allows time to sort out what's being said by whom and to think through and make a good response. If your loved one has trouble recognizing acquaintances or remembering names of long-time friends or family members, offer a prompt of the unknown name such as, "Bob was just telling me about his new car."

Some stroke survivors appear to not be as responsive because their sensory functions (sight, hearing, smell, touch or taste) have been impaired. Provide stimulation with pleasant background music from the radio or stereo, flowers or plants, bright colors, books and magazines that feature pictures, new clothes or foods with stronger flavors and colors.

## **The Grieving Process**

The five stages of the grieving process are described on **page 22**. Below, we elaborate on the last three stages, which may affect you and your family as caregivers.

Stages one and two, **shock** and **denial**, will affect each family differently. It's important for you to remain supportive, offering positive feedback and encouragement on the road to recovery. If you experience any of these feelings, try not to feel guilty. They're all part of the grieving process.

## **Reaction**

While a funeral formally recognizes a death and encourages support for a grieving family, there is no socially acceptable way to grieve the loss of a person who hasn't died. Yet in many ways you may be facing a kind of death — the death of your loved one's former self.

Another normal reaction is to feel that death would be better than surviving with a disability. Families must grieve the loss of the person they knew before they can begin a comfortable relationship with the survivor.

This is difficult for a spouse and the survivor as they struggle to know a "new" self. It's important that you feel free to openly and honestly grieve the loss of the old self.

Stroke survivors and their families are sometimes surprised by feelings of anger. For example, the survivor may feel that nobody can do anything right. Or a spouse may feel resentful toward his or her mate for having a stroke.

It's important to understand the feelings that go along with the experience of loss. The only way to get beyond anger, guilt or sadness is to experience them. Gradually, healing takes place.

## **Mobilization**

When the stroke survivor begins to experience the frustrations and anxieties associated with returning to the community environment, he or she may fluctuate between the mobilization stage and the reaction stage. This is a time when people who have not experienced the process may be insensitive and unaware of the level of progress the survivor and family have experienced.

## **Acceptance**

It's impossible to say how long it will take a person or a family to enter the acceptance stage. Grief and loss are a personal experience. Compromise and patience will help a family and a survivor get through these very tough times.

## **Relationships and Intimacy**

### **Sexuality**

The closeness that a couple shared before a stroke will affect how their relationship evolves after a stroke. Sexual satisfaction, both giving and receiving, can be accomplished in many ways.

Refer to **page 23** for details about the emotional and physical issues that may arise when you and your partner resume sexual relations. Whatever is comfortable and acceptable between you and your partner is normal sexual behavior. Be assured that it takes time, but with time, many couples discover new ways of caring for and relating to each other.

It's normal for married couples to experience a sense of profound loss when one partner suffers a stroke. For many people, marriage is the central and most enduring relationship

in their lives. Married couples share a common history of joys and sorrows, as well as hopes and dreams for the future. They depend on one another for companionship, understanding, support and sexual fulfillment. They are accustomed to sharing the responsibilities of the household as well as the enjoyment of social activities.

For many spouses, when the partner suffers a stroke, it's as though part of the self is lost. You may face prolonged separation, often for the first time in years, during hospitalization and rehabilitation. Your spouse may not be able to offer the same level of participation. You might have to shoulder all the responsibilities previously shared. You may feel that the situation is a terrible physical and emotional burden that you are not prepared to handle.

### Family Relations

Often a parent's stroke comes at a time when their children are carrying significant work, family and community responsibilities. Adult children can get 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 to accept, partly because it involves the loss of the parent in many ways. Once again, grieving is essential.

### Siblings

Sometimes a brother or sister is responsible for the stroke survivor's care. Once again, a stroke can change relationships. Sibling caregivers may face unique challenges, such as deciding which sibling should bear most of the care, especially when 24-hour caregiving is required. Other challenges to consider include:

- Be aware that not all family members will be available to help.
- Identify what you can and cannot do as far as providing care.
- Create a schedule for those available to help.
- Seek training and support as a caregiver.
- Communication is vital while sharing caregiving tasks and responsibilities.

## 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. If you can give yourself a break from caregiving, you'll be helping your loved one and yourself.

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. Don't be shy about enlisting the occasional help of other relatives, friends, neighbors or community volunteers to give you a break for a few hours. A paid helper may offer you time away from your hard work as a caregiver.

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 doctor or therapist. Strive to create a rhythm to daily life that respects the needs of everyone in your life, including yourself.

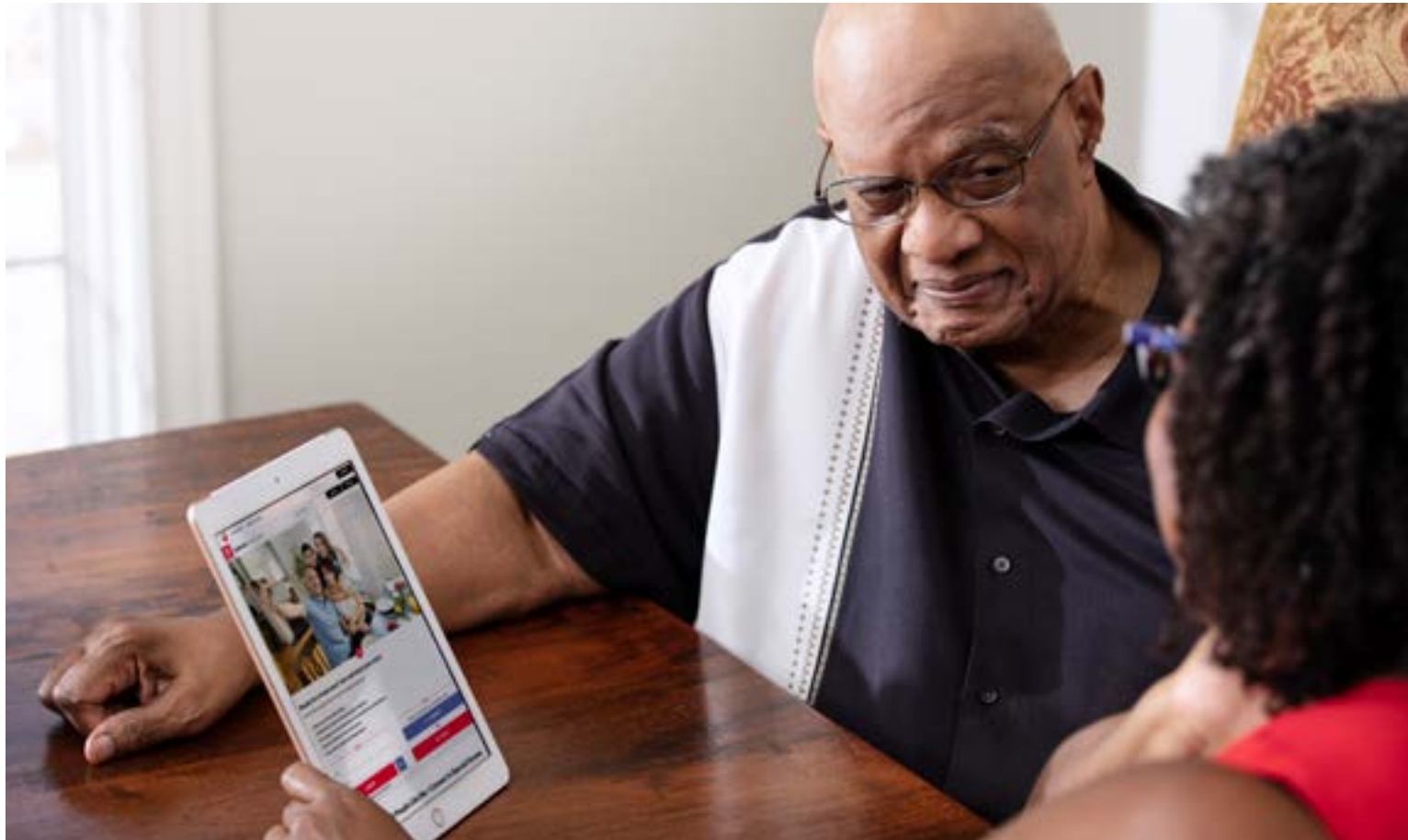
Don't be afraid to seek additional support if you have questions or concerns or just need to talk to someone. Some communities have separate support groups for stroke caregivers. Whether it's in person, online or on the phone, the American Stroke Association is here to help:

- Call our **Stroke Family Warmline** to talk with our trained specialists who can provide helpful information, connect you to local services or just be a listening ear. **1-888-4-STROKE (1-888-478-7653)** Monday-Friday 8 a.m.-5 p.m. or learn more at [stroke.org/SpeakWithUs](https://stroke.org/SpeakWithUs).
- Join our FREE online **Support Network** to be a part of a community of survivors and caregivers that knows what you're going through and can help you find your footing on the path to better health. Join at [stroke.org/SupportNetwork](https://stroke.org/SupportNetwork).

### For More Information

- Family Caregiver Alliance: **1-800-445-8106**; [caregiver.org](https://caregiver.org)
- National Alliance for Caregiving: **301-718-8444**; [caregiving.org](https://caregiving.org)

## SUPPORT THAT **EMPOWERS**



Recovery from a stroke becomes so much more manageable when you have the right kind of emotional support. We're a community of survivors and caregivers who know what you're going through and can help you find your footing on the path to better health.

Find encouragement at:  
**[stroke.org/SupportNetwork](https://stroke.org/SupportNetwork)**

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# CHAPTER SEVEN

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## MOVEMENT AND EXERCISE

Many stroke survivors have trouble moving around safely and easily. These problems range from balance issues to arm or leg paralysis. But rehabilitation and therapy may improve your balance and ability to move.

### Movement

Common physical effects of stroke are muscle weakness and less control of an affected arm or leg. Survivors often work with therapists to restore strength and control through exercise programs. They also learn skills to deal with the loss of certain body movements.

### Paralysis and Spasticity

Paralysis is the inability of a muscle or a group of muscles to move. After stroke, signals from the brain to the muscles often don't work correctly. This is due to damage to the brain.

- Paralysis can be complete or partial.
- It can occur on one or both sides of the body.
- It can occur in just one area, or it can be widespread.
- Paralysis of the lower half of your body, including both legs, is called paraplegia.
- Paralysis of the arms and legs is quadriplegia.

Spasticity is a condition in which muscles are stiff and resist being stretched. It can happen throughout the body, but it's most common in the arms, fingers or legs. Depending on where it occurs, it can result in an arm being pressed against the chest, a stiff knee or a pointed foot that interferes with walking. It can also cause painful muscle spasms.

## Treatment Options for Spasticity

Treatment for spasticity is often a combination of therapy and medication. Therapy can include range-of-motion exercises, gentle stretching, splinting or casting.

- Medication can treat the general effects of spasticity and act on multiple muscle groups in the body.
- Injections of botulinum toxin can prevent the release of chemicals that cause muscle contraction.
- One treatment involves delivering a drug directly into the spinal fluid with a surgically placed pump.
- Surgery is the last option to treat spasticity. It can be done on the brain or the muscles and joints. Surgery may block pain and restore some movement.

## Exercise

Walking, bending and stretching can help strengthen your body and keep it flexible. Mild exercise, which should be performed every day, can include a short walk or a simple activity such as sweeping the floor. Stretching exercises, such as extending the arms or bending the torso, should be done regularly. Moving weakened or paralyzed body parts can be done while seated or lying down. Swimming is another beneficial exercise if the pool is accessible and a helper is available. Use an exercise program that's in writing, with illustrations and guidelines for a helper if necessary.

## Fatigue

Fatigue while exercising is to be expected. Like everyone else, you'll have good and bad days. You can modify these programs to accommodate for fatigue or other conditions. Avoid overexertion and pain. However, some discomfort may be necessary to progress.

## Sample Exercise Programs

The first exercise program on the following pages is for the person whose physical abilities have been mildly affected by the stroke. The second is for those with greater limitations. If you're not sure which is appropriate, consult the profile that precedes each program.

Consult with your doctor and/or therapist before beginning the program. If any exercises are too difficult and cause pain or increased stiffness in your limbs, don't do them.

All of the exercises may be performed alone if you're able to do so safely. For many stroke survivors, it's advisable for someone to stand nearby during an exercise session. Your caregiver should watch for errors in judgment that could affect safety. For instance, some stroke survivors aren't aware that their balance is unsteady, nor can they tell left from right. Others may have lost the ability to read the exercise instructions or may need help remembering a full sequence of movements.

In general, each exercise is performed five to 10 times daily, unless otherwise directed. The exercise session should be scheduled for when you feel alert and well. You might have these ups and downs frequently. If the exercises are too tiring, divide them into two sessions — perhaps once in the morning and again in the afternoon.

Because the effects of stroke vary, it's impossible to devise a single exercise program suitable for everyone. The two programs are general and serve as a guide. You should consult an occupational therapist and/or physical therapist, who can help in selecting the specific exercises that will benefit you, and who will provide instruction for both you and your caregiver.

## Resources

For a referral to an occupational or physical therapist, consult your doctor or contact a home health agency, family service agency or the physical therapy department of your community hospital.

As with any exercise program, consult with your doctor and/or therapist before beginning this program.

You may also contact:

- American Occupational Therapy Association (AOTA): [aota.org](http://aota.org); 301-652-6611
- American Physical Therapy Association (APTA): [apta.org](http://apta.org); 1-800-999-2782

## EXERCISE PROGRAM I

### *For those mildly affected by stroke*

#### Profile

You may still have some degree of weakness in the affected arm and leg but generally have some ability to control your movements. You may also have some obvious stiffness or muscle spasms, particularly with fatigue or stress.

You may be able to walk without someone's assistance but may use a walker, cane or brace. For managing longer distances or uneven terrain, you may require minimal assistance from another person, a more supportive walking aid or a wheelchair.

Abnormalities may be present when you walk but may be corrected by exercise and fitting shoes with lifts or wedges. A doctor can prescribe these shoe modifications after a physical therapist evaluates you. You can usually use the stairs with or without handrails, with a helper close by or with minimal assistance.

Clothing that doesn't restrict movement is appropriate for exercising. It's not necessary to wear shorts like those in the illustrations. Leisure clothes such as sweat suits or jogging suits are appropriate. Sturdy, well-constructed shoes with non-skid soles, such as athletic shoes, are recommended at all times. It's important to periodically check your foot on the

affected side for reddened areas, pressure marks, swelling or blisters — especially when there's poor sensation or a lack of sensation. Reddened areas and pressure marks should be reported to a doctor or physical therapist.

### The following exercises can help you:

- Move more steadily when you walk.
- Improve balance and endurance.
- Strengthen and refine movement patterns.
- Require less assistance for stair climbing.
- Improve the coordination and speed of movement necessary for fine motor skills, such as fastening buttons or tying shoelaces.

**Note:** In the illustrations, non-shaded areas show body position at the beginning of the exercise. Shaded areas show body position at the end of the exercise. Arrows show the direction of movement. The word “floor” is used to simplify the instructions. You can perform the exercises on the floor, a firm mattress or on any appropriate supportive surface.

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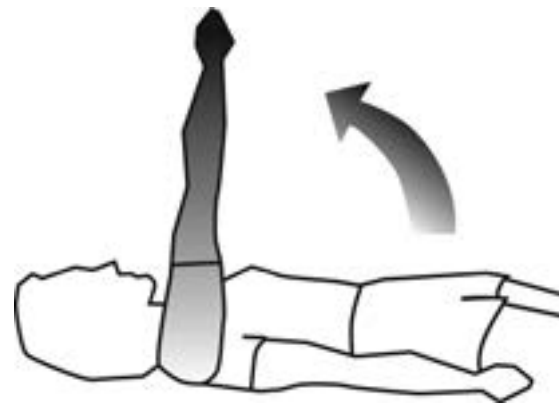
**Rehabilitation is an important step during a stroke survivor's road to recovery. These exercises can supplement or enhance therapy. Please speak with your health care professional and/or physical therapist before performing any of these exercises.**

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### Exercise 1

#### To strengthen the muscles that stabilize the shoulder:

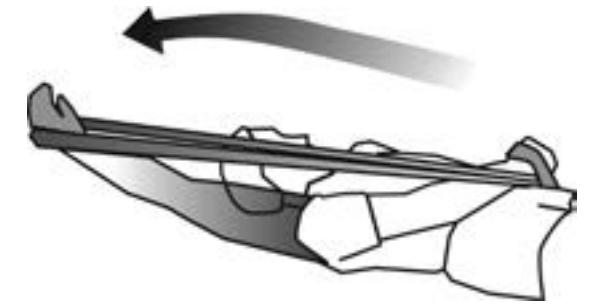
- Lie on your back with your arms resting at your sides.
- Keep your elbow straight, lift your affected arm to shoulder level with your hand pointing to the ceiling.
- Raise your hand toward the ceiling, lifting your shoulder blade from the floor.
- Hold for three to five seconds, then relax, allowing your shoulder blade to return to the floor.
- Slowly repeat the reaching motion several times.
- Lower your arm to rest by your side.



### Exercise 2

#### To strengthen the shoulder muscles as well as those that straighten the elbow:

- Lying on your back, grasp one end of an elasticized resistance band\* in each hand with enough tension to provide light resistance to the exercise, but without causing undue strain.
- Place both hands alongside the unaffected hip, keeping your elbows as straight as possible.
- Move your affected arm upward in a diagonal direction, reaching out to the side, above your head, keeping your elbow straight\*\*. Your unaffected arm should remain at your side throughout the exercise.
- During the exercise, stretch the band so that it provides resistance.



\*Elasticized bands are marketed as resistance bands. They're available in varying strengths (color-coded) to provide progressive resistance. Initially, a three- or four-foot length band — perhaps with the ends knotted together to improve grip — is sufficient for the exercise. To increase resistance as strength improves, purchase the next density of resistance bands, or use two or more bands of the original density at once. Resistance bands can be obtained from a medical supply company. Similar elastic bands or cords are also available at many sporting goods stores where exercise equipment is sold.

\*\*If it's too difficult to keep the elbow straight, do the exercise with the elbow bent. If you can't grip with your hand, a loop can be tied at the end to slip your hand partially through the loop, leaving the thumb out to “catch” the loop during upward movement.

### Exercise 3

#### To strengthen the muscles that straighten the elbow:

- Lie on your back with your arms resting at your sides and a rolled towel under the affected elbow.
- Bend the affected elbow and move your hand up toward your shoulder. Keep your elbow resting on the towel.
- Hold for a few seconds.
- Straighten your elbow and hold.
- Slowly repeat several times.

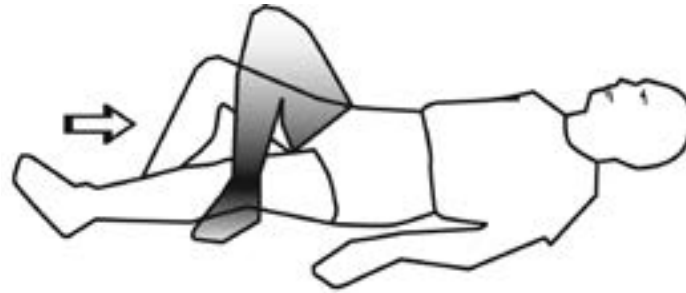


**Note:** Try not to let the hand roll in towards your midsection/stomach.

#### Exercise 4

To improve hip control in preparation for walking activities:

- Start with your unaffected leg flat on the floor and your affected leg bent.
- Lift your affected foot and cross your affected leg over the other leg.
- Lift your affected foot and un-cross, resuming the position of step b.
- Repeat the crossing and un-crossing motion several times.



#### Exercise 5

To enhance hip and knee control:

- Start with your knees bent, feet resting on the floor.
- Slowly slide the heel of your affected leg down so that the leg straightens.
- Slowly bring the heel of your affected leg along the floor, returning to the starting position. Keep your heel in contact with the floor throughout the exercise.



**Note:** Your foot will slide more smoothly if you do this exercise without shoes.

#### Exercise 6

To improve control of knee motions for walking:

- Lie on your unaffected side with the bottom knee bent for stability and your affected arm placed in front for support.
- Starting with your affected leg straight, bend your affected knee, bringing the heel toward your buttocks, then return to the straightened position.
- Concentrate on bending and straightening your knee while keeping your hip straight.



#### Exercise 7

To improve weight shift and control for proper walking technique:

- Start with your knees bent, feet flat on the floor and knees close together.
- Lift your hips from the floor and keep them raised in the air.
- Slowly twist your hips from side to side. Return to center and lower your hips to the floor.
- Rest. Repeat motion.



**Note:** This exercise may be difficult for some stroke survivors and it may worsen back problems. Don't do it if you experience pain.

#### Exercise 8

To improve balance, weight shift and control to prepare for walking activities:

- The starting position is on your hands and knees. Weight should be evenly distributed on both arms and both legs.
- Rock in a diagonal direction back toward your right heel as far as possible, then as far forward toward your left hand as possible.
- Repeat motion several times, slowly rocking as far as possible in each direction.
- Return to center.
- Rock in a diagonal direction toward your right hand. Move as far back as possible in each direction slowly.



**Note:** For safety, an assistant may be nearby to prevent loss of balance. This position may not be appropriate or safe for elderly stroke survivors. Consult your doctor and/or physical therapist before attempting this exercise.

### Exercise 9

To simulate proper weight shift and knee control necessary for walking:

- Stand with your unaffected side next to a countertop or other firm surface. Rest your unaffected arm on the surface for support.
- Lift your unaffected foot from the floor so that you are standing on your affected leg.
- Slowly bend and straighten the leg on which you're standing through a small range of motion. Try to move smoothly, not allowing your knee to buckle when you bend or snap back when you straighten.
- Repeat the knee bending and straightening several times, slowly.



### Exercise 10

To simulate proper weight shift while strengthening hip and pelvis muscles:

- Stand facing a countertop or other firm surface for support.
- Shift your weight onto your right leg and lift your knee straight.
- Return to center with both feet on the floor.
- Shift your weight onto your left leg and lift your right leg out to the side keeping your back and knee straight.
- Repeat several times, alternating lifts.



## EXERCISE PROGRAM II

For the person moderately affected by stroke

### Profile

You may use a wheelchair most of the time. You're probably able to walk — at least around the house — with the aid of another person or by using a walking aid. A short leg brace may be needed to help control foot drop or inward turning of the foot. A sling may help the arm and aid in shoulder positioning for controlling pain. Your affected arm and leg may be stiff or may assume a spastic posture that's difficult to control. The toe may turn inward or the foot may drag. When walking, you may "lead" with the unaffected side, leaving the other side behind. Often there are balance problems and difficulty shifting weight toward the affected side.

Clothing that doesn't restrict movement is appropriate for exercising. It's not necessary to wear shorts like those in the illustrations. Leisure clothes such as sweat suits or jogging suits are appropriate. Sturdy, well-constructed shoes with non-skid soles, such as athletic shoes, are recommended at all times. It's important to periodically check your foot on the affected side for reddened areas, pressure marks, swelling or blisters — especially when there's poor sensation or a lack of sensation. Reddened areas and pressure marks should be reported to a doctor or physical therapist.

The purpose of this exercise program is to:

- Promote flexibility and relaxation of muscles on the affected side.
- Help you return to more normal movement.
- Improve balance and coordination.
- Decrease pain and stiffness.
- Maintain range of motion in the affected arm and leg.

### For the Stroke Survivor

Begin with exercises done lying on your back, and then move on to those performed lying on your unaffected side, then sitting, and then standing. Make sure that the surface on which you lie is firm and provides good support. Take your time when you exercise. Don't rush the movements or strain to complete them.

**Note:** In the illustrations, non-shaded areas show body position at the beginning of the exercise. Shaded areas show body position at the end of the exercise. Arrows show the direction of movement.

### For the Helper

You may not need to assist the stroke survivor, but you should be nearby during the exercise session. If the survivor has difficulty reading or remembering the sequence of movements, you can hold the illustration up where it can be seen or repeat the instructions one by one. You can also offer physical assistance and encouragement when needed.

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Rehabilitation is an important step during a stroke survivor's road to recovery. These exercises can supplement or enhance therapy. Please speak with your health care professional and/or physical therapist before performing any of these exercises.

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**Exercise 1**  
To enhance shoulder motion and possibly prevent shoulder pain:

- Lie on your back on a firm bed. Interlace your fingers with your hands resting on your stomach.
- Slowly raise your arms to shoulder level, keeping your elbows straight.
- Return your hands to resting position on your stomach.

**Note:** If pain occurs, it may be reduced by working within the range of motion that's relatively pain-free, then going up to the point where pain is felt. The arm should not be forced if pain is excessive, but an effort should be made to daily increase the range of pain-free motion.



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**Exercise 2**  
To maintain shoulder motion:

(May be useful for someone who has difficulty rolling over in bed.)

- Lie on your back on a firm bed. Interlace your fingers, with your hands resting on your stomach.
- Slowly raise your hands directly over your chest, straightening your elbows.
- Slowly move your hands to one side and then the other.
- When all repetitions have been completed, bend your elbows and return your hands to a resting position on your stomach.

**Note:** If shoulder pain occurs, move only to the point where it begins to hurt. If the pain continues, don't do this exercise.



**Exercise 3**  
To promote motion in the pelvis, hip and knee:

(Can help to reduce stiffness and is also useful for rolling over and moving in bed.)

- Lie on your back on a firm bed. Keep your interlaced fingers resting on your stomach.
- Bend your knees and put your feet flat on the bed.
- Holding your knees tightly together, slowly move them as far to the right as possible. Return to center.
- Slowly move your knees as far as possible to the left, still keeping them together. Return to center.

**Note:** The helper may provide assistance or verbal cues to help you keep your knees together during this exercise.

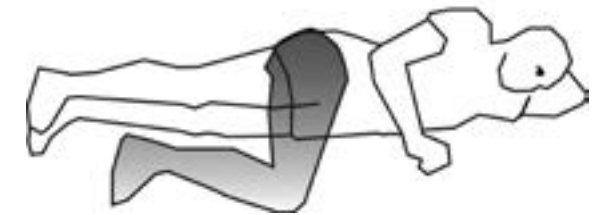


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**Exercise 4**  
To improve motion at the hip and knee, simulating the movements needed for walking:

(Can be useful when moving toward the edge of the bed before coming to a sitting position.)

- Lie on your unaffected side, with your legs together.
- Bend and move your affected knee as far as possible toward your chest. You may need your helper's assistance to support the leg you're exercising.
- Return to starting position.



## Exercise 5

### To strengthen the muscles that straighten the elbow:

(Necessary for getting up from a lying position.)

- Sitting on a firm mattress or sofa, put your affected forearm flat on the surface with your palm facing down if possible. You may want to place a firm pillow under your elbow.
- Slowly lean your weight onto your bent elbow. You may need your helper's assistance to maintain your balance.
- Push your hand down against the support surface, straightening your elbow and sitting more upright. (Assistance may be required to prevent sudden elbow collapse.)
- Slowly allow your elbow to bend, returning your forearm to the support surface.
- Work back and forth between the two extremes (completely bent or completely straight) in a slow, rhythmical manner.



**Note:** This exercise should not be performed if your shoulder isn't yet stable and/or will not support your upper body weight. Consult your doctor and/or physical therapist before attempting this exercise.

## Exercise 6

### To reduce stiffness in the trunk and promote the body rotation needed for walking:

- Sit on a firm straight chair with both feet flat on the floor. If necessary, use a firm mattress, sofa or wheelchair.
- Interlace your fingers.
- Bend forward and reach with your hands toward the outside of your right foot, rotating your trunk.
- Move your hands upward in a diagonal direction toward your left shoulder, keeping your elbows as straight as possible.
- Repeat the motions, moving your hands from your left foot to your right shoulder.



**Note:** Only people with good balance who can sit independently should do this exercise. If balance is impaired, an assistant may stand in front, guiding the arms through the motions.

## Exercise 7

### Movements needed to rise from a sitting position:

- Sit on a firm chair placed against the wall to prevent slipping.
- Interlace your fingers. Reach forward with your hands.
- With your feet slightly apart and your hips at the edge of the seat, lean forward, lifting your hips up slightly from the seat.
- Slowly return to sitting.

**Note:** In a progression of the exercise, try to rise to a complete standing position (see step C) and return to sitting. However, this should only be done by someone with good balance who can come to a standing position safely.



## Exercise 8

### To maintain the ankle motion needed for walking:

(Also maintains motion at the wrist and elbow.)

- Stand at arm's length from the wall, knees straight, feet planted slightly apart and flat on the floor with equal weight on both feet.
- With your unaffected hand, hold your affected hand in place against the wall at chest level.
- Slowly bend your elbows, leaning into the wall. This places a stretch on the back of your lower legs. Keep your heels on the floor.
- Straighten your elbows, pushing your body away from the wall.

**Note:** If the stroke survivor's affected arm is very involved, he or she may find this exercise too difficult. Consult your doctor and/or physical therapist before attempting this exercise.



## GETTING UP FROM A FALL

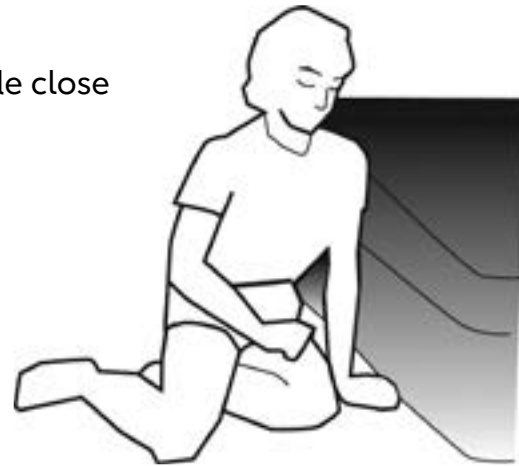
Up to 73% of stroke survivors fall in the first six months after leaving the hospital. Falls may have serious consequences such as hip fractures. A survivor may be so fearful of falling that it decreases efforts at physical activity, limits social activities and interaction and impacts the potential to improve independence.

Rehabilitation is an important step during a stroke survivor's road to recovery. So work with your health care team to learn how to prevent falling. It's just as important to know what to do if you fall and how to properly get up from a fall.

Before attempting to help a person stand up after a fall, make sure he/she has not been injured. If there are any cuts, bruises or painful areas, make the person comfortable on the floor while you get help. Don't attempt to move the person until help arrives. The illustrations that follow outline a recommended method for getting from the floor onto a chair. The person who has fallen may need assistance but should be able to rise using this technique.

### Step 1

Assume a side-sitting position with the unaffected side close to a heavy chair or another object that will not move.



### Step 2

Place the unaffected forearm on the seat of the chair and lean on the elbow or hand. Shift weight forward onto your knees and lift your hips until you're in a kneeling position.



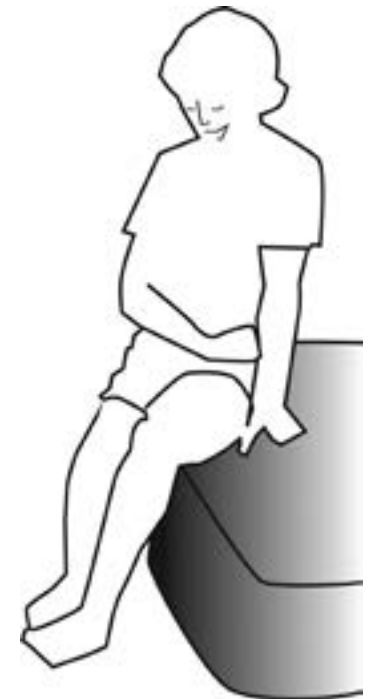
### Step 3

Supporting yourself with your unaffected arm, bring your unaffected foot forward and place it flat on the floor. Some assistance may be required to keep the affected limb in the kneeling position while placing the unaffected one in the position illustrated.



### Step 4

Lift yourself up by pushing with your unaffected arm and leg. Twist your hips toward the chair and sit on the seat.







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