STROKE EDUCATION NOTEBOOK
Stroke Education Notebook

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THANK YOU FOR CHOOSING THE ROGER C. PEACE REHABILITATION HOSPITAL STROKE PROGRAM

The Stroke Rehabilitation Program at Roger C. Peace Rehabilitation Hospital is an important part of the continuum of care provided to individuals with stroke by the Greenville Health System. Rehabilitation is initiated as soon as possible by a specialized medical team including physicians, nurses, therapists, neuropsychologists, and case managers experienced in assessing and treating stroke. Comprehensive evaluations are used to develop an individualized treatment program designed to meet the specific needs of the patient. Specialized intervention is focused on improving functional status to meet the goals of each patient. Care is carefully coordinated during the patient’s stay. Each member of the treatment team provides education to help patient and family understand the new needs of the survivor. Case management keeps patient and family informed of progress toward goals and coordinates discharge planning, including arranging for any necessary equipment and follow-up treatment.

The purpose of this notebook is to supplement staff teaching of patients and their family and friends and provide them with an ongoing reference. In this notebook you will learn about all aspects of living with stroke.

We have provided a page for “Questions I Would Like to Ask” near the front of the notebook. Also, behind each therapy section, you will find pages for family training notes. You will be given a lot of information, so we encourage you to make notes during family/caregiver training sessions. Your treatment team will be adding to and reviewing information in this notebook throughout your stay, so we encourage you to return the book to the Roger C. Peace backpack between uses.

Again, thank you for choosing Roger C. Peace for your rehabilitation needs.
QUESTIONS I WOULD LIKE TO ASK

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Stroke 101: Fast Facts on Stroke

- Stroke is a **brain attack**, cutting off vital blood flow and oxygen to the brain.
- In the United States, stroke is a leading cause of death, killing nearly 130,000 people each year, and a leading cause of serious, long-term adult disability.¹ ²
- There are an estimated **7,000,000 stroke survivors** in the U.S. over age 20.
- Approximately **795,000 strokes** will occur this year, one occurring every 40 seconds, and taking a life approximately every four minutes.²
- Stroke can happen to anyone at any time, regardless of race, sex or age.
- From 1997 to 2007, the annual stroke death rate fell approximately 34 percent, and the actual number of deaths fell by 18 percent.²
- Approximately **55,000 more women than men** have a stroke each year.
- **African Americans have almost twice the risk** of first-ever stroke compared with whites.
- Types of Stroke:
  - **Ischemic stroke** occurs when arteries are blocked by blood clots or by the gradual build-up of plaque and other fatty deposits. About 87 percent of all strokes are ischemic.
  - **Hemorrhagic stroke** occurs when a blood vessel in the brain breaks, leaking blood into the brain. Hemorrhagic strokes account for thirteen percent of all strokes, yet are responsible for more than thirty percent of all stroke deaths.
- Two million brain cells die every minute during stroke, increasing risk of permanent brain damage, disability or death. Recognizing symptoms and **acting FAST** to get medical attention can save a life and limit disabilities.
- The prevalence of transient ischemic attacks (TIA – “mini strokes”) increases with age. Up to 40 percent of all people who suffer a TIA will go on to experience a stroke.
- The estimated direct and indirect cost of stroke in the United States in 2010 is **$73.7 billion**.
Time is Brain. Call 9-1-1.

Few Americans know the signs of stroke. Learning them – and acting FAST when they occur – could save your life or the life of a loved one. Remember that stroke strikes FAST and you should too. Call 9-1-1.

Use the FAST test to recognize and respond to the signs of stroke.

F = FACE
Ask the person to smile. Does one side of the face droop?

A = ARMS
Ask the person to raise both arms. Does one arm drift downward?

S = SPEECH
Ask the person to repeat a simple sentence. Does the speech sound slurred or strange?

T = TIME
If you observe any of these signs (independently or together), call 9-1-1 immediately.

Reducing Stroke Risk

Everyone has some stroke risk. Some risk factors are beyond your control, including being over age 55, being a male (stroke is more common in men than women at younger ages, but more women experience strokes at older ages and more women than men die from stroke), being African-American, having diabetes, and having a family history of stroke. If you have one of these risk factors, it is even more important that you learn about the lifestyle and medical changes you can make to prevent a stroke. However, everyone should do what they can to reduce their risk for stroke – learn more by reading and following the Prevention Guidelines below.

Medical stroke risk factors include:
Previous stroke, previous episode of TIA (or mini stroke), high cholesterol, high blood pressure, heart disease, atrial fibrillation and carotid artery disease. These
medical risk factors can be controlled and managed even if you have already had issues with any of them in the past. Talk with your doctor about what will work best for you.

**Lifestyle stroke risk factors include:**

Smoking, being overweight and drinking too much alcohol. You can control these lifestyle risk factors by quitting smoking, exercising regularly, watching what and how much you eat and limiting alcohol consumption.

**Public Stroke Prevention Guidelines**

1. **Know your blood pressure.**
   If it is elevated, work with your doctor to keep it under control. High blood pressure is a leading cause of stroke. Have your blood pressure checked at least once each year—more often if you have a history of high blood pressure.

2. **Find out if you have atrial fibrillation (AF).**
   If you have AF, work with your doctor to manage it. Atrial fibrillation can cause blood to collect in the chambers of your heart. This blood can form clots and cause a stroke. Your doctor can detect AF by carefully checking your pulse.

3. **If you smoke, stop.**
   Smoking doubles the risk for stroke. If you stop smoking today, your risk for stroke will begin to decrease.

4. **If you drink alcohol, do so in moderation.**
   Drinking a glass of wine or beer or one drink each day may lower your risk for stroke (provided that there is no other medical reason you should avoid alcohol). Remember that alcohol is a drug - it can interact with other drugs you are taking, and alcohol is harmful if taken in large doses. If you don’t drink, don’t start.

5. **Know your cholesterol number.**
   If it is high, work with your doctor to control it. Lowering your cholesterol may reduce your stroke risk. High cholesterol can also indirectly increase stroke risk by putting you at greater risk of heart disease - an important stroke risk factor. Often times, high cholesterol can be controlled with diet and exercise; some individuals may require medication.
6. **Control your diabetes.**
   If you are diabetic, follow your doctor’s recommendations carefully because diabetes puts you at an increased risk for stroke. Your doctor can prescribe a nutrition program, lifestyle changes and medicine that can help control your diabetes.

7. **Include exercise in the activities you enjoy in your daily routine.**
   A brisk walk, swim or other exercise activity for as little as 30 minutes a day can improve your health in many ways, and may reduce your risk for stroke.

8. **Enjoy a lower sodium (salt), lower fat diet.**
   By cutting down on sodium and fat in your diet, you may be able to lower your blood pressure and, most importantly, lower your risk for stroke.

9. **Ask your doctor if you have circulation problems.**
   If so, work with your doctor to control them. Fatty deposits can block arteries that carry blood from your heart to your brain. Sickle cell disease, severe anemia, or other diseases can cause stroke if left untreated.

10. **Act FAST.**
    If you have any stroke symptoms, seek immediate medical attention.

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Stroke is a “brain attack” cutting off vital supplies of blood and oxygen to the brain. Each year, 795,000 Americans will have a stroke and 160,000 people will die as a result.

The majority of strokes occur in two ways:

- Ischemic stroke occur when arteries are blocked by blood clots or by the gradual build-up of plaque and other fatty deposits. About 87 percent of all strokes are ischemic.
- A hemorrhagic stroke occurs when a blood vessel in the brain breaks leaking blood into the brain. Hemorrhagic strokes account for about fifteen percent of all strokes, yet are responsible for more than thirty percent of all stroke deaths.

How are hemorrhagic strokes diagnosed?

Immediate medical attention is extremely important following any stroke. Once a patient arrives at the hospital, doctors are likely to use a computer-imaging test such as a computed tomography (CT) scan or magnetic resonance imaging (MRI). These tests determine the type of stroke and the area of the brain that is affected. If doctors suspect a blood vessel abnormality, they may perform an angiogram, an x-ray test that provides a picture of the blood vessels in the brain.

What is an intracerebral hemorrhage (ICH)?

ICH is the most common type of hemorrhagic stroke. It occurs when a blood vessel inside the brain ruptures and leaks blood into surrounding brain tissue.

What are the symptoms of an ICH?

A feature common to most ICH cases is a sudden onset of symptoms. However, the signs that accompany this type of stroke are not always the same. Depending on the location and amount of bleeding in the brain, ICH symptoms may include:

> Partial or total loss of consciousness
Vomiting or severe nausea, when combined with other symptoms

Sudden numbness or weakness of face, arm or leg, especially on one side of the body

Sudden severe headache with no known cause

Call 911 if you see or have any of these symptoms. Treatment can be more effective if given quickly.

How are intracerebral hemorrhages treated?

Treatment of ICH involves a variety of medical and surgical techniques, depending on the exact cause and size of the stroke. In cases where ICH is caused by high blood pressure, doctors try to reduce the blood pressure. They then address the swelling or pressure that often builds up inside the head after the blood vessel ruptures. In some cases, surgery may be needed to limit the damage to brain cells.

What is a subarachnoid hemorrhage (SAH)?

While an ICH causes blood to leak into the brain itself, a subarachnoid hemorrhage occurs when blood spills into the space surrounding the brain. This type of hemorrhage has many possible causes, but is usually the result of a ruptured aneurysm. An aneurysm is a balloon-like bulging of an artery’s wall. As it enlarges, the vessel becomes weak and more likely to break.

What are the symptoms of SAH?

Typically, there are no warning signs of an SAH. Occasionally, an aneurysm is detected through a warning leak. These small leaks may cause headaches prior to a more damaging SAH.

The symptoms of a SAH include:

- Sudden severe headache – often described as the “worst headache of my life”
- Vomiting or nausea, especially when combined with other symptoms such as headache
- Intolerance to light
- Stiff neck
- Loss of consciousness, especially when combined with a severe headache

How are subarachnoid hemorrhages treated?

Treatment of SAH targets the cause of bleeding and its related complications. Ruptured aneurysms are generally repaired through direct surgery to clip the aneurysm or treating the aneurysm from...
inside the vessel. Operating on the aneurysm from the inside, called embolization, is done by guiding a small metal coil through the brain artery until it reaches the aneurysm. Once there, the coil allows for a clot to form and prevent more blood from entering.

A vessel-narrowing condition called vasospasm is also a common cause of death and disability following a SAH. Vessels in vasospasm become irritated by blood and begin to spasm. As the vessels narrow, it becomes more difficult to supply surrounding brain tissue with enough blood to survive. This condition occurs in at least thirty percent of all subarachnoid hemorrhages. It generally lasts for two or more weeks after the first vessel rupture. Vasospasm treatment often includes the use of the oral medication, nimodipine. Taking the medication exactly as prescribed is critical to control the condition. Doctors may also manage vasospasm by closely monitoring the pressure, volume and concentration of blood in the brain.

What are the risk factors for hemorrhagic stroke?

- **High blood pressure** is the most common cause of ICH, responsible for about sixty percent of all cases. It is the most important controllable stroke risk factor. Have your blood pressure checked regularly. If it is consistently more than 135/85, speak with your healthcare provider about treatment options.

- **Excessive alcohol and drug use** have been associated with higher incidences of ICH and SAH. About 85-90 percent of drug-associated ICH cases occur in people in their 20s or 30s. If you drink alcohol, do so only in moderation.

- **Blood anti-clotting medication** may prevent ischemic stroke. But, if your blood becomes too thin, you may be at risk for an ICH. Check with your doctor for guidance about anti-clotting medication.

- If you have any type of **blood clotting disorder** such as hemophilia or sickle cell anemia, be sure to speak with your healthcare provider.
There are ways you can control it to decrease your stroke risk.

All publications are reviewed for scientific and medical accuracy by National Stroke Association’s Publications Committee. © 2009 National Stroke Association. 06/09
# HOPE: The Stroke Recovery Guide

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Dear Friend,

Recovery from stroke is a lifelong process. For many people recovery begins with formal rehabilitation. It is important for you and your family to know that no matter where you are in your recovery journey – there is always hope. Learn as much as you can about stroke and recovery, and the resources that are available.

National Stroke Association has designed this publication to provide you with valuable information and help you on your road to recovery.

**HOPE: The Stroke Recovery Guide** is divided into four sections:

**Helpful information**: a collection of important post-stroke issues and suggestions for how to address these concerns.

**Opportunity through self-advocacy**: find out how to be an active participant in your recovery and why it is so important.

**Preventing another stroke**: life-saving information about stroke awareness, symptom recognition, and how to decrease your chances of having another stroke.

**Exercises and recommendations**: two illustrated exercise programs to help you gain strength and range of motion.

National Stroke Association is a leading nonprofit organization focusing 100 percent of its resources and attention to reduce the incidence and impact of stroke. Please contact us at 1-800-STROKES (1-800-787-6537) or visit www.stroke.org on the Internet if you need further information or support. We look forward to helping you in any way we can.

Best wishes,

Jim Baranski
Executive Director/CEO
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1-800-STROKES
www.stroke.org
Helpful Information

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 the stroke may have affected, such as eating, dressing and walking.

Rehabilitation should start in the hospital, as soon as possible after the stroke. If you are medically stable, rehabilitation may begin within one day after the 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 intensity of rehabilitation (hours/stamina), degree of disability, available funding, insurance coverage, and your geographical area.
The following chart reviews the main rehabilitation options:

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

**Rehabilitation Health Care Team**

During all phases of your rehabilitation and recovery, you will most likely work with a team of professionals from different specialties. It’s important that you get to know your health care team and feel comfortable addressing any recovery issue with them. See table on 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 like walking and range of motion, and addresses issues such as partial or one-sided paralysis, faulty balance and foot drop. Read Chapter 4 of this manual for exercise examples.
Occupational Therapy
Occupational therapy (OT) involves re-learning the skills needed for everyday living including eating, going to the bathroom, dressing and taking care of yourself.

Speech Therapy
As a result of stroke, you may have problems communicating, thinking or swallowing. Speech and language therapy (SLT or ST) will involve techniques to reduce and compensate for these problems.

Two conditions – dysarthria and aphasia – can cause speech problems among stroke survivors. With dysarthria, a person is no longer able to pronounce speech sound properly because of weakness or trouble controlling the face and mouth muscles. With aphasia (see details in Appendix A), a person thinks clearly but is unable to process language to either talk or understand others. Speech and language therapy can teach you and your family methods for coping with these communication challenges. If your communication difficulties are severe, a therapist may suggest alternative ways of communicating, such as using gestures or pictures.

Speech and language therapists also work with memory loss and other “thinking” problems brought about by the stroke. A therapist can teach you and your family ways to help you with these problems.

<table>
<thead>
<tr>
<th>Rehabilitation Team</th>
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<tbody>
<tr>
<td><strong>Physiatrist</strong></td>
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<td><strong>Neurologist</strong></td>
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<tr>
<td><strong>Rehabilitation Nurse</strong></td>
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<tr>
<td><strong>Physical Therapist (PT)</strong></td>
</tr>
<tr>
<td><strong>Occupational Therapist (OT)</strong></td>
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<tr>
<td><strong>Speech-Language Pathologist (SLP)</strong></td>
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<tr>
<td><strong>Dietician</strong></td>
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<tr>
<td><strong>Social Worker</strong></td>
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<tr>
<td><strong>Neuropsychologist</strong></td>
</tr>
<tr>
<td><strong>Case Manager</strong></td>
</tr>
<tr>
<td><strong>Recreation Therapist</strong></td>
</tr>
</tbody>
</table>
For help in locating a private speech and language therapist, you can also contact the American Speech – Language – Hearing Association at 1-800-638-8255 or 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 within this therapy is getting back into the community and developing social skills again. A therapeutic recreation specialist may be available through your hospital, in community-based programs/organizations (eg, YMCA or senior centers), and adult day programs.

Health Insurance
Rehabilitation programs can be costly. So, it is important to know what portion of the bill your health insurance will pay and what you will have to pay “out-of-pocket.” It is 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 what settings you are covered under.

If you worked prior to your stroke, it is important that you apply for disability benefits shortly after your stroke. These benefits can assist you financially until you are able to go back to work.

There are several types of disability benefits that 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 on your own. 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)
- Supplemental Security Income (SSI)

Because of the time needed to process the paperwork, be sure to contact them as soon as possible. Apply for benefits even if you plan to go back to work. Also, make and keep copies of all the documents you send to them and letters they have sent to you. Keep track of the names of all the people you talked to, dates and what they told you. If you are denied, find out what the appeal process is, and challenge your denial.

You can learn more about Social Security programs on the Web at www.ssa.gov or by calling (800) 772-1213.
Every health insurance plan has coverage limitations. But you may have options for getting the rehabilitation services you need:

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

**Discharge Planning**

Discharge planning is the process of preparing you to live independently in the home. The purpose is to help 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 rehab team. You should be discharged from rehab soon after your goals have been reached.

**Discharge planning can include:**

- Making sure you have a safe place to live after discharge.
- Deciding what care, assistance, or special equipment you will need.
- Arranging for more rehab services or for other services in the home.
- Choosing the health care provider 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 rehab center, visitor programs and caregiver relief programs.

**Social Support**

Socializing with family and friends is an important part of stroke recovery. Everyone needs support. And, stroke survivors are no exception. There are many ways to get the support you need.
**Support Group**
A support group allows you to interact with other stroke survivors who know what you are 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.
- Give you a chance to share your story.
- Become your new friends.

**Family and Friends**
Friends and family can also provide support. They 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 most about, allowing you easy access to them when you need it most.
- Help you buy and write cards or letters to send to people.
- Give you rides to social events.

For a group near you, contact National Stroke Association at (800) STROKES or at www.stroke.org and then select the Recovery button at the top of the screen and choose “Stroke Support Groups” from the list of options.

**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 a nursing home
- your loved ones may not be prepared to face the major and unexpected responsibility of caring 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.
Modifications to the Home

Renovating the structure
The home usually can be modified so that narrow doorways, stairs and bathtubs do not interfere with your ability to manage personal needs. Obviously, the expense involved in remodeling must be considered. Many families cannot afford to pay for extensive alterations or move to more convenient living quarters.

Renovating the environment
The alternative to costly renovations is to modify your home environment, removing barriers and adding assistive devices such as ramps and grab bars. A local rehabilitation hospital can usually give suggestions on assistive devices as well.

Safety is an important consideration when making adaptations to a home. Many areas of the home can be made safer through the removal of throw rugs and furniture that may cause an accident as you move around the house or apartment. 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 assist you in using 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 hand-held shower can be attached to the bath or shower faucet so a shower may be taken while seated. Plastic strips that adhere to the bottom of the tub or shower help guard against falls. Long-handed brushes, washing mitts with pockets for soap or soap-on-a-rope aid in bathing. Electric toothbrushes, razors and hair dryers are also useful.

Modifications in Daily Living Activities

Meal Preparation
Meal preparation is easier with the assistance of small electric appliances such as food processors, mixers, blenders, toaster ovens, can openers and juicers. “Lazy Susans” placed on kitchen counter tops and in low cupboards make spices and utensils more accessible. Dishes and pot lids can be stored vertically. If the counter top is too high, 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 for locations, times and menus.

Eating & Nutrition
Eating well after a stroke is important to your recovery. Choosing healthy foods can help your energy level for therapy, exercise and favorite activities. Be sure to plan ahead and keep things as simple as possible.
Weight control is also important. Inactive people can easily become overweight from eating more than a sedentary lifestyle requires. Obesity can also make it difficult for someone with a stroke-related disability to move around and exercise.

- Eat the biggest meal early in the day when you have energy; keep the last meal of the day simple.
- 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**
Nutritional charts, recipes, and other suggestions for restricted diets can be obtained from many sources, including your state health department, the local Office on Aging, public libraries or through stroke support groups and other self-help groups. In addition, the consumer affairs departments of many food companies publish free booklets on diet and nutrition.

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

**Swallowing**
If you have trouble swallowing, you may need to be observed while eating so that you do not 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 are unable to obtain adequate nutrition by mouth, a dietician can suggest dietary supplements or alternative means of food preparation and eating.

**Diet Concern for Diabetic Stroke Survivors**
Usually diabetic stroke survivors have had diabetes prior to their stroke and are used to taking the disease into account when planning meals. However, sometimes a stroke changes the severity of your diabetes or eating problems interfere with your previous diabetic diet. If you require insulin treatment for your diabetes, it is particularly important that you consult with a registered dietician. Also, some diabetic stroke survivors who previously gave themselves daily injections of insulin will need training by a nurse or occupational therapist in how to do this with one hand. This training should be done before leaving the hospital. For more information, contact the American Diabetes Association, 1701 N. Beauregard Street, Alexandria, VA 22311 or 1-800-DIABETES (1-800-342-2383).
**Dressing/Grooming**

Dressing yourself is a basic form of independence. The added value of being neatly and attractively dressed enhances your self-image. You should always try to change from nightclothes and robes into comfortable day wear.

**There are many ways to minimize the difficulties of getting dressed:**

- 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 (e.g., crepe-soled shoes); they 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 in medical supply houses.

Having a systematic approach can make it easier to get dressed. Clothing for the day should be laid out before beginning to dress. You should be safely seated and permitted to dress yourself to the extent possible. Enough time should be allowed for dressing.

It may be possible for an occupational therapist to visit your home and recommend adaptations.

**Oral Hygiene**

Regular oral hygiene care is important for maintaining good health and for reducing the risk of serious illnesses such as pneumonia. Make sure that your mouth is kept thoroughly clean, including the tongue, roof of the mouth and dentures. Clean your mouth after every meal. A dry mouth can lead to increased concentration of harmful oral bacteria. If your mouth is dry, you can moisten it every few hours using a damp swab or a small amount a water mist sprayed from an atomizer. If you have decayed teeth, see your dentist.

**Loss of Bowel or Bladder Control**

You are not alone when it comes to incontinence. This common condition for stroke survivors can be distressing. You are encouraged to address this issue or issues of frequency and urgency with caregivers and your doctor. Having trouble urinating may also be a problem. You may need to use a small flexible tube called a catheter to urinate. It’s important to rule out urinary tract infections. There are many medicines available that may be able to prevent these conditions. A consultation with a urologist may be necessary.
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.

The following suggestions might help to 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. This system can often improve bowel and bladder function.
- 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.
- Have a ready supply of disposable or washable bed pads and underclothing, which are commonly available in drug stores and medical supply houses.

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

- Avoid fluids for two or three hours before bedtime.
- Use a bedside commode or urinal if you have difficulty getting out of bed.
- 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 be used to waken a caregiver if needed.

**Medicines**

You, your family and your doctor need to work as a team to ensure that medicines produce the desired benefits, particularly if drugs are taken for more than one condition. For example, medicines may be prescribed for high blood pressure, diabetes and heart disease as well as stroke. In combination, these can counteract each other or may produce undesirable side effects. If several doctors have been consulted, select one with whom you can discuss all of the drugs you are currently taking.

Make a list of every medicine you are now taking or place all the bottles in a plastic bag and take them to the appointment. Be sure to include all of your prescriptions (even those from the dentist), over-the-counter drugs such as aspirin, laxatives, cough medicines and weight control pills. Also be sure to include any herbal remedies you may be taking, as these might interact with other medicines. If you regularly drink wine, beer or liquor, the doctor needs to know that, too.
**Interactions** between medicines may cause confusion, memory loss, insomnia, nervousness and hallucinations or can contribute to depression. If medicines are causing problems, the doctor can often alter dosage or substitute other drugs.

Medicines should be taken in the **prescribed dose** at the scheduled time, including weekends and holidays. If there are instructions to take a drug over a period of time, the prescription should be followed.

Medicine should not be stopped because you are “feeling better,” nor should you ever take more than has been prescribed, believing that “if so much is good, more will be better.”

To help keep track of the medicine schedule, you can use a commercial medicine dispenser. You might also consider asking a relative or close friend to give you a daily reminder call regarding your medicines. Ask your doctor for other suggestions and be sure to communicate any problems you experience.

If you take medicines for chronic illness, it’s wise to carry some form of medical identification with you in case of an accident or other emergency. This makes any doctors who treat you aware of your current illness and prescriptions. A wallet-sized card designed for this purpose can usually be obtained from your local pharmacy. Drug stores and medical supply houses 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. Often the source of pain can be traced to 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 stroke damage to the brain can make even normal touch feel painful. You may experience one type of pain or several kinds. The key is to figure out what is causing the pain so that you can treat it.

**Types of Pain**

Pain after stroke can be:

- Mild, moderate or severe
- Constant or on-and-off
- On 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
Pain should always be reported to your doctor so that the cause can be determined and steps 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 relieve pain.
• Pain in the shoulder resulting from the weight of a paralyzed arm can be alleviated by providing support for the arm on a lapboard or an elevating armrest, or with a pillow while lying in bed.

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

Driving Again
Most people consider the ability to drive an essential activity of daily life. Driving provides us with an easy way to get around, independence and self-assurance. It is not an activity that anyone could give up easily.

Driving is a very complicated activity, requiring multiple levels of information processing and mobility. In many cases, it is possible to regain the ability to drive a car safely after a stroke. About 80 percent of stroke survivors who learn to drive again make it back onto the road safely and successfully. However, this does not apply to everyone. People with perceptual problems are much less likely to regain safe driving skills.

The key to finding out if you’re ready and able to drive again is to participate in driver evaluation and specialized training. It is critical that you have an individualized, comprehensive driving evaluation by a health care practitioner with expertise in driver training. This person has knowledge and understanding of the physical and cognitive issues brought on by stroke, as well as the ability to tell the difference between temporary changes in driving ability and a permanent inability to drive.

Driver’s Evaluation
A driver’s evaluation will usually include:

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

Training is the hands-on experience of teaching you to use the equipment on the road. Specially trained instructors should do this.
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.

Regular driving schools are not specialized enough for people who have experienced stroke. Because instructors do not always know about the medical aspects of a stroke, they are often not prepared to teach stroke survivors, particularly those who have other hidden problems in addition to paralysis.

Physical Problems and Solutions for Driving

Possible physical problems and solutions for driving can be:

• If you have use of only one hand, a spinner knob is appropriate. A spinner knob is attached to the steering wheel and allows you to steer the car easily with one hand. If you are unable to use the right arm and leg, a left gas pedal and spinner knob can be installed in your car.
• If you have use of only one leg, an automatic transmission will be easier than a standard transmission.
• If you have trouble reading or understanding what is read, training to read the road sign symbols rather than words can be helpful. However, this problem requires careful evaluation.
• If you have trouble judging distances or if you have a visual field cut (hemianopsia), you should not drive. You will only endanger yourself and others on the road.
• If you are unable to use the left extremities, a directional signal extender may be helpful.

Steps to Consider

• If you are receiving rehabilitation services speak to your occupational therapist about driving. Occupational therapists are involved with providing driver evaluations, treatment, educational resources, and guidance to people who want to drive again.
• If you are concerned about the safety of someone who has finished with his/her formal rehabilitation but appears to be unsafe while driving, speak to that person’s doctor and request a driver’s evaluation by a qualified healthcare professional.
• 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, there are several things you can do:

- Ask your doctor or the physical or occupational therapist at the hospital where you were treated.
- Get in touch with the state office of vocational rehabilitation or your local Department of Motor Vehicles office.
- Go to www.aota.org/olderdriver for extensive information on driver rehabilitation. It also includes a searchable database of national driving rehabilitation programs.

Easing Back Into Life
You don’t have to stop doing the things you enjoyed before your stroke. Favorite leisure activities can be adapted for almost every situation. Involvement in 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 be used to improve perception and coordination and to strengthen muscles.

If you like to cook, then peel and slice vegetables, put frosting on a cake, roll out pastry or assemble salads from a stable position, whether in a wheelchair, seated or supported standing stance. If you like gardening you could tend to potted plants on the window sill and start new plants from cuttings.

If you enjoy needlework you can continue with your hobby using a special clamp and embroidery hoop to hold the fabric steady. Braille, large-type books, and “talking books” are available for the visually impaired.

Leisure activities can either be things done individually or as a group in more social situations. Social leisure activities can be found at community centers, senior centers, church groups, municipalities and other organizations offering recreation programs.

Involvement in recreation and leisure promotes health by providing a buffer for stress and creates a sense of balance. For instance, it can give you a break from a stressful situation. 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 are skill building and can assist with transition to volunteer opportunities, continued education, employment or return to work. The social worker or case manager that worked with you should be able to suggest resources in your community to assist with this transition.
Setting Goals

The work of recovering from a stroke begins in the hospital, but continues at home. To achieve as much progress as possible, both you and your caregiver need a plan to follow.

Many stroke survivors feel that they have lost control over their lives. Developing a plan of action 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 is easy to become discouraged and overlook the progress you’ve made.

In everyday life, all of us rely on our work, family and community activities, as well as on 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 positively about life under changed conditions.

Developing these new interests, strengths and abilities will be made easier by setting long-range as well as 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 take into consideration 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 children or grandchildren. For more information on how to set goals, see Chapter 2.

Dealing with Emotional Changes

The Grieving Process

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

Recognizing common stages of grief can help you better cope with the emotional changes that go along with it. Friends can gain insight into the grieving process as well, so they can better understand your thoughts, feelings and actions.

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

Stage 1: Shock

Shock usually occurs during the initial phase of hospitalization or rehabilitation. A feeling of helplessness may accompany the shock. During this time the support of family and friends is extremely important.
Stage 2: Denial
Not being able to believe that something terrible has happened after a crisis and great loss is normal. Denial offers you and your family a psychological way to escape the overwhelming aspects of the disability. The only thing that matters now is getting well. You may be much more motivated to work toward recovery than to learn to function with a disability. The focus should be on today – the “here and now.” Focus on essentials and the new realities you now 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 then eventual mourning of losses and changes. If these reactions interfere with rehabilitation or usual activities, it is important to be evaluated, and if necessary, treated by a mental health professional. (See Appendix B.)

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

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

Behavior Changes (see details, Appendix B)
Behavior changes can result from many things including depression, which can be due to either emotional reactions or physical injury to the brain (resulting from the stroke). It’s important for you and your family members to learn to tell the difference between these two causes.

Depression
An often overlooked, yet extremely common condition after stroke is depression. It can be overwhelming, affecting the spirit and confidence of everyone involved. There is a certain amount of depression or despair that is a normal part of the grieving process.
Low self regard, harsh self criticism, the desire to hide or isolate yourself — these emotions can prevent you from engaging in activities that might actually help increase your self-esteem. 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.

**What to do About Depression**

Family can help by trying to stimulate your interest in other people, encourage leisure activities and, where it fits your values and lifestyle, provide opportunities to participate in spiritual activities. You might consider attending a stroke support group to help with depression. For a list of groups in your area, contact National Stroke Association at (800) STROKES or via the Web at www.strokes.org. Some 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 backwards to try to change how you feel by changing how you act.

**But there are some simple ways to combat depression by changing your actions:**

- Be as physically active as possible.
- Set goals and structure time to provide a way of measuring real accomplishments.
- Schedule daily activities to provide structure and a sense of purpose.
- Enjoy social activities that provide stimulation and help enhance language recovery and self-esteem.

**Changes in Thinking and Behavior Resulting from Stroke**

Certain changes you experience could be related to the brain damage caused by your stroke. Those changes may include:

**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 very much like it), and may require an evaluation by a neuropsychologist to sort it out. Treatment may be different from that for depression.

**Memory Loss**

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

**Perception/Concentration Problems**

These are common after stroke. Social situations can be especially difficult for people with these problems. Choose to attend small, quiet, slow-paced gatherings.
One-sided Neglect
Damage to the right side of the brain 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.

Emotional Lability (also called pseudobulbar affect, or PBA)
Sudden laughing or crying for no apparent reason and difficulty controlling emotional responses are common after stroke. Oddly, there may be no real mood changes involved, and the emotional display may end very quickly.

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

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. Consultation with a psychologist may be helpful if this is an area of difficulty for you 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 and how often they have sexual relations. 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. Medicines and/or counseling can be effective.

Fear of Further Damage
Most stroke survivors can resume a happy and healthy sexual life. However, you should 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, but 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 a psychological issue continues to stand in the way of your sexual relationship, discuss this with a psychologist or mental healthcare professional.
Common Physical Obstacles

Paralysis and Sensory Loss
If there is sensory loss, it is helpful to be aware of this. In the case of 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 Medicines
In the male stroke survivor, if there is no morning erection, impotence may be a result of medicines. Some blood pressure or heart drugs, diuretics, anti-depressants, tranquilizers, sedatives, and alcohol are known to cause decreased sex drive. If this has happened, it is important to let your doctor know, as medicines 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. In the case of the male, 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. In the case of the female, 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 do not resolve, there are many treatments for sexual dysfunction. Such problems are not always permanent. There are doctors and psychologists who specialize in this area. Your psychologist, doctor or the social worker at a rehabilitation hospital should be able to refer you.

It’s important to remember that sexuality is more than the act of sexual intercourse. It involves the whole process of relating to another person. Tenderness, the desire to give and receive caresses, holding, cuddling, touching, intimacy, reciprocal concerns, tolerance and love — all are a part of sexual communication that goes beyond words. After the separations and loss caused by a stroke, a couple can reclaim a closeness that is 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 is safe to have sex again.
• Focus on being loving, gentle and caring with each other.
• Speak honestly with your partner about your sexual changes. They will be glad you did, and together, you can often work out the best solution.
• Get more information on sexuality from National Stroke Association.
• Join a stroke support group. Other survivors will understand, validate your issues and offer encouragement and ideas.
Helpful Information for Caregivers

This section, intended to focus on some specific issues you might encounter as a primary caregiver, is a supplement to the previous section written specifically for the stroke survivor.

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 is important to take things slowly and realize the road to recovery is a lifelong journey. When he or she doesn’t want to take part in an activity, be sensitive to the needs and wishes of your loved one and don’t insist. Many stroke survivors feel better and more energetic during one part of the day. Activities can be scheduled to take advantage of these “up” periods. A smile or caress can often change the mood. By giving the stroke survivor choices, you allow them to still feel “in control.” An example would be: “Do you want to do your exercises at two o’clock or three o’clock?” instead of “You have to do your exercises now.”

Changes in Your Loved One

You will notice several changes in your loved one as you both move through the recovery process. The changes may be physical, cognitive or emotional, or may be a combination of these. 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 him or herself or understanding others, a condition known as aphasia. (See details Appendix A). He or she may not make sense when talking, have trouble finding the right words, or barely be able to speak at all. He or she may also have trouble reading or writing.

Communication problems are among the most frightening after-effects of stroke for both the survivor and the family. Assistance of 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 the 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.
You can help make this condition easier to manage by following these simple suggestions:

- Watch for signs indicating a need for toileting.
- Facial expressions, sudden agitation or an aimless pulling at clothes will tell you that the individual needs help.
- A regular toileting schedule may help create predictability and control for you both.
- Persistent difficulties with bowel and bladder function should be discussed 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 cannot always tell you that they are in pain. Moreover, a confused person may not understand that they are suffering pain and will not alert you.

It is important for you to pay attention and react to swelling, bleeding, or any other sign that indicates 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 is intended to improve 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 will have to work together to make sure your loved one has the willingness and the necessary 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, have been established to serve the elderly and the chronically ill. If you are worried about the eating habits of a stroke survivor who lives apart from you, seek help from these sources or from a dietician 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 does not sit or lie in the same position for long periods of time. The bedfast person should be turned frequently to lie first on one side and then the other. Pillows should be used 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 in more positioning techniques. Try to keep the bedding smooth and wrinkle-free. Special mattresses or cushions 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 be helpful in relieving pressure and increasing comfort.

A mild cream can be applied to points of roughness, redness or inflammation. 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 does not clear up or seems to be spreading, or if any red or white areas do not fade in 15 to 20 minutes after pressure is relieved. A history of bedsores or being at risk for skin breakdown may qualify Medicare recipients for a pressure relief mattress and/or cushion.

**Behavior Changes Resulting from Stroke** *(see details, Appendix B)*

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

**Depression**

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

Depression may dampen the family’s enthusiasm for helping with recovery or drive away others who want to help. This creates a vicious cycle by depriving the stroke survivor of social contacts, which could help dispel the depression. It is sometimes the case that as a person improves from stroke, depression may lift by itself.
However, 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 is important to be able to identify the warning signs of depression so that something may be done. Depressed people frequently express feelings of hopelessness, helplessness and a lack of pleasure in usually enjoyed activities. They may feel and act generally slowed down, both in their body movements and in their speech patterns. They may find themselves thinking 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
- Giving a gentle reminder when you notice an instance of neglect.

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

**Poor Judgment and Insight or Self-Awareness**

Some survivors display poor judgment and insight or self-awareness. These individuals should not drive a car, operate any machinery (including small appliances) and should be accompanied when walking outdoors or near stairways. They also should be guided when making important decisions. Impulsivity can appear, as well as other significant issues 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 issues with poor judgment must be guided when making important decisions. At times he or she may be apathetic, which can be made worse if the environment is too quiet and simple. If you notice problems in your loved one’s behavior, try to identify the cause and work to make it easier for both of you (see details in Appendix B).

Concentration

Problems with concentration are common after stroke. Social situations can be especially difficult for people with these problems. As a caregiver, you can help by choosing or arranging small, quiet, slow-paced gatherings. This type of setting allows 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 now has trouble recognizing acquaintances or remembering names of long-time friends or family members, be ready to offer a prompt of the unknown name such as, “Bob was just telling me about his new car.”

Some stroke survivors appear to be not 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 detailed on pages 15–16. The following are details of the last three stages that may affect you and your family as caregivers. Stages one and two – shock and denial – will affect each family differently. It is important for you to remain supportive, offering positive feedback and encouragement on the road to recovery. If you should experience any of the following feelings, try not to feel guilty. They are essential parts of the grieving process.

Reaction

A funeral formally recognizes a death and encourages support for a bereaved family. But there is no socially acceptable way to grieve for the loss of a person who hasn’t died. Yet in many ways you may be facing a kind of death—the death of your loved one’s former self as you both may have known and experienced it. A stroke changes a person. It can be more troublesome than death because there is a living reminder of the person who used to be.

Another normal reaction of the survivor and the family is to feel that death would be preferable to survival with a disability. Only after grieving the loss of the person they knew are families able to learn who that person has become and begin to develop a comfortable relationship. This is often most difficult for a spouse. It is also difficult for the stroke survivor who must begin to develop and know a new self. It is important that the person feels free and able to express feelings openly and have time to grieve the loss of the old self.
Stroke survivors and their families are sometimes surprised by unexpected feelings of anger. The survivor may feel that nobody can do anything right. Husbands or wives may feel resentful toward their mates for having had a stroke. It is important to realize that frustration and anger go along with the experience of loss. The only way to get beyond these feelings of anger, guilt, or sadness is to experience them. Gradually, healing takes place.

**Mobilization**

When the person 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 transition; a time when people who have not experienced the process may be insensitive, unaware of the level of progress the survivor and family have experienced.

**Acceptance**

It is impossible to say how long it will take any given individual or family to enter the acceptance stage. Loss hits each person differently. Grief is 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 shares before a stroke will affect how their relationship evolves after the stroke. It is important to remember that sexual satisfaction, both giving and receiving, can be accomplished in many ways.

You can refer to pages 18-19 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 of 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 is as though part of the self is lost. You may face prolonged separation, often for the first time in years, during the hospitalization and rehabilitation stages. Your spouse may not be able to offer the same level of participation in the relationship as before. You might have to shoulder all the responsibilities previously shared. You may feel the whole 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 children are carrying significant work, family and community responsibilities. These adult children become caught between the demands of their own families and the needs of their parents for care. 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 a very real sense. Once again, the grieving process must occur in order for coping to begin.

Siblings
Sometimes the family member responsible for care of the stroke survivor is a brother or sister. Once again, the results of the stroke can change relationships. Frequently brothers and sisters of the survivor are just at the stage in life when they are planning for retirement, free for the first time from family responsibilities. Sometimes the problems and competitive feelings of childhood can resurface during stress. Adult siblings may find themselves playing out the same old power struggles with each other. Resolving these kinds of difficulties is possible. When people are under stress and suffering from loss, even the most solid relationships can be affected.

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

As a caregiver, try to encourage as much independence as possible. Allow your loved one to make decisions. Support his or her participation in leisure activities, and then try to find some fun activities for yourself. If you can give yourself a break from caregiving, you’ll be helping both yourself and your loved one. Don’t be shy about enlisting the occasional help of other relatives, friends, neighbors or community volunteers who may be able to give you a break for a few hours each week. A paid helper may be available to offer you time away 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 loved one’s doctor or therapist. Strive to create a rhythm to daily life – a rhythm that respects the needs of everyone in your life – including yourself.

For more information, contact the National Family Caregivers Association at (800) 896-3650.
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 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 aphasics understand better. Gestures and visual information (such as objects or demonstration) 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.

Different 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 the 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 sounds 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 conversation. 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 means 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 (like “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, there is difficulty in finding the right words to 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, it cannot be overemphasized how important stimulation from the outside world can be. Although the tendency of many persons with aphasia is to avoid social situations, they need to take an active role in their own 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 brought about by the stroke. If 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
350 7th Avenue, Suite 902
New York, NY 10001
(800) 922-4622

American Speech-Language, Hearing Association (ASHA)
2200 Research Blvd. Rockville, MD 20850-3289
(800) 638-8255

National Academy of Neuropsychology (NAN)
2121 South Oneida Street, Ste 550
Denver, CO 80224-2594
(303) 691-3694
Changes in Behavior, Emotions and Thinking Following Stroke

A stroke can cause many bewildering changes in a person’s emotions and behavior. Suddenly, he or she can seem like a completely different person than the one you knew before the stroke. In a way, this is true. 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 that are dealt with in the rehabilitation process.

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 from moving on in the recovery process. Identify some warning signs of depression so that steps can be taken to alleviate it: depressed people frequently express feelings of worthlessness and loss of interest in once pleasurable activities, exhibit changes in appetite and weight, and may attempt or talk about suicide. The best way to deal with depression is to seek help from a social worker, psychologist or other trained mental health professional.

Anger

Feelings of anger and resentment are also common for survivors following their stroke. Such feelings may be expressed verbally or physically, or even by withdrawing from others. Some stroke survivors may express their anger more openly by being overly critical of other people. In such cases the individual may actually not be angry with others, so much as because the stroke has disabled them in some way.

When a survivor becomes upset, he or she may take anger out on others. When this happens, the caregivers should keep their 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, you can also 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 is important for caregivers to devise a plan to help them 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, caregivers should continue the conversation or activity and basically 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 any embarrassment and continue the current activity or discussion.

Right-Brain Injury

Behavioral changes can vary depending on the severity of the stroke and where in the brain it takes place. Since the right hemisphere in most people typically heavily influences emotions, nonverbal communication and spatial orientation (sense of body position), damage to this side of the brain may cause an array of emotional and behavioral problems. Among these problems can be an impulsive style that can be very 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 these individuals have problems performing simple activities, they may be seen as uncooperative, overly dependent, confused or unmotivated. Once the limitations of right-brain injury are realized, steps can be taken to better deal with this problem:

- Keep 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.
- Monitor the person’s activities. If left unattended, the stroke survivor may become confused or injured.
- Be sensitive to the visual and sensory problems of stroke survivors. For example, if people cannot perceive things on their left side, place items they may need on their right.
- Encourage them to acknowledge the affected half of their body as part of them.
- Give frequent reminders of the affected side by touching it, rubbing it, or asking the survivor to massage it.
- Encourage them to scan (turn their heads from side to side) in order to see what they usually ignore on the affected side.
• Minimize 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 individual focus on the task at hand.

• Prevent injuries caused by the individual’s inability to determine depth and distance by clearly marking pointed edges on furniture, doorways and other items.

Although stroke survivors with right-brain injuries do not have aphasia (see Appendix A), 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 Injury**

Along with some right-side paralysis and communication problems, left-brain survivors may experience personality changes. In contrast to those who suffer 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 that the survivor is slow to respond to questions or to take action.

Mood and behavior changes associated with left-brain injury can be frustrating to the survivor and caregiver alike. To assist the survivor in his or her attempts to perform as normally as possible:

• Develop strategies that will allow the survivor to function at a comfortable pace. Care should be given to organization of daily routines and schedules.

• Recognize and deal with fatigue, a major barrier to recovery. Encouraging the person to ask for help or to pass on duties to someone else 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 individual has a hearing problem.

For those around individuals with aphasia on a daily basis, developing strategies that allow them to function at a comfortable pace will help them to accept themselves. This initially involves constant reflection and planning. Care should be given to organization of daily routines and schedules, such as handling outside errands during quieter rather than “peak” hours, which are often full of noise and distraction.
Join the Heritage Society

Heritage Society members are an exclusive group of people who, through a gift in their wills, trusts, or estate plans, make it possible for National Stroke Association to continue to reduce the incidence and impact of stroke.

Receive a certificate of appreciation.
Be publicly recognized for your gift, unless you prefer to give anonymously.

How do I join?

Arrange for a bequest or other planned gift.
Notify us of your Heritage Society eligibility and become a member.
Leave a lasting legacy that will educate and empower the country in the fight against the devastating effects of stroke.

Contact:
The Development Office at
1-800-STROKES
(1-800-787-6537)
www.stroke.org
CHAPTER TWO

Self-Advocacy

After a stroke, there is rarely any “going back.” While the road to recovery almost always takes more time and effort than anticipated, there are things you can do to make the journey easier to travel. This chapter is designed as a road map for your stroke recovery journey.

Foremost, it is essential to recognize that while you have suffered a stroke, you are not a victim – you are a survivor. Taking a positive approach to your recovery is the single most important step you can take. You may hear from different people including family or members of your own healthcare team to not get your hopes up, or to only expect a certain amount of progress. While a significant portion of recovery is done within the first 6 months to a year after a stroke, research shows that progress can be made years after a stroke. Remember – recovery is a lifelong journey. Stay positive. Stay the course.

What is Advocacy vs. Self-Advocacy?

The definition of advocacy is “active support,” especially the act of pleading or arguing for something. In this case it is for yourself – your well-being. To be a self-advocate is to be a supporter, believer, encourager, and activist of and for yourself. It is standing up for your needs in a clear, specific and firm way. It is not being afraid to ask for help when you need it.

Why is Self-Advocacy Important?

Suffering a stroke is often an overwhelming experience that takes from you a sense of control – over your physical and mental health and well-being. Practicing self-advocacy allows you to empower yourself – to personally 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 own quality of life.

Self-Advocacy Steps

Prevent another stroke

Take the steps necessary as prescribed by your doctor to prevent another stroke. This includes things such as monitoring your blood pressure, finding out your cholesterol numbers and working to control them, quitting smoking, etc. (see next chapter).
**Educate yourself**

One of the most important things you can do is educate yourself. Gather information to help you understand what has happened to you, and what to do next. Learn about stroke, your disabilities, and what treatment options you have. Find out what resources are available to you. You can find this information by:

- Reading books, pamphlets and fact sheets
- Watching informational videos, CD-ROMs or DVDs
- Browsing the Web or having a friend or family member do it for you
- Attending a workshop, seminar or talk
- Talking to a social worker, case manager or community resource specialist
- Contacting National Stroke Association at www.stroke.org or 1 - (800) STROKES

**Ask questions**

Seek out and listen to those individuals who are familiar with or specialize in the area of stroke and rehabilitation. This not only includes members of your healthcare team or other stroke experts in the community, but other stroke survivors as well. If you are uncertain or not satisfied with what they are telling you, seek a second opinion.

**Determining Wants and Needs**

There are many considerations which should go into planning for your care after hospitalization. Your needs and the resources available to meet these needs are key. Many families have found it helpful to think about several alternative plans. This way it is possible to respond effectively to whatever situation confronts you. Your social worker and therapists are the best sources of accurate, reliable information on options that fit your values and resources. It is important to try to address the following questions in an open manner. Be sure to take a realistic inventory of your strengths and weaknesses.

**Physical**

- Can you transfer from a wheelchair to a bed independently?
- Can you move independently whether walking or in a wheelchair?
- Can you control bowel and bladder functions during the day and at night?
- Can you carry out basic independent activities of daily living (dressing, personal hygiene, etc.)?
- What communication limitations are there? 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.?
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 for improvement in each of these areas?
- What follow-up services, such as outpatient or homebound occupational therapy, physical therapy, speech therapy, psychotherapy, etc. are required to achieve the goals?

Financial

- What are your financial resources, including whether or not insurance will cover needed services?
- Are you eligible for assistance through government entitlement programs, such as Medicare, Medicaid, Social Security Disability, etc.?

Caregiver Needs and Limitations

- What other responsibilities and time commitments does the potential caregiver have? (Include family, work, community, and recreational commitments.)
- Is the caregiver emotionally and physically healthy?
- What are the family financial resources?
- What is the physical layout of the place of residence (home)?
- How does the 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?

These are tough questions that you and potential caregivers must ask and answer for the sake of everyone involved. As difficult as they may be, if these questions are answered either before discharge from the hospital, or prior to a specific type of care being needed, everyone will face the new situation having made a conscious choice. Remember, whatever decisions you make should be based on your own individual situation, not on what some other family did or what you think is expected of you.
Goal Setting

Developing Goals
Developing goals or a plan of action can help you make decisions and choices. In the months following a stroke, the rate of recovery predictably slows. Don’t become discouraged. Most hospital rehabilitation programs take place in a highly structured environment where you follow a daily schedule of therapies designed to meet rehabilitation goals. There is a great deal of opportunity to 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, all of us rely on our work, family and community activities, as well as on our hobbies and interests to give us a sense of purpose and self worth. After your stroke, you may find that physical changes require you to develop new interests and involvements so that you can continue to feel good about life under changed conditions.

Developing these new interests, strengths and abilities will be made easier by setting long-range as well as short-term goals. A good way to achieve these goals is by planned daily activities.

Setting goals can help you deal with the times of discouragement that come during the recovery period. A crucial part of setting goals is examining what you can reasonably accomplish. You must take into consideration what you would like to do given your current abilities and disabilities. Goals need to be realistic. Goals also need to be flexible. It is also helpful to set time guidelines for completion of your goals. There are four main areas to think about:

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

In each area, there will be certain activities necessary to reach the goal. Breaking each step into smaller parts can help both yourself and your family see that real progress is taking place. Some of your goals could fall into several categories. Place your goals in the category that seems most sensible to you.

Achieving Goals
All goals should be “measurable,” meaning you must be able to tell when you have accomplished the goal or how close you have come by measuring tangible results. “Doing a better job at my leg exercises” is not specific enough to be measurable. “Walking around the block with my cane” is measurable, because you can clearly tell when you have accomplished a trip around the block.
Setting Long-Term Goals
To begin goal setting, write down your long-range goals in each of the areas described earlier – physical rehabilitation, recreational/social, family/community and personal. Don’t rush the process. Take your time during quiet moments to think carefully; allow goal planning to be a personal process that helps you learn more about yourself.

Setting Short-Term Goals
Short-term goals are measurable goals that are necessary in order to accomplish the long-term goals, but may or may not be activities in and of themselves. For example, if your long-term goal is “joining a stroke club,” your short-term goal might be “locate available stroke clubs in my area.” If your long-term goal is “taking a weekend trip,” your short-term goal might be “ride in the car for an hour.”

Problem Solving
When you encounter unusual periods of stress in your life, problem-solving methods which worked in the past can begin to break down. Sometimes stress makes even small problems seem overwhelming. It is impossible to anticipate all the problems that might be encountered by you or your family upon leaving the hospital or rehab program. However, there are techniques which, when applied to any problem, can contribute to finding a solution. One thing to keep in mind is that problems need to be solved one at a time.

• Acknowledge the problem.
• Identify the problem/make the problem clear.
• Observe yourself carefully and write down how you behaved, reacted, responded or thought when confronted with the problem.
• Identify possible causes.
• Decide what you want to accomplish.
• Brainstorm solutions.
• Review your solution list.
• List specific things that you will do that will contribute to carrying out your chosen solution.

Evaluating Evidence to Make Informed Decisions
If you are like many stroke survivors, conventional medical approaches may have only taken your recovery so far. Perhaps you still have speech, movement, and/or cognitive problems that impact your quality of life and ability to perform valued activities. Today more and more survivors are turning to alternative medicine treatments.

An “alternative medicine” treatment is one that is not traditionally embraced by Western medicine. For example, acupuncture is one “alternative medicine” approach that is used in many diagnoses, including stroke; another is hyperbaric oxygen therapy. However, whereas acupuncture has many research studies supporting its effectiveness, hyperbaric oxygen therapy does not. So how do you determine which, of many available approaches, might have merit?
You and your family need to be able to sift through the multitude of rehabilitation choices and make an informed decision on what is best for you. In addition, it is very important that you be sure that your healthcare providers are aware of good care options that may be available. There are several things that you can do to make yourself a more informed consumer, and to ensure that the therapies that you are receiving have a body of evidence supporting them:

- Look at the “evidence.” A body of “evidence” consists of research studies that have been performed on a particular device or therapy; if several studies with a large group of people have been performed on a particular therapy, and they support the effectiveness of the particular therapy, we say that the therapy is effective and it has evidence to support it.

- Ask your healthcare providers to share the evidence supporting the techniques that they are providing to you. Don’t just assume that what they are doing works. Indeed, even if you are showing changes, it may be due to the therapy, but it may also be due to other factors. Ask for articles, as well as reasons why they think it is the best fit for you.

- Use Medline. Medline (www.pubmed.gov) is a computerized index of most “good” articles that have been published in a certain area. For example, if you were interested in speech therapy after stroke, you could go to Medline, type in “speech therapy stroke.” The latest studies on speech therapies would then come up. Furthermore, if a company is selling a particular product or therapy, making certain claims, or if a therapist tells you the specific name of the technique or device he/she is using, look it up on Medline. Medline is run by the National Library of Medicine and is, thus, supported by your tax dollars. It is also what researchers use when looking up the effectiveness of certain techniques.

- There should be MULTIPLE studies performed on a technique. Be skeptical of therapies where only one study, or no studies, have been performed. The more positive studies that there are, the more people on whom the technique has been successfully tried, and the more generalizable it may be to your circumstances.

- Be skeptical of any product claimed to be effective against a wide range of unrelated diseases – particularly diseases that are serious. Often, stroke survivors and families approach their doctor about new therapies that are being advertised. While some of these therapies are legitimate, some of the claims are grandiose, and often the company will claim that the technique is a “cure all” (called “snake oil” or an “elixir” in the early 1900s). Be very skeptical of products with such claims. Even if the symptoms sometimes look similar, every disease has its own cause(s) and progression(s). Do not assume that just because something may be effective in one group that it applies to your circumstances.

- If you are reading an ad from a company and there are claims that it works, ask where the data were published and, if not published, ask why. There are many alternative therapies that are heavily advertised but do not actually have scientific evidence to justify their use. Be wary of “infomercials” as well. Many of the people shown are paid to talk about the product.
• Be skeptical of a device or technique that only has subjective claims. Videos or testimonials can be great ways to sell a product, or illustrate how something was successful for one particular person. But there may be alternative explanations for one person’s (or even a group of persons’) successes. Some stroke symptoms also pass with time, or improve on their own. The only way to truly discern if something is going to work reliably from patient to patient, and to rule out the effect of something else, is to systematically test it with a group of patients, as is done in research. Demand these types of studies from companies marketing products and techniques.
• Be sure to tell your doctor about any herbal or over the counter medications or alternative therapies you are taking/are involved with. These actions could negatively impact other areas of your treatment regimen (i.e. other medications or therapies).
National Stroke Association’s new stroke recovery resource provides convenient and easy-to-use information about how to cope with post-stroke lifestyle and medical issues.

iHOPE is a series of FREE web presentations and “Ask the Experts” Q&A sessions led by a team of experts who will give you information and resources needed to bring hope to your recovery experience.
Preventing Another Stroke

After stroke, survivors tend to focus on rehabilitation and recovery. But, preventing another (or recurrent) stroke is also a key concern. Of the 795,000 Americans who have a stroke each year, 5 to 14 percent will have a second stroke within one year. Within five years, stroke will recur in 24 percent of women and 42 percent of men.

**Percentage of Reoccurrence After First Stroke**

<table>
<thead>
<tr>
<th>Time Period</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Within 30-Days</td>
<td>3% to 10%</td>
</tr>
<tr>
<td>Within 1-Year</td>
<td>15% to 14%</td>
</tr>
<tr>
<td>Within 5-Years</td>
<td>25% to 40%</td>
</tr>
</tbody>
</table>

**Your Lifestyle Choices**

Everyone has some stroke risk. But, there are two types of stroke risk factors. One type you can’t control. The other you can.
Stroke risk factors you can’t change include:

- Your age – the older you are, the higher your risk
- Being a man
- Being African American
- Someone in your family has had a stroke.

Having one or more of these factors doesn’t mean you will have a stroke. By making simple lifestyle changes, you may be able to reduce the risk of a first or recurrent stroke.

These simple lifestyle changes can greatly reduce your chance of having a stroke:

- Monitor your blood pressure; if it is high, make sure it is treated.
- Find out if you have atrial fibrillation (an irregular heartbeat which allows blood to pool in the heart and cause blood clots).
- Quit smoking.
- Limit alcohol.
- Check your cholesterol levels and make sure bad cholesterol is controlled.
- Manage your diabetes.
- Exercise often.
- Eat foods low in sodium (salt) and saturated or trans fat.
- Monitor circulation problems with the help of your doctor.

Monitor Your Blood Pressure

High blood pressure is one of the most important and easily controlled stroke risk factors. So it’s important to know your blood pressure!

Blood pressure is given in two numbers, for example 120/80. The first number, the systolic blood pressure, is a measurement of the force your blood exerts on blood vessel walls as your heart pumps. The second, diastolic blood pressure, is the measurement of 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 lower than 120/80. A blood pressure reading consistently higher than 120/80 is pre-hypertension. If yours falls in this range, you are more likely to progress to high blood pressure. High blood pressure, also called hypertension, is a reading of 140/90 or higher.
- Have your blood pressure checked at least once each year — more often if you have high blood pressure, have had a heart attack or stroke, are diabetic, have kidney disease, have high cholesterol or are overweight. If you are 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 – a brisk walk, bicycle ride, swim or yard work - can make a difference. Adults should do some form of moderate physical activity for at least 30 minutes five or more days per week, according to the Centers for Disease Control and Prevention. Regular exercise may reduce your risk for stroke. Before you start an exercise program, check with your doctor.
If Your Blood Pressure is High
What do you do if you still have high blood pressure, even though you have made an effort to eat healthy foods and exercise? Then it’s time to talk to your doctor. A doctor can advise you about better lifestyle choices. Medicine may also be needed.

Many drugs can help treat high blood pressure, and most don’t produce side effects. The most common are calcium channel blockers and ACE-inhibitors. You and your doctor may have to try several different drugs before you find one that works for you. This is common. So, try not to be discouraged if this happens. Once you find a drug that works, take it as directed and exactly as prescribed, even when you feel fine.

Medicines
Medicine may help reduce stroke risk. In addition to those that treat high blood pressure, drugs are also available to control high cholesterol and treat heart disease. There are also drugs that can interfere with the blood’s tendency to form potential stroke-causing blood clots.

Heart Disease
Many forms of heart disease can increase your stroke risk. One form - known as atrial fibrillation or AF – causes blood to form clots that can travel to the brain and cause a stroke. AF is an irregular heartbeat.

Anticoagulants and antiplatelets are often prescribed to treat AF. It is important that people prescribed an anticoagulant are regularly monitored by a healthcare provider.

High Cholesterol
High levels of cholesterol may also increase stroke risk by not letting blood move freely through the arteries. Cholesterol build-up can break off. This can cause a clot to form or a stroke to occur. Several drugs, including a class of drugs called statins, may help lower cholesterol levels. The risk of having another stroke can be lowered by taking a statin. Unless cholesterol levels are already low, taking a statin is generally beneficial.

Blood Clotting
There are two classes of drugs that can help prevent clotting: anticoagulants and antiplatelets. Both types of drugs can prevent clots, helping reduce the risk of stroke. Anticoagulants require regular monitoring by a healthcare provider.
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 another stroke. During surgery, blockages and build-up in the arteries are removed to restore the free flow of blood. Your doctor is the best judge 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 suggestions about diet, exercise and weight loss, and take any medicine as directed. Your doctor will decide what’s best for you based on your general health and your 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) or mini-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 the first strokes, many recurrent strokes and TIAs can be prevented through lifestyle changes, surgery, medicine, or a mix of all three.

Symptoms of TIA (and Stroke)
What are the symptoms of TIA? 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 trouble seeing in one or both eyes
- Sudden trouble walking, dizziness, loss of balance or coordination
- Sudden severe headache with no known cause.

If you experience any of these symptoms, for even the briefest amount of time or notice them in someone else, seek medical attention immediately. Don’t wait for the symptoms to go away, because you cannot tell whether you are having a stroke or a TIA. If you are having a TIA, a doctor can evaluate and treat the causes and set up a plan of action to prevent a stroke.
Different Causes of TIAs

Three things 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 have had a TIA, you are at high risk for another TIA or a full stroke if not treated.

Managing TIAs

The goal of TIA management is to prevent a future stroke. The treatment used depends on the exact cause 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.

There are many medicines that help prevent blood clots from forming, reducing the risk of a full-blown stroke. Furthermore, statins and blood pressure control may also reduce stroke risk.

Better Nutrition for Stroke Prevention

Healthy eating is good for you. It 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 dietician. The dietician will teach you how to plan meals and snacks to improve your health.

- Plan to eat a variety of foods each day.
- 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. Substituting complex carbohydrates for sugars is recommended. These foods include beans, peas, nuts, fruits, vegetables, whole grain breads and cereals.
Avoid Excess Sugar

Sugar provides only empty calories to the body. To cut down on sugars, try the following:

• Use less of all sugars, including white, brown and raw sugars, honey, and syrups.
• Eat less of foods containing large amounts of sugar, such as candy, soft drinks, cakes, ice cream and cookies.
• Substitute 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, then there is a large amount of sugar in that product.

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:

• Choose 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 3 a week) and organ meats (eg, 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 try the following:

• 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 any other sodium compound in the list of ingredients indicates 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 may increase risk of stroke. Drink only in moderation.

Maintain Ideal Weight

Being overweight increases the risk of a number of diseases including hypertension, 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 start or maintain an exercise program.

Tips for Eating Healthy

- Rather than frying, switch to baking, broiling, steaming or grilling. If sautéing something, use nonstick cookware and a nonstick spray.
- Replace your morning cup of coffee with a glass of orange juice.
- Rather than eating the same vegetables you are used to, be adventurous. Make it your goal to try one new vegetable each time you visit the grocery store.
- To help keep blood pressure under control, exchange high sodium ingredients such as soy sauce with low sodium, high flavor alternatives such as herbs or orange juice.
- Instead of an afternoon 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.
- Ask family members and friends to make healthy meals that you can store in the refrigerator or freezer. Save these foods for the days you are too tired to cook.
STARS Steps Against Recurrent Stroke

Be a StrokeSmart STAR

- Stop smoking
- Keep blood pressure, cholesterol and diabetes under control
- Manage atrial fibrillation
- Eat healthy
- Increase activity

Also be sure to follow your doctor’s directions and take your medicine even if you feel fine.

To get a brochure and more information on the STARS program contact
National Stroke Association

1-800-STROKES • 1-800-787-6537 • www.stroke.org
CHAPTER FOUR

Movement and Exercise

Moving around safely and easily may not be something you think about, unless you’ve had a stroke. Many stroke survivors have trouble moving around. These problems range from balance issues to arm or leg paralysis. As a result, about 40 percent of stroke survivors have serious falls within a year of their strokes. But, there is good news. Rehab and therapy may improve your balance and ability to move.

Movement

The most common physical effect of stroke is muscle weakness and having 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 muscle or group of muscles to move on their own. After stroke, signals from the brain to the muscles often don’t work right. This is due to stroke damage to the brain. This damage can cause an arm or leg to become paralyzed and/or to develop spasticity.
Spasticity is a condition where muscles are stiff and resist being stretched. It can be found throughout the body but may be 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 be accompanied by painful muscle spasms.

Treatment Options for Spasticity

- Treatment for spasticity is often a combination of therapy and medicine. Therapy can include range-of-motion exercises, gentle stretching, and splinting or casting.
- Medicine 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 form of treatment involves the delivery of a drug directly into the spinal fluid using 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 are forms of exercise that can help strengthen your body and keep it flexible. Mild exercise, which should be undertaken every day, can take the form of a short walk or a simple activity like 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 is written down, with illustrations and guidelines for a helper if necessary.

Fatigue

Fatigue while exercising is to be expected. Like everyone else, you will 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 make progress.

Sample Exercise Programs

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

All of the exercises may be performed alone if you are able to do so safely. However, for many stroke survivors, it is advisable for someone to stand nearby while an exercise session is in progress. Your caregiver should watch for errors in judgment that could affect safety. For instance, some stroke survivors are not 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 assistance to remember 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 a time of day 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 is impossible to devise a single exercise program suitable for everyone. The two programs detailed here are general and are intended to 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 referral to an occupational or physical therapist, consult your doctor or contact a home health agency, a family service agency, or the physical therapy department of your community hospital. You may also try contacting the American Occupational Therapy Association at (301) 652-2682 or the American Physical Therapy Association at (800) 999-2782 for a referral in your area.

As with any exercise program, consult with your doctor and/or therapist before beginning this program. If any exercises are too difficult and cause pain or increased stiffness in your limbs, do not do them.
Exercise Program I
For those mildly affected by stroke

Profile
If you were mildly affected by stroke, 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 some 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 by fitting shoes with lifts or wedges. A prescription for these shoe modifications can be obtained from a doctor following evaluation by a physical therapist. You can usually use the stairs with or without handrails, with a helper close by or with very minimal assistance.

Clothing that does not restrict movement is appropriate for exercising. It is not necessary to wear shorts, such as those shown in the illustrations. Leisure clothing such as sweat suits or jogging suits is appropriate. Sturdy, well-constructed shoes with non-skid soles, such as athletic shoes, are recommended at all times. It is important that your foot on the affected side be checked periodically for reddened areas, pressure marks, swelling or blisters – especially when there is 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:
• Require less assistance for stair climbing
• Move more steadily when you walk
• Improve balance and endurance
• Strengthen and refine movement patterns
• Improve the coordination and speed of movement necessary for fine motor skills, such as fastening buttons or tying shoelaces.

Note: In the illustrations that follow, 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. Also, the word “floor” has been used to simplify the instructions; the exercises can be performed on the floor, on a firm mattress, or on any appropriate supportive surface.
Exercise 1

To strengthen the muscles that stabilize the shoulder

a. Lie on your back with your arms resting at your sides.

b. Keep your elbow straight, lift your affected arm to shoulder level with your hand pointing to the ceiling.

c. Raise your hand toward the ceiling, lifting your shoulder blade from the floor.

d. Hold for three to five seconds, and then relax, allowing your shoulder blade to return to the floor.

e. Slowly repeat the reaching motion several times.

f. Lower your arm to rest by your side.

Exercise 2

To strengthen the shoulder muscles as well as those which straighten the elbow

a. Lying on your back, grasp one end of an elasticized band* in each hand with enough tension to provide light resistance to the exercise, but without causing undue strain.

b. To start, place both hands alongside the unaffected hip, keeping your elbows as straight as possible.

c. 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.

d. During the exercise, stretch the band so that it provides resistance.

*Elasticized bands are marketed as Theraband. They are 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, the next density of Theraband can be purchased, or two or more bands of the original density can be used at once. Theraband 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 is too difficult to keep the elbow straight, the exercise can be done with the elbow bent. If you cannot 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 which straighten the elbow

a. Lie on your back with your arms resting at your sides and a rolled towel under the affected elbow.

b. Bend affected elbow and move your hand up toward your shoulder. Keep your elbow resting on the towel.

c. Hold for a few seconds.

d. Straighten your elbow and hold.

e. Slowly repeat several times.

Note: Try not to let the hand roll in towards your mid-section/stomach.

Exercise 4
To improve hip control in preparation for walking activities

a. Start with your unaffected leg flat on the floor and your affected leg bent.

b. Lift your affected foot and cross your affected leg over the other leg.

c. Lift your affected foot and un-cross, resuming the position of step b.

d. Repeat the crossing and un-crossing motion several times.

Exercise 5
To enhance hip and knee control

a. Start with your knees bent, feet resting on the floor.

b. Slowly slide the heel of your affected leg down so that the leg straightens.

c. 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

a. Lie on your unaffected side with the bottom knee bent for stability and your affected arm placed in front for support.

b. Starting with your affected leg straight, bend your affected knee, bringing the heel toward your buttocks, then return to the straightened position.

c. Concentrate on bending and straightening your knee while keeping your hip straight.

Exercise 7

To improve weight shift and control for proper walking technique

a. Start with your knees bent, feet flat on the floor and knees close together.

b. Lift your hips from the floor and keep them raised in the air.

c. Slowly twist your hips side to side. Return to center and lower your hips to the floor.

d. Rest. Repeat motion.

Note: This exercise may be difficult for some stroke survivors and it may worsen back problems. Do not do it if you experience pain.

Exercise 8

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

a. The starting position is on your hands and knees. Weight should be evenly distributed on both arms and both legs.

b. Rock in a diagonal direction back toward your right heel as far as possible, then as far forward toward your left hand as possible.

c. Repeat motion several times, slowly rocking as far as possible in each direction.
d. Return to center.

e. 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.

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**Exercise 9**

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

a. Stand with your unaffected side next to a countertop or other firm surface. Rest your unaffected arm on the surface for support.

b. Lift your unaffected foot from the floor so that you are standing on your affected leg.

c. Slowly bend and straighten the leg on which you are standing through a small range of motion. Try to move smoothly, not allowing your knee to buckle when you bend, or to snap back when you straighten.

d. Repeat the knee bending and straightening several times, slowly.

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**Exercise 10**

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

a. Stand facing a countertop or other firm surface for support.

b. Shift your weight onto your right leg and lift your knee straight.

c. Return to center with both feet on the floor.

d. Shift your weight onto your left leg and lift your right leg out to the side keeping your back and knee straight.

e. Repeat several times, alternating lifts.
Exercise Program II

For the person moderately affected by stroke

Profile
If you were moderately affected by your stroke, you may use a wheelchair most of the time. You are 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 be used to 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 is 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 does not restrict movement is appropriate for exercising. It is not necessary to wear shorts, such as those shown in the illustrations. Leisure clothing such as sweat suits or jogging suits is appropriate. Sturdy, well-constructed shoes with non-skid soles, such as athletic shoes, are recommended at all times. It is important that your foot on the affected side be checked periodically for reddened areas, pressure marks, swelling or blisters – especially when there is 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 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 that follow, 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. In addition, the word “floor” has been used to simplify the instructions; the exercises can be performed on the floor, on a firm mattress or on any appropriate supporting surface.

For the Helper
There may be no need to assist the stroke survivor in the exercises, 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 to where it can be seen or repeat the instructions one by one. You can also offer physical assistance and encouragement when needed.
Exercise 1

To enhance shoulder motion and possibly prevent shoulder pain

a. Lie on your back on a firm bed. Interlace your fingers with your hands resting on your stomach.

b. Slowly raise your arms to shoulder level, keeping your elbows straight.

c. 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 is relatively pain-free, then going up to the point where pain is felt. The arm should not be forced if pain is excessive, but effort should be made to daily increase the range of pain-free motion.

Exercise 2

To maintain shoulder motion

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

a. Lie on your back on a firm bed. Interlace your fingers, with your hands resting on your stomach.

b. Slowly raise your hands directly over your chest, straightening your elbows.

c. Slowly move your hands to one side and then the other.

d. When all repetitions have been completed, bend your elbows and return your hands to 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)*

- a. Lie on your back on a firm bed. Keep your interlaced fingers resting on your stomach.
- b. Bend your knees and put your feet flat on the bed.
- c. Holding your knees tightly together, slowly move them as far to the right as possible. Return to center.
- d. 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)*

- a. Lie on your unaffected side, with your legs together.
- b. 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.
- c. Return to starting position.

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**Exercise 5**

To strengthen the muscles that straighten the elbow
*(Necessary for getting up from a lying position)*

- a. 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.
- b. Slowly lean your weight onto your bent elbow. You may need your helper's assistance to maintain your balance.
c. Push your hand down against the support surface, straightening your elbow and sitting more upright. (Assistance may be required to prevent sudden elbow collapse).

d. Slowly allow your elbow to bend, returning your forearm to the support surface.

e. 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 is not yet stable and/or will not support your upper body weight. Consult your doctor and/or physical therapist before attempting this exercise.

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**Exercise 6**

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

a. Sit on a firm straight chair with both feet flat on the floor. If necessary, a firm mattress, sofa, or wheelchair may be used.

b. Interlace your fingers.

c. Bend forward and reach with your hands toward the outside of your right foot, rotating your trunk.

d. Move your hands upward in a diagonal direction toward your left shoulder, keeping your elbows as straight as possible.

e. Repeat the motions, moving your hands from your left foot to your right shoulder.

**Note:** Only individuals with good balance who can sit fairly 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

a. Sit on a firm chair that has been placed against the wall to prevent slipping.

b. Interlace your fingers. Reach forward with your hands.

c. With your feet slightly apart and your hips at the edge of the seat, lean forward, lifting your hips up slightly from the seat.

d. 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)

a. 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.

b. With your unaffected hand, hold your affected hand in place against the wall at chest level.

c. 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.

d. 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

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. Do not attempt to move the individual until help arrives.

Most falls, however, do not result in injury. The illustrations that follow outline a recommended method for getting from the floor onto a chair. The individual 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 other 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 are 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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Neuropsychology

Neuropsychologists are psychologists with specialized training working with people who’ve developed a neurological problem, such as a stroke. The neuropsychologist on your treatment team has three primary roles in working with you:

1. To identify and make treatment recommendations regarding any emotional distress you may be experiencing, e.g. anxiety, depression, etc. Treatment may include therapy and/or medication.

2. To identify and make treatment recommendations regarding any cognitive difficulties you may be experiencing. Cognitive difficulties that may occur after stroke include concentration/attention, memory, language (expressing oneself clearly and understanding others), spatial skills, problem-solving, etc.

3. Patient and family education regarding stroke symptoms, recovery, and post-stroke sexuality.
FAMILY TRAINING NOTES

- PSYCHOLOGY -

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Stroke Support Group

Stroke survivors face many types of challenges as they return to everyday life. Join other survivors and their caregivers to share information, locate resources, solve problems and celebrate victories. Meetings are held monthly and coordinated by rehabilitation staff.

Survivors at all stages of recovery are welcome, as are their caregivers and others interested in stroke recovery.

Meetings are held on the first Thursday of each month at 1:00 pm in the third floor conference room at Roger C. Peace Rehabilitation Hospital.

For more information please call Dr. Anita McQuillen at 455-3755.
Dealing with a flood of emotions can be hard for stroke survivors. Some emotions are normal responses to the changes in your life after stroke. Others are common but should not be considered a normal part of stroke recovery. If you suffer from depression, anxiety or emotions that are not in line with the occasion, seek help.

Dealing with Depression

Grieving for what you have lost is good for you. But when sadness turns to depression, it’s time to act. Depression can take hold right after a stroke, during rehabilitation (rehab) or after you go home. It can be – but not always – caused by brain damage from the stroke. Mild or major, it is the most common emotional problem faced by survivors.

Depression symptoms include:

- Feeling sad or “empty” most of the time
- Loss of interest or pleasure in ordinary activities
- Fatigue or feeling “slowed down”
- Sudden trouble sleeping or oversleeping
- Sudden loss of appetite or weight gain
- Being unable to concentrate, remember or make decisions like you used to
- Feeling worthless or helpless
- Feelings of guilt
- Ongoing thoughts of death or suicide, suicide planning or attempts
- A sudden change in how easily you are annoyed
- Crying all the time

Some useful tips:

- Make the most of rehab; the more you recover, the better you will feel
- Spend time with family and friends
- Maintain your quality of life by staying active and doing things you enjoy
- Seek help soon after you note symptoms
Your treatment may include counseling, medicine or both.

Having Extreme Anxiety
Anxiety is an overwhelming sense of worry or fear. It can include increased sweating or heart rate. Among stroke survivors, feelings of anxiety are common. Often, stroke survivors suffer from both depression and anxiety at the same time.

Anxiety can affect rehab progress, daily living, relationships and quality of life. So, be sure to seek help right away.

Anxiety symptoms include:
- Ongoing worrying, fear, restlessness and irritability that don’t seem to let up
- Low energy
- Poor concentration
- Muscle tension
- Feeling panicky and out of breath
- Scary rapid heart beat
- Shaking
- Headache
- Feeling sick to your stomach

Again, treatment may include counseling, medicine or both.

Uncontrolled Emotions
Do you find yourself laughing or crying at all the wrong times? If so, you may suffer from Pseudobulbar Affect (PBA). Also called emotional incontinence or pathologic lability, PBA is a common medical problem among stroke survivors. It can cause you to laugh at a funeral or cry at a comedy club. It can even make you cry uncontrollably for little or no reason. For this, it is often confused with depression. But, PBA is not depression.

People with PBA are unable to control their emotional expressions the way they used to. When this happens in social settings, they feel embarrassed, frustrated and angry. They also sense that others are uneasy. They may avoid work, public places and family get-togethers. This can lead to feelings of fear, shame and isolation.

There is no treatment approved by the Federal Drug Administration (FDA) for PBA, though antidepressant drugs can help.

These things may help you cope with PBA:
- Be open about it. Warn people that you cannot always control your
emotions. Explain that the emotions you show on the outside don’t always reflect how you feel on the inside.

- Distract yourself. If you feel an outburst coming on, focus on something boring or unrelated. Try counting the number of items on a shelf.
- Note the posture you take when crying. When you think you are about to cry, change your posture.
- Breathe in and out slowly until you are in control.
- Relax your forehead, shoulders and other muscles that tense up when crying.

What Can Help

- Ask your doctor about emotional changes and symptoms early on.
- Ask your family to stimulate your interest in people and social activities.
- Stay as active as possible and stay involved in your hobbies.
- Set goals and measure accomplishment.
- Plan daily activities to provide structure and sense of purpose.
- Stay involved with people, thoughts and activities that you enjoy.
- Contact your local stroke association.
- Join a stroke support group. Other survivors will understand your issues, and offer support and ideas to help you manage your emotions.
- Speak openly and honestly to your caregivers about your emotional changes. They’ll be glad you did, and together you can work out a solution.

Professionals Who Can Help

- Psychologists, psychiatrists and other mental health professionals experienced with stroke-related emotional disorders.
Rehabilitation is a lifetime commitment and an important part of recovering from a stroke. Through rehabilitation, you relearn basic skills such as talking, eating, dressing and walking. Rehabilitation can also improve your strength, flexibility and endurance. The goal is to regain as much independence as possible.

Remember to ask your doctor, “Where am I on my stroke recovery journey?”

Note: This fact sheet is compiled from general, publicly available medical information and should not be considered recommended treatment for any particular individual. Stroke survivors should consult their doctors about any personal medical concerns.

NSA publications are reviewed for scientific and medical accuracy by the NSA Publications Committee.
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Part of getting back into a normal routine involves resuming a healthy sex life. The need to love and be loved, and to have the physical and mental release sex provides, is important. But, having sex after stroke can present problems or concerns for you and your partner. Stroke can change your body and how you feel. Both can affect sexuality.

Stroke survivors often report a decrease in sexual desire and how often they have sexual relations. Women report a strong decrease in vaginal lubrication and the ability to have an orgasm. Men often have weak or failed erections and ejaculations.

Communication Is Key

Talking about sex is hard for many people – more so if you are unable to understand or say words or if you have uncontrollable crying or laughing (a common problem after stroke). But it is critical to talk openly and honestly with your partner about your sexual needs, desires and concerns. And give your partner a chance to do the same.

Fear of having another stroke during sex is common. But it is unlikely that a stroke will occur during sexual activity. Again, talk to your partner about this. It may make both of you feel better. Counseling may also help.

Getting Started

- Start by re-introducing familiar activities such as kissing, touching and hugging.
- Create a calm, non-pressure environment where both of you will feel comfortable.

Depression, Medicines, Pain

It is common for stroke survivors and/or their partners to suffer from depression. When you are depressed, you tend to have less interest in sexual intimacy. The good news is that depression can be treated with medicines. The medicines may increase your interest in sexual activity but also may have side effects that interfere with your ability to enjoy sex.
The same can be said for anxiety, high blood pressure, spasticity (stiffness or uncontrolled jerking), sleeping problems and allergies. Problems in these areas can be treated by medicines. But, the medicines may decrease your ability to enjoy sex. If your ability to enjoy sex has decreased since your stroke, talk with your doctor about medicines that have fewer sexual side effects.

After stroke, many survivors have problems with pain. The pain can contribute to loss of sexual desire, impotence and the ability to have an orgasm. Talk to your doctor about ways to manage your pain.

**Incontinence and Impotence**

If you are having trouble with controlling your bladder or bowel, you may be afraid that you will have an accident while making love. One tip is to go to the bathroom – if you can – before having sex.

If you have a catheter (small, flexible tube) placed in your bladder or urethra, you can ask your doctor’s permission to remove it and put it back in afterwards. A woman with a catheter can tape it to one side. A man with a catheter can cover it with a lubricated condom (rubber). Using a lubricant or gel will make sex more comfortable. Other suggestions:

- Don’t drink liquids before sexual activity.
- Place plastic covering on the bed, or use an incontinence pad to help protect the bedding.
- Store cleaning supplies close in case of accidents.
- Avoid positions that put pressure on the bladder.

Impotence refers to problems that interfere with sexual intercourse, such as a lack of sexual desire, being unable to keep an erection, or trouble with ejaculation. Today, there are many options available to men with this problem. For most, the initial treatment is an oral medicine. If this doesn’t work, options include penile injections, penile implants or the use of vacuum devices. Men who are having problems with impotence should check with their doctors about corrective medicines. This is especially true if you have high

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blood pressure or are at risk for a heart attack.

**Tips for Enjoying Sex**

- Communicate your feelings honestly and openly.
- If you have trouble talking, use touch to communicate. It is a very intimate way to express thoughts, needs and desires.
- After stroke, your body and appearance may have changed. Take time for you and your partner to get used to these changes.
- Maintain grooming and personal hygiene, to feel attractive not only for yourself but your partner.
- Explore your body for sexual sensations and areas of heightened sensitivity.
- Have intercourse when you are rested and relaxed and have enough time to enjoy each other.
- Try planning for sex in advance, so you can fully enjoy it.
- Be creative, flexible and open to change.
- The side of the body that lacks feeling or that causes you pain needs to be considered. Don’t be afraid to use gentle touch or massage in these areas.
- Use pillows to prop yourself up on one side. You can lie on that side or have your partner take the position on top.
- If you are not able to make thrusting motions, your partner may want to perform that part of intercourse.
- If intercourse is too hard, remember there are other pleasurable forms of lovemaking, including touching and caressing, hugging, massage, oral sex, self touching and using a vibrator.

**If Not in A Relationship**

If you are not in a relationship, you may be able to fulfill your needs and desires through masturbation (the act of self-stimulation). This is a perfectly normal activity. You should not feel shame or guilt about it.

This practice can help you focus on the touch that is most pleasing and comfortable to you. It allows you to go at your own pace to re-
familiarize yourself with your sexual needs. In fact, self-pleasuring can help you relax and become accepting of your feelings. You can focus on yourself and not worry about someone else.

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 is safe to have sex again.
- Focus on being loving, gentle and caring with each other. Be romantic with soft music and candlelight dinners.
- Speak honestly with your partner about your sexual changes. They’ll be glad you did, and, together, you can often work out the best solution.
- Contact your local stroke association.
- Join a stroke support group. Other survivors will understand, validate your issues, and offer encouragement and ideas.

Professionals Who Can Help

- A general physician or doctor.
- A urologist, who specializes in urinary functions as well as the male reproductive system and can help answer questions and provide solutions.
- A gynecologist, who specializes in the female reproductive system and sexual problems.
- A licensed counselor can help you or your partner talk about uncomfortable feelings about sex, the effects of stroke on the relationship/individual, or any other issues.

More References

Resurrecting Sex: Solving Sexual Problems and Revolutionizing Your Relationship by David
Rehabilitation is a lifetime commitment and an important part of recovering from a stroke. Through rehabilitation, you relearn basic skills such as talking, eating, dressing and walking. Rehabilitation can also improve your strength, flexibility and endurance. The goal is to regain as much independence as possible.
PHYSICAL THERAPY

Your physical therapist will perform an initial evaluation to test your strength, joint movement, sensation and mobility. The therapist will then develop an individualized treatment program based on the results of the evaluation.

This program may include strengthening and conditioning exercises, balance activities, and training for functional mobility such as walking or using a wheelchair. You and your family/caregiver will also be actively involved in education.

Your family/caregiver will be educated on how to help you do the things that you may not be able to do for yourself at this time.

The overall goal is to increase your independence by working toward overcoming the physical disability caused by the stroke so that you may return to a satisfying, productive lifestyle.
FAMILY TRAINING NOTES
PHYSICAL THERAPY

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BARRIER – FREE DESIGN

This information will help you decrease obstacles in the following rooms of your home:

a. Barrier – free bathroom  
b. Barrier – free kitchen  
c. Barrier – free bedroom  
d. Barrier – free ramp

A barrier prevents a person from using a building or part of that building. For a person in a wheelchair, this would be stairs, a curb, or a narrow doorway. Here are some things you need to know to make your home barrier-free.

BATHROOM

1. Doors should open out into the hall to avoid taking up space inside the bathroom.

2. The bottom of the sink should be 29-inches from the floor. There should be an open space under the sink. Exposed pipes must be insulated or covered.

3. The bottom of the mirror over the sink should be 40-inches from the floor.

4. Lever handles on water facets are recommended.

5. Toilet seats should be the same height as the wheelchair seat. When it is possible, a padded, elevated seat may be necessary.

6. Grab bars should be placed by or around the toilet and in the tub for safety (always mounted in the wall studs).

7. You may need a transfer style tub bench to enter/exit your bathtub safely.

8. A roll-in shower should be 5-feet wide and 5-feet long with a level entryway and a drain that is level or slightly below the level of the floor.

9. A stand-in shower should be at least 32-inches wide to leave room for a shower chair.

10. A flexible handheld shower hose for the tub or shower is recommended.

11. There should be no throw rubs on the bathroom floor.
GRAB BAR PLACEMENTS FOR TOILET TRANSFERS

a. For standing or sitting transfers:

1. An 18-inch to 24-inch grab bar is needed.
2. It should be placed either horizontal or vertical (not diagonally) on the wall beside the toilet.
3. Grab bar should be mounted 33-36” from floor.
4. Space between a grab bar and the wall must be exactly 1” to 1-1/2” – a wider gap is dangerous because user’s arm could slip between wall and bar.
5. Grab bars must be firmly attached in wall studs and capable of supporting 250 lbs.

(add illustration)

b. For toilets with no side wall nearby:

1. An 18 to 24-inch grab bar is needed.
2. Placed 33-36” up from floor level.
3. It needs to have a bar coming down which is bolted to the floor.
4. You may use a bar coming from the back wall (Figure A).
5. You may use brackets attached to the toilet seat (Figure B).

(add illustration)
BATHTUB

Grab bars at the tub can be placed at many different positions. The important point is to place them where the patient will be able to use them.

To transfer to bottom of tub:
1. An 18 to 24 inch grab bar is needed (Figure A).
2. Place the bar across the wall and secure it into a stud for stability (horizontal placement).
3. The bar should be 2 inches above the top of the tub.

To transfer using a shower bench or shower chair:
1. An 18 to 24 inch grab bar is needed (Figure B).
2. Most benches will have an armrest attached and allow one to sit down before lifting legs over side of tub.
3. For the chair, place the grab bar across the wall 10 inches above the top of the tub.

For standing transfers:
1. An 18 to 24 inch grab bar is needed (Figure C).
2. Place the grab bar across the wall at the end of the tub. Vertical placement is suggested for people who just need hand support to step over wall.
3. Place the bar up and down on the wall near the faucet.

(add illustration)
SHOWER

A roll-in shower does not need bars, but would assist other standing users for general safety.

For a bench shower:

1. An 18 to 24 inch bar is needed (Figure A).
2. Place the bar across the shower at waist level (horizontal).
3. Place the bar under the showerhead (horizontal).

For a standing shower:

1. Use a L-shaped grab bar (Figure B).
2. It should be 18 to 24 inches long.
3. Place the bar on the side or the end of the shower near the faucets.

(add illustration)
BEDROOM

1. The bed should have a firm mattress and be as close to the same height as the wheelchair seat as possible.
2. If the bed is placed in a corner against the wall, it will be more sturdy to get in and out of.
3. You should be able to get (or fit) the wheelchair beside the bed.

KITCHEN

1. Tables and counters should be 30 to 32 inches high.
2. Open space under the sink will be needed for the wheelchair.
3. Exposed pipes under the sink should be insulated or covered.
4. Controls on the front of the stove are better than those on top.
5. An oven door hinged on the side is better than one hinged at the bottom.
6. Cabinets should be low enough to be reached from a wheelchair.

CLOSETS

Closets should have a clothes rod low enough to be reached from a wheelchair.

FLOORS

Tile floors, hardwood floors, or low pile carpet are best if a wheelchair is used. It is easier to propel on these surfaces, as opposed to thicker pile carpet.
A ramp constructed to increase wheelchair accessibility must be a proper length, to avoid the hazards posed to a helper and/or a wheelchair user when an incline is too steep. The formula for a proper ramp is for every 1-inch of vertical rise there needs to be 12-inches of ramp length. This 1:12 ratio is termed a minimal slop (ADA specifications) and allows a person to safely propel himself up this slop or will allow a helper to push a wheelchair-bound without unnecessary exertion of the helper. **PLEASE DO NOT SKIMP ON REQUIRED LENGTH OF RAMP.**

**GETTING STARTED WITH YOUR RAMP.** First, you must measure the height of the steps plus the height to the top of the door threshold. This will give you the required length of the incline. Ramps must also have a level platform, at least 4 x 4 feet, at the entranceway and at a turn if the ramp is angled secondary to limited space in yard.

**OTHER SUGGESTED REQUIREMENTS:**
- Ramp should be at least 3 feet wide … 4 feet is better!
- Use deck-grade planks, not plywood.
- Should have non-skid surface.
- Should have curbing on either side of ramp to prevent wheelchair from wheeling off the edges.
- A handrail is suggested when a helper is involved, or if the patient is walking up the ramp.
- The required level platform, 4 feet square, needs to be added on to the calculated length of the incline.

Let’s suppose that the height of the steps at a door is found to be 10 inches from the ground to the door threshold. To provide a proper incline, the ramp should be 10 feet long, but remember, you also need a level platform right outside the entrance, unless there is an existing porch, so you have to add another 4 ft. to the construction, with the actual slope being 10 ft. long (see picture). * If there is already a porch 4 x 4 feet then you only need to either level the porch with the threshold step or ramp the threshold step if there is adequate room.

(add illustration)
Lying on the Hemiplegic Side

- Gently glide the shoulder blade and shoulder complex forward so the person is not lying directly on top of the shoulder. Allow the arm to externally rotate so the hand is palm face up pointing towards the head of the bed. The affected arm \textit{SHOULD NOT} be internally rotated and facing down.
- The unaffected arm may be supported by a pillow
- Place a pillow behind the back
- Both legs bent at the knees and hips with a pillow placed in between.

Sitting in Bed

- Hemiplegic arm supported on two pillows at the side with the forearm facing forward and hand supported.
- Trunk in midline
- Pillows may be placed under the unaffected arm for support as needed
- Avoid placing the arm across the body

Positioning the Hemiplegic Arm

The pictures below demonstrate a person with Right hemiplegia. For a person with Left hemiplegia, position the Left upper extremity as the Right is positioned in these pictures.

Lying on the Unaffected Side

- The hemiplegic arm should be supported on two pillows at the level of the shoulder joint so that the arm does not fall down across the body causing tension or pulling on the shoulder.
- Place a pillow behind the back.
- Both legs bent at the hips and knees with a pillow placed in between.

Sitting in Wheelchair

- Tray or trough on the wheelchair to support the affected upper extremity. A physical or occupational therapist may select a specialized arm support for the wheelchair.
- Position the shoulder in slight abduction, forearm pointing straight forward, and the hand supported.
- Pillows may be used when a tray or trough are unavailable to avoid the arm hanging at the side.
Ways to prevent pressure sores

Check your skin completely twice a day, once in the morning and once at night.

- Carefully look for skin damage or redness, especially on bony areas.

* The four most common areas for a pressure sore to develop in individuals are on the sacrum, or tailbone, the heel of the foot, the ischium, which is at the base of the buttocks and the bony areas of the foot. The trochanter or hip is another area at high risk for individuals who spend a lot of time in bed. (See picture at left).

* Always use proper equipment when seated or lying down. Have a doctor or qualified professional recommend what specialized equipment you need to protect your skin.

- Your seat cushion needs to fit your body and your chair. It needs to be properly adjusted to offer the best protection against pressure areas.
- Your mattress needs to provide proper support and protection.
- Use pillows or sheepskin to help protect areas of the body that get too much pressure.

Move often. Sitting or lying in the same position for too long causes the flow of blood to be cut off. The skin or underlying tissue begins to die, and it results in a pressure sore.

While in bed it is usually recommended that you change position at least every 2 hours.
* Keep skin clean and dry. Wet skin can become soft or inflamed and is less resistant to damage. Moisture weakens the skin and causes it to breakdown more quickly.

- Wash and dry skin right away after any bowel or bladder accident.
- Change clothes when they become wet.
- Use lotion instead of powder on your skin.

* Eat a well balanced diet. Foods high in protein, vitamins and minerals help your skin stay healthy and heal more quickly.
* Drink the recommended amount of fluids to help your skin stay soft.
• Drink plenty of water each day.
• Limit the number of caffeinated drinks like coffee, tea and soft drinks.

* Protect your skin from harm.

• Avoid movement or activities that rub, scratch or cut your skin.
• Avoid clothes and shoes that are too loose or too tight fitting.
• Avoid clothes with thick seams, buttons or zippers located in areas where they put pressure on your skin.
• Take special caution when doing transfers and participating in new activities or sports.

* Do not smoke. Smoking decreases oxygen to the skin and can make it more difficult for skin to heal.
* Do not abuse drugs or alcohol. Both can damage your skin and can also lead to other health problems.

Friction and shear from movement can contribute to pressure ulcers.

• Dragging the heels on the bed or sliding the buttocks against the bed or chair can remove the first layer of skin.
• Shear happens when the deeper tissues are pulled and torn from these shifts as well.

When sliding up in bed, the feet should be placed flat and used to help push.

When sitting upright in bed, all of the pressure is on the buttocks. Sliding down can result in friction and shear that harms the skin.

**Do not** rub red areas on the skin, as this causes shearing of the tissues below the skin surface.

Some examples of positioning options

**Side lying** use pillows and/or wedges to help keep you on your side. Try to avoid rolling fully on to the hip as pressure can build up in that area.

**Lying on your back** with heel pressure relief
OCCUPATIONAL THERAPY

The therapists within this department are trained to provide therapy in the areas of activities of daily living, upper extremity retraining, and visual-perceptual skills. The definition of ADL’s is any self-maintenance task such as grooming, hair care, make-up application, bathing, dressing, and toileting.

While you are here, your occupational therapist will be teaching you and your family alternative techniques for dressing, the safest and easiest way for you to take a bath, and groom yourself.

In addition, occupational therapy will focus on the skills needed to perform ADL’s. Your therapist will address upper extremity performance and fine motor coordination after a stroke.

Also, visual-perceptual skills will be addressed. Visual-perceptual skills involve your brain’s ability to interpret your world through your senses and allow you to manipulate your environment and objects to perform ADL’s.

The following pages will describe dressing techniques, visual-perceptual definitions, bathroom equipment, home modifications, and upper extremity exercises, which will be provided by your therapist.
Protect Your Shoulder after Your Stroke

It is common, after a person has a stroke, for a person to have weakness on one side of the body. This is called hemiplegia. You should protect the shoulder joint on the side that has hemiplegia so that you prevent injury and promote recovery.

The shoulder is made up of:
1. The Scapula (shoulder blade)- it has a protrusion that comes off if it called the Acromion. The acromion makes the “roof” of the shoulder joint.
2. The Clavicle (collar bone)- The clavicle is the bone that connects the shoulder blade to the rest of your body-at your sternum (breast bone).
3. The Humerus (arm bone)- The humerus is connected to the scapula mostly by muscles and other tissues. These muscles must work together for the humerus and scapula to move freely so you can use your arm.

The weakness you have on one side makes it difficult for those muscles in your shoulder to work right. When the muscles aren’t working right things can get pinched and hurt when you or someone else moves your shoulder. This can be a cause of shoulder pain and can lead to long term damage.

How can you protect your shoulder?

You can protect your shoulder by avoiding pinching those tissues in your shoulder. You can do that by…

1. Not lifting your arm above shoulder level- especially with your less affected arm.
2. DON’T let others lift your arm above shoulder level
3. DON’T let anyone pull on your arm or shoulder.

What about a sling? A sling is not helpful in regaining the use of your affected arm. Wearing a sling can promote tightness and holds your arm in a position that is best to avoid after having a stroke. You should only use a sling as directed by your therapist.
Putting on a Pullover Shirt with One Hand

If you have weakness on one side of your body because of an injury or stroke, follow these steps to put on a pullover shirt using your strong hand. It is easier to do this if you are seated on a firm chair.

Putting the shirt on

1. Place the shirt on your lap with the front of the shirt face down and the collar or tag at your knees.

2. Roll the bottom edge of the shirt back to expose the sleeve for the weak arm.

3. Move the sleeve opening for the weak arm between your knees and open it as large as possible.

More on next page ➔
4. Use your strong hand to grab your weak arm and place the weak hand into the sleeve opening. Make sure your fingers do not get caught in the sleeve. It may help to lean forward to let your weak arm drop down into the sleeve.

5. Pull the shoulder seam up the arm past the elbow.

6. Put your strong arm into the other sleeve opening.
7. Pull the shirt on the weak side up to the shoulder as much as you can.

8. Gather the back of the shirt up in your strong hand.

9. Lean slightly forward, lower your chin and pull the shirt over your head.

10. Use your strong hand and push the bulk of the shirt material over your weak shoulder towards your back.

11. Pull the shirt down over your stomach on both sides. Pull to adjust as needed.
Taking off the shirt

1. Reach back with your strong hand behind your neck and start to gather the shirt up in your hand.

2. Lean slightly forward, lower your chin and pull the shirt over your head.

3. Pull your strong arm out of the sleeve.

4. Use your strong hand to pull the other sleeve off the weak arm.

Talk to your doctor or others on your health care team if you have questions. You may request more written information from the Library for Health Information at (614) 293-3707 or email: health-info@osu.edu.
Putting on a Button Up Shirt
with One Hand

If you have weakness on one side from an injury or stroke, follow these steps to put on a button up shirt. It is easier to do this when you are seated on a firm chair.

Putting the shirt on

1. Use your strong hand and pick up the shirt by the collar and shake it to untwist it.

2. Spread the shirt out over your lap with the inside facing up and the collar next to your abdomen. Shirt tail will drape over your knees.

More on next page ➔

Learn more about your health care.
3. Open the sleeve opening of the shirt as much as you can on the weak arm side.

4. Pick up the weak hand with your strong hand. Place the weak hand into the sleeve opening.

5. Pull the sleeve up over your elbow on your weak side.

6. For the this step, follow either option A or B.
   - Option A
     ■ Grab the collar at the end closest to your strong side with your strong hand.
     ■ Hold the collar tightly and lean forward. Bring your strong hand up and take the shirt back around your head and across your back to your strong side.
- Put your strong hand into the armhole. Raise your arm out and up to push through the sleeve.

Option B

- Put your strong hand into the other armhole and raise your arm up to push through the sleeve.

- Use your strong hand and gather the back of the shirt from the tail to the collar in front of your body.

- Lift the gathered shirt up and lean forward. Duck your head and put the shirt over your head.
7. Lean forward and straighten your shirt by working the shirt down over your shoulders. Reach back and pull the shirt tail down.

8. Line up the shirt fronts and match up the buttons with the button holes. Start with the bottom button and start to button the shirt.

**To remove the shirt**

1. Unbutton the shirt.

2. Lean forward and reach up and back with your strong hand to gather up the shirt at the back of your neck.

3. Duck your head and pull the shirt forward over your head.

4. Take the sleeve down off your strong arm then take the shirt off your weak arm.
Putting on Pants with One Hand

If you have weakness on one side of your body because of an injury or stroke, you can follow these steps to put pants on using your one strong arm.

Putting the pants on

1. Sit on a firm chair or side of the bed. If you are in a wheelchair, have the foot rests up and your feet on the floor. Be sure the chair is locked.

2. Use your strong hand and grab hold of the ankle of your weak leg and cross it over your strong leg.
3. Pull your pants around your foot then onto the weak leg up to your knee. Do not pull them above the knee.

4. Use your strong hand on your weak leg and uncross your leg. Be sure to hold onto the weak leg when lowering it to the floor and make sure your pants remain on your weak leg.

5. Put your strong leg into the other leg of the pants.

6. Stay seated and pull your pants up above your knees.
7. Use your strong hand and lift your weak hand to place it in the pocket of the pants. This will keep your pants from falling down when you stand up.

8. Stand up and pull your pants up over your hips. If you are not able to stand on your own, you will need a caregiver to help you up.

9. If you have good balance, button and zip your pants while standing. If you have poor balance, sit back down on the chair and button and zip your pants.
Removing your pants

1. Sit on a firm chair or side of the bed. If you are in a wheelchair, have the foot rests up and your feet on the floor. Be sure the chair is locked.
2. Unbutton and unzip your pants.
3. Work your pants down over your hips as much as you can.
4. Stand up or stand up with help and let your pants drop past your hips.
5. Sit back down.
6. Cross your weak leg over your strong leg.
7. Remove the pant leg from your weak leg.
8. Uncross your legs and take the pants off your other leg.

Talk to your doctor or others on your health care team if you have questions. You may request more written information from the Library for Health Information at (614) 293-3707 or email: health-info@osu.edu.
SOCKS

To Put On:

1. Sit in a chair with your feet touching the floor.
2. Cross your affected leg over your strong leg.
3. Open the top of the sock by putting your thumb and first two fingers into the opening and spreading the fingers apart.
4. Put your sock over your big toe first and then work it over the rest of your foot.
5. Pull the sock over your heel and up your calf.
6. Adjust the sock so that you do not see any wrinkles.

To Remove:

To take off your socks, reverse the steps for putting them on.

SHOES

Putting On:

1. Sit in a chair with your feet touching the floor.
2. Cross your affected leg over your unaffected leg.
3. Hold your shoe by its tongue and put it on over your toes.
4. Grab your shoe by the heel and push it onto your heel.

To Remove:

To take your shoes off, reverse the steps of putting it on.
BARRIER–FREE DESIGN

This information will help you decrease obstacles in the following rooms of your home:

a. Barrier–free bathroom
b. Barrier–free kitchen
c. Barrier–free bedroom
d. Barrier–free ramp

A barrier prevents a person from using a building or part of that building. For a person in a wheelchair, this would be stairs, a curb, or a narrow doorway. Here are some things you need to know to make your home barrier-free.

BATHROOM

1. Doors should open out into the hall to avoid taking up space inside the bathroom.

2. The bottom of the sink should be 29-inches from the floor. There should be an open space under the sink. Exposed pipes must be insulated or covered.

3. The bottom of the mirror over the sink should be 40-inches from the floor.

4. Lever handles on water facets are recommended.

5. Toilet seats should be the same height as the wheelchair seat. When it is possible, a padded, elevated seat may be necessary.

6. Grab bars should be placed by or around the toilet and in the tub for safety (always mounted in the wall studs).

7. You may need a transfer style tub bench to enter/exit your bathtub safely.

8. A roll-in shower should be 5-feet wide and 5-feet long with a level entryway and a drain that is level or slightly below the level of the floor.

9. A stand-in shower should be at least 32-inches wide to leave room for a shower chair.

10. A flexible handheld shower hose for the tub or shower is recommended.

11. There should be no throw rubs on the bathroom floor.
GRAB BAR PLACEMENTS FOR TOILET TRANSFERS

a. For standing or sitting transfers:
   1. An 18-inch to 24-inch grab bar is needed.
   2. It should be placed either horizontal or vertical (not diagonally) on the wall beside the toilet.
   3. Grab bar should be mounted 33-36” from floor.
   4. Space between a grab bar and the wall must be exactly 1” to 1-1/2” – a wider gap is dangerous because user’s arm could slip between wall and bar.
   5. Grab bars must be firmly attached in wall studs and capable of supporting 250 lbs.

b. For toilets with no side wall nearby:
   1. An 18 to 24-inch grab bar is needed.
   2. Placed 33-36” up from floor level.
   3. It needs to have a bar coming down which is bolted to the floor.
   4. You may use a bar coming from the back wall (Figure A).
   5. You may use brackets attached to the toilet seat (Figure B).

BATHTUB

Grab bars at the tub can be placed at many different positions. The important point is to place them where the patient will be able to use them.

To transfer to bottom of tub:
  1. An 18 to 24 inch grab bar is needed (Figure A).
  2. Place the bar across the wall and secure it into a stud for stability (horizontal placement).
  3. The bar should be 2 inches above the top of the tub.

To transfer using a shower bench or shower chair:
  1. An 18 to 24 inch grab bar is needed (Figure B).
  2. Most benches will have an armrest attached and allow one to sit down before lifting legs over side of tub.
  3. For the chair, place the grab bar across the wall 10 inches above the top of the tub.

For standing transfers:
  1. An 18 to 24 inch grab bar is needed (Figure C).
  2. Place the grab bar across the wall at the end of the tub. Vertical placement is suggested for people who just need hand support to step over wall.
  3. Place the bar up and down on the wall near the faucet.
SHOWER

A roll-in shower does not need bars, but would assist other standing users for general safety.

For a bench shower:

1. An 18 to 24 inch bar is needed (Figure A).
2. Place the bar across the shower at waist level (horizontal).
3. Place the bar under the showerhead (horizontal).

For a standing shower:

1. Use a L-shaped grab bar (Figure B).
2. It should be 18 to 24 inches long.
3. Place the bar on the side or the end of the shower near the faucets.
WHERE TO INSTALL GRAB BARS

These suggestions for grab bar placement include ADA guidelines and recommendations from universal design specialists.

Tub/Shower:

Vertical bar: (18" long) at entrance to tub; bottom of bar 32 to 38" above the floor.

Horizontal bar on control wall: 24" long; 34 to 38" above the floor.

Horizontal bar on back wall: 32 to 48" long; 34 to 38" above the floor for shower only; 6 to 10" above top of tub for bath only.

Angled bar: 24" long; bottom end 6 to 10" above top of tub (not necessary in stand-alone showers).

Toilet:

Horizontal bar at side: 42" long (min.); 12" (max.) from the back wall; 33 to 36" above the floor.

Horizontal bar behind: 24" long (min.); 6" (max.) from the side wall; 33 to 36" above the floor.
BEDROOM

1. The bed should have a firm mattress and be as close to the same height as the wheelchair seat as possible.
2. If the bed is placed in a corner against the wall, it will be more sturdy to get in and out of.
3. You should be able to get (or fit) the wheelchair beside the bed.

KITCHEN

1. Tables and counters should be 30 to 32 inches high.
2. Open space under the sink will be needed for the wheelchair.
3. Exposed pipes under the sink should be insulated or covered.
4. Controls on the front of the stove are better than those on top.
5. An oven door hinged on the side is better than one hinged at the bottom.
6. Cabinets should be low enough to be reached from a wheelchair.

CLOSETS

Closets should have a clothes rod low enough to be reached from a wheelchair.

FLOORS

Tile floors, hardwood floors, or low pile carpet are best if a wheelchair is used. It is easier to propel on these surfaces, as opposed to thicker pile carpet.
WHEELCHAIR RAMP SPECIFICATIONS

A ramp constructed to increase wheelchair accessibility must be a proper length, to avoid the hazards posed to a helper and/or a wheelchair user when an incline is too steep. The formula for a proper ramp is for every 1-inch of vertical rise there needs to be 12-inches of ramp length. This 1:12 ratio is termed a minimal slop (ADA specifications) and allows a person to safely propel himself up this slop or will allow a helper to push a wheelchair-bound without unnecessary exertion of the helper. PLEASE DO NOT SKIMP ON REQUIRED LENGTH OF RAMP.

GETTING STARTED WITH YOUR RAMP. First, you must measure the height of the steps plus the height to the top of the door threshold. This will give you the required length of the incline. Ramps must also have a level platform, at least 4 x 4 feet, at the entranceway and at a turn if the ramp is angled secondary to limited space in yard.

OTHER SUGGESTED REQUIREMENTS:

♦ Ramp should be at least 3 feet wide … 4 feet is better!
♦ Use deck-grade planks, not plywood.
♦ Should have non-skid surface.
♦ Should have curbing on either side of ramp to prevent wheelchair from wheeling off the edges.
♦ A handrail is suggested when a helper is involved, or if the patient is walking up the ramp.
♦ The required level platform, 4 feet square, needs to be added on to the calculated length of the incline.

Let’s suppose that the height of the steps at a door is found to be 10 inches from the ground to the door threshold. To provide a proper incline, the ramp should be 10 feet long, but remember, you also need a level platform right outside the entrance, unless there is an existing porch, so you have to add another 4 ft. to the construction, with the actual slope being 10 ft. long (see picture). * If there is already a porch 4 x 4 feet then you only need to either level the porch with the threshold step or ramp the threshold step if there is adequate room.
Speech therapists are trained to provide a number of services for individuals who have sustained a stroke. Your speech therapist will evaluate and treat problems in the following areas:

1. One area of focus is to evaluate for and treat for swallowing problems.

2. A second area of focus is to work with you to regain or enhance your ability to communicate your thoughts and needs clearly, as well as to understand language.

3. A third area of focus is to work with you if you are experiencing problems with cognitive skills such as memory, problem solving, confusion or disorientation.

4. As always, patient and caregiver teaching is an important component of treatment.

In this section, you will learn about these areas.
Greenville Health System
Diet Consistencies

In November of 2003, GHS adopted, with some modifications, the National Dysphagia Diet (NDD) classifications for patients with dysphagia (swallowing difficulty).

**Puree** (NDD1): Pureed (“blended” or “blenderized”), homogenous, cohesive foods, “pudding like.” Note some facilities may call this diet “Dysphagia Pureed.”

**Dysphagia** (NDD2): Consists of foods that are moist, soft-textured, and easily formed into a bolus. Meats are ground or minced no longer than 1/4” pieces. Note that other facilities may call this diet “Dysphagia mechanically altered.”

**Dysphagia Advanced** (NDD3): Consists of foods that are of nearly regular textures, with the exception of hard, sticky, or crunchy foods. Foods still need to be moist and should be in “bite size” pieces. Allows some sandwiches.

**Mechanical Soft**: This diet is not part of the NDD system. It was kept at GHS since many physicians were familiar with it, and it is sometimes ordered even when Speech Pathology is not involved. It is generally used with patients without teeth or dentures. All meats are ground.

**GI Soft**: This is not a dysphagia diet. However, it is an option for physicians to order, and consists of bland, easily digestible foods.

**Regular**: No consistency restrictions.

Note: These diet consistency levels can be ordered in conjunction with diabetic (ADA), cardiac (AHA), or renal diets.

**Liquids/Thickening**

**Regular/thin**: Any liquid textures allowed.

**Nectar-thick**: All liquids must be at least the consistency of nectar or syrup.

**Honey-thick**: All liquids must be at least the consistency of honey.

Jell-O and ice cream are considered thin liquids because of their rapid melting properties. Vegetable juice, nutritional drinks (Boost, Ensure), nutritional “shakes,” and whole milk are all considered thin liquids and must be thickened before drinking. Buttermilk is considered nectar-thick. Soups such as chicken noodle or vegetable have broth, which is considered thin liquid. Creamed soups are considered nectar-thick.
Good nutrition is important to any rehab effort, but plays an even more essential role in stroke recovery and prevention. During your stay at Roger C. Peace Rehabilitation Hospital a registered dietitian is available to address any nutritional issues and to provide education to patient and family. The Food and Nutrition Department works to make sure your nutritional needs are met. In addition, we make every effort to meet those needs with food that is as enjoyable and appetizing as possible.

Please feel free to request a meeting with your dietician for assistance with nutrition or with your menu host/hostess for menu selections. You may make this request by speaking with any member of your rehab team or by calling the Food and Nutrition Department at 455-7095.
Recovery After Stroke: Healthy Eating

Eating well after stroke is key to your recovery. Choosing healthy foods can help you keep up your energy level for therapy, exercise and favorite activities. And, healthy eating will be easier once you learn to deal with new eating challenges brought on by your stroke.

After a stroke, 8-34% of survivors suffer from malnutrition. This means they aren’t getting enough vitamins and minerals because they aren’t eating enough healthy foods.

Choosing Healthy Foods

Healthy eating is good for you. It 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 dietician. The dietician will teach you how to plan meals and snacks to improve your health.

- Plan to eat a variety of foods each day.
- Have a rainbow of color on your plate.
- Eat at least five servings of fruits and vegetables per day.
- Your doctor may suggest a special diet to help you lose weight. Or you may need to eat foods with less salt or fat.

Too Tired to Eat or Cook?

Meal planning, grocery shopping and cooking require a lot of energy. But being tired doesn’t mean you should give up on healthy eating.

Planning ahead can help you get the nutrition you need for your stroke recovery.

- Eat your biggest meal early in the day when you have the most energy. The last meal of the day can be simple, such as a sandwich or cereal.
- 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.
- Ask family members and friends to make healthy meals for you.

www.stroke.org
meals that you can store in the refrigerator or freezer. Save these foods for the days you are too tired to cook.

- If preparing and eating three meals a day takes too long or takes too much energy, eat six small meals per day instead.
- Many communities offer a “Meals on Wheels” program. Check with your local social services to see how you can get healthy meals delivered to your home through this program.
- Seniors can often get healthy, low-cost meals at senior centers. Check your local newspaper for locations, times and menus.

Have You Lost Your Appetite?

Many survivors don’t feel as hungry as they used to and forget to eat during the day.

- Try eating smaller healthy meals throughout the day.
- Attractive, tasty, pleasant-smelling foods may enhance appetite.

- Be sure to plan three meals a day plus snacks to maintain your health and energy – even when you’re not so hungry.
- Eat high-calorie foods in your meal first.
- Sometimes, poor appetite is caused by depression. Your appetite is likely to improve after depression is treated.
- Walk or do some light exercise to stimulate your appetite.

Challenges When Eating

It’s hard to eat healthy when you have trouble swallowing, chewing, or using eating utensils.

Swallowing or Chewing Problems

Stroke can weaken or paralyze muscles that help us swallow or chew. About 40-60% of survivors have swallowing difficulties, called dysphagia.
Dysphagia can lead to serious medical problems such as dehydration (not enough water), malnutrition (not enough vitamins and minerals), choking, pneumonia and aspiration (when food or liquid leaks into the airways).

Talk to your doctor if you have any of these signs of dysphagia:

- Cough and sputter frequently.
- An unusually husky voice or the need to clear your throat often.
- Food and saliva escape from your mouth or nose when you try to eat.

Most people recover quickly. Some require treatment with a speech-language pathologist (SLP). The SLP can test for dysphagia and suggest strategies or treatments for swallowing and eating.

What can help:

- Cut foods into smaller pieces before chewing.
- Use a blender or food processor to puree foods to the texture of baby food.
- Choose soft foods such as cooked cereal, mashed potatoes, eggs, cottage cheese, applesauce, canned fruits and soups.
- Thicken liquids to keep them from going down the wrong pipe. Natural thickeners include tapioca, flour, instant potato flakes, oats and matzo meal.
- A normal swallow is complex. It involves 25 different muscles and 5 nerves. Your SLP may help you exercise these muscles or teach you new ways of swallowing.
- Sometimes, a feeding tube is needed.

Eating Utensils

After your stroke, you may have trouble grasping or holding utensils. Take advantage of special products that can help you:

- Flatware with larger handles or Velcro straps can be easier to grasp.
- Knives with curved blades can help you cut food with one hand.
- Plate guards can help keep food on the plate when using one hand.
- Rubberized pads under the plate can keep it from sliding around.
Search for these products and more on the Internet or go to one of the web sites below:

- www.dynamic-living.com
- www.elderstore.net/disabled
- www.abledata.com

Vision and Eating

Vision loss on one side can make it hard to see everything on the plate.

- During meals, rotate your plate or move it right or left so that it is easier to see.

Meals and Social Outings

Eating out is common in the United States. It can also be good for your recovery. Eating out on occasion relieves you of the duties of cooking meals and washing dishes. It also can help you connect socially with others. But, many stroke survivors shy away from restaurants and social outings because they have problems getting around or filtering out noise. Some of the following tips may help:

- Call ahead to see if the place has parking, entry ramps, eating space and bathrooms needed to host guests in wheelchairs.
- Choose a place that is less crowded, doesn’t have a lot of blaring music, and has smaller tables.
- Find a quite corner, if possible.
- Avoid busy times.
- Go to a familiar restaurant where you know the menu.
- Request a booth or table where you can sit across from others but face a wall; this can reduce distractions in the restaurant.
- Mentally rehearse what you want to order.
- Have family or friends help you order.
- Consider using picture cards if you have problems ordering.
- Bring a card that says “I have aphasia” and show it to the restaurant staff.

Visit the following web site to get the “I have aphasia” cards or for more information on companies that offer photo cards:

- www.aphasia.org/aphasiaaddresources.php#speech
What Can Help

- If you wear dentures, see your dentist to check how they fit. Loose dentures can interfere with chewing and swallowing. Dentures that don’t fit well can also cause you pain, which can kill your appetite. Medicines, mouth dryness and other medical changes can affect denture fit. Have your dentist check them at least once a year.

- Nutrition drinks and liquid supplements, such as Ensure®, can be used to supplement your diet if you are not getting enough nutrients due to eating problems.

- If you’re diabetic, be aware that a stroke can change your ability to eat the same foods or give yourself insulin shots. Talk to your doctor about how to manage your diabetes given your changes.

- Medical conditions such as high blood pressure or bladder and bowel problems require changes in your diet.


- Contact your local stroke association.

- Join a stroke support group. Other survivors will understand, validate your issues, and offer encouragement and ideas for eating healthy.
Eating is important to your health. After stroke, small changes can make a big difference.

Professionals Who Can Help

✓ A dietician or nutritionist
✓ Speech and language therapist – to find one in your area call the American Speech-Language-Hearing Association at (800) 638-8255.
✓ Dentist
✓ A general physician or doctor, for diet recommendations or referrals.

Rehabilitation is a lifetime commitment and an important part of recovering from a stroke. Through rehabilitation, you relearn basic skills such as talking, eating, dressing and walking. Rehabilitation can also improve your strength, flexibility and endurance. The goal is to regain as much independence as possible.

Remember to ask your doctor, “Where am I on my stroke recovery journey?”

Note: This fact sheet is compiled from general, publicly available medical information and should not be considered recommended treatment for any particular individual. Stroke survivors should consult their doctors about any personal medical concerns.
RECREATIONAL THERAPY

Your recreational therapist will use various recreation and leisure activities as a form of treatment to restore or improve independent physical, cognitive, social and emotional functioning.

Also, your therapist will help you to practice and relearn skills needed for activities that are enjoyable to you.

Recreational therapy will focus on community re-integration, which will take you out of the hospital and return you to the community.

During this time, you will take all of the skills learned in your rehab stay and apply them in a practical community setting while under the guidance of a therapist.

You and your family will also work with the therapist to better understand your stroke diagnosis, stroke prevention, and life after stroke.
Recreation and Leisure

Leisure and recreation are important parts of our lives. There are three major points of leisure activities:

- Relaxation
- Entertainment
- Personal Development

Many communities have opened up their recreational programs and facilities to individuals with disabilities. Taking part in sports and recreational activities following a disability is not only possible but can also be a wonderful way to meet people, make friends and depending on the activity you chose, better your health.

After a stroke, many people think they cannot enjoy the same activities as they did before. Many activities can be done with one hand such as bowling, darts, fishing and racket sports. Other activities can be adapted with special equipment such as playing cards with a cardholder.

Sporting activities from the wheelchair include archery, basketball, camping, canoeing, flying, golf, horseback riding, water and snow skiing. These activities can be done for fun or at a competitive level.

The hardest step for many people is believing they can take part in these activities and finding the resources they need to do them. The information on the next few pages can help you find these resources.
Resources for Leisure/Recreation Activities

**Recreation and Parks Department:**
Assist individuals with disabilities in finding classes, accessibility information and activities. There may be a therapeutic recreation specialist on staff to help clients pursue recreational activities that match individual interests and abilities.

**Chamber of Commerce:**
Provide information about points of interest, clubs and organizations, community events and accessibility of public buildings and transportation.

**Community Colleges:**
Offer academic and non-academic activities, including adaptive physical education classes, travel opportunities, recreational programs and wheelchair sports teams.

**Independent Living Centers:**
Sponsor recreational programs and trips; provide information on leisure opportunities available in a particular community.

**Service Organizations:**
The YMCA, YWCA, Boy and Girl Scouts, Red Cross and various churches offer many opportunities for individuals with disabilities to perform service in the community.

**Support Groups:**
Created and run by individuals with particular disabilities who share specific interests and needs. For information about groups for stroke survivors, contact the National Stroke Association at 1-(800)-STROKES or the American Stroke Association at 1-(888) 478-7653.
Recreation Equipment

**Swimming**: For many people, swimming is the perfect activity because it is inexpensive and requires little equipment. Water cushions the joints and the lack of gravity makes movement easier.

Equipment:
- Aquatic lifts provide access into the pool.
- Balance rings, hip belts, and neck collars are used to ease movement in the pool.

Resources for Purchasing:
- **Sprint/Rothhammer**: 1-(800) 235-2156
  www.sprintaquatics.com
- **Aquatic Access**: 1-(800) 325-5438
  www.aquatic-access.com
- **Access to Recreation**: 1-(800) 634-4351
  www.accesstr.com

**Gardening**: Gardening is good for the body and the soul. Working in a garden can be a form of physical exercise for the body and can also provide a sense of relaxation and accomplishment.

Equipment:
- Gardening tools with wrist supports for individuals with decreased hand control.
- There are raised garden beds that are wheelchair accessible.

Resources for Purchasing:
- **Access to Recreation**: 1-(800) 634-4351
  www.accesstr.com
Recreation Equipment, cont

**Bowling:** Bowling may be an activity that you participate in before your stroke or it may be an activity that you would like to take up now. There is adaptive equipment that may help you keep or start bowling!

**Equipment:**
- A ball pusher can be used for pushing and guiding the ball down the lane.
- A handle grip bowling ball has a handle that can be used to grip the ball instead of using the fingers.
- A bowling ramp can be used if you have limited use of your arms. The ramp is placed in front of the lane and the ball is pushed down the ramp.

**Resources for Purchasing:**
- Access to Recreation: 1-(800) 634-4351
  www.accesstr.com

**Fishing:** Fishing may be a source of relaxation for you. After your injury, you may need some assistive devices to help you keep up your hobby.

**Equipment:**
- A rod holder can be strapped around your waist to hold your fishing pole if you are unable to hold it.
- A strong arm can be used to hold your fishing pole around your wrist if you are unable to grip the pole.
- A fishing pole holder clamps onto the side of your wheelchair to hold the pole.

**Resources for Purchasing:**
- Access to Recreation: 1-(800) 634-4351
  www.accesstr.com
- Fishing Has No Boundaries (502) 898-4466
  www.apex.net/handicapable
Recreation Equipment, cont

**Golf:** Golf is a sport that takes dedication. There is equipment that can assist you in keeping your golf passion.

Equipment:
- Shortened clubs can be used from the wheelchair level.
- A “Back tee” can hook onto a gold tee and pull it form the ground without forcing the golfer to bend over.
- An assistive golf stick can pick-up a golf ball from a seat position.

Resources for Purchasing:
- Access to Recreation: 1-(800) 634-4351
  www.accesstr.com
- Get a Grip: (602) 728-0218
- Professional Clubmakers: 1-(800) 548-6094
  www.proclubmakers.org

**Cards:** Card games are a recreational activity that does not take much physical effort, but it does require fine motor skills.

Equipment:
- A card shuffler will shuffle the cards if you have limited hand use.
- A cardholder will hold the cards for you if you are unable to.

Resources for Purchasing:
- Access to Recreation: 1-(800) 634-4351
  www.accesstr.com

These are just a few recreation activities and pieces of adaptive equipment! Access to Recreation is a great resource for equipment, but you can also search the internet or contact a local recreation resource or national sports association.
## Recreation and Leisure: Adaptive Equipment Catalogs

<table>
<thead>
<tr>
<th>Company</th>
<th>Address</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Adaptability</strong></td>
<td>Products for Independent Living</td>
<td>PO Box 515, Colchester, CT 06415</td>
</tr>
<tr>
<td><strong>After Therapy Catalog</strong></td>
<td>Access to Recreation, Inc.</td>
<td>2509 East Thousand Oaks Boulevard, Suite 430, Thousand Oaks, CA 91362, 1-(800) 634-4351</td>
</tr>
<tr>
<td><strong>Don Kreb’s – Adaptive</strong></td>
<td>Access to Recreation, Inc.</td>
<td>2509 East Thousand Oaks Boulevard, Suite 430, Thousand Oaks, CA 91361, 1-(800) 634-4351</td>
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<tr>
<td><strong>Recreation Equipment</strong></td>
<td>Access to Recreation, Inc.</td>
<td>2509 East Thousand Oaks Boulevard, Suite 430, Thousand Oaks, CA 91361, 1-(800) 634-4351</td>
</tr>
<tr>
<td><strong>Sammons</strong></td>
<td>PO Box 32, Brookfield, IL 60513-0032</td>
<td>1-(800) 323-5547</td>
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</table>
Travel

Traveling does not have to be a problem for individuals with disabilities. There are several travel agencies that specialize in making travel plans for people with disabilities. Here are some tips for worry-free travel:

- Call ahead to find out accessibility of the places you want to visit. Be very specific about your physical problems and your needs.

- Do not take your first trip during the holidays or busy travel times. These “peak” times are already stressful for both travelers and transportation employees. Instead, take a few trips during less busy times so you can learn your way around and be better prepared for busier times down the road.

- Try not to travel alone, especially in your first trip. If you do not have someone to travel with you, think about calling a travel company that specializes in planning trips for individuals with disabilities. These tours are made for people with mobility and communication problems.

- If you walk slowly, tire easily, or have any questions about your endurance, think about renting a wheelchair that you can use for longer tours.
<table>
<thead>
<tr>
<th>Travel Companies</th>
<th>Access to the World</th>
<th>Tailored Tours, Inc.</th>
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<tbody>
<tr>
<td></td>
<td>2828 East Colfax Avenue</td>
<td>1518 North Howe</td>
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<tr>
<td></td>
<td>Denver, CO 80206</td>
<td>Chicago, IL 60614</td>
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<td></td>
<td>(International Tours)</td>
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<tr>
<td>Evergreen Travel Service</td>
<td></td>
<td>Wheelchair Wagon Tours</td>
</tr>
<tr>
<td></td>
<td>4114 198th Street Southwest</td>
<td>PO Box 1270</td>
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<tr>
<td></td>
<td>Lynwood, WA 98036-5699</td>
<td>Kissimee, FL 32742</td>
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<tr>
<td>Flying Wheels Travel</td>
<td></td>
<td>Wheels on Tour, Inc.</td>
</tr>
<tr>
<td></td>
<td>143 West Bridge</td>
<td>20202 Cohasset</td>
</tr>
<tr>
<td></td>
<td>Owatonna, MN 55060</td>
<td>Canoga Park, CA 01306</td>
</tr>
<tr>
<td>Lampert Tours, Inc.</td>
<td></td>
<td>Whole Person Tours</td>
</tr>
<tr>
<td></td>
<td>1359 North Wells Street</td>
<td>PO Box 1084</td>
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<td></td>
<td>Chicago, IL 60610</td>
<td>Bayonne, NJ 07002</td>
</tr>
</tbody>
</table>
“The longer I live, the more I realize the impact of attitude on life. Attitude to me is more important than facts. It is more important than the past, then education, than money, than circumstances, than failures, than successes, then what other people think or say or do. It is more important than appearance, giftedness or skill. It will make or break a company – a church – a home. The remarkable thing is we have a choice every day regarding the attitude we will embrace for that day. We cannot change the past … We cannot change the fact that people will act in a certain way … We cannot change the inevitable. The only thing we can do is play the one string we have, and that is our attitude. I am convinced that life is 10% what happens to me and 90% how I react to it.”
Recovery After Stroke: Recurrent Stroke

After stroke, survivors tend to focus on rehabilitation and recovery. But, preventing another (or recurring) stroke is also a key concern. Of the 750,000 Americans who have a stroke each year, 5 to 14 percent will have a second stroke within one year. Within five years, stroke will recur in 24 percent of women and 42 percent of men.

<table>
<thead>
<tr>
<th>Percentage of Recurrence After First Stroke</th>
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<tbody>
<tr>
<td>3% to 10%</td>
<td>30-Day</td>
</tr>
<tr>
<td>5% to 14%</td>
<td>1-Year</td>
</tr>
<tr>
<td>25% to 40%</td>
<td>5-Year</td>
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</table>

Stroke prevention is also crucial for those who have had transient ischemic attacks (TIAs) or mini-strokes. TIAs are brief episodes of stroke-like symptoms that last from a few minutes to 24 hours. TIAs usually don’t cause permanent damage or disability. But, they can be a serious warning sign of an impending stroke. Up to one third of people who have a TIA are expected to have a stroke. Just like the first strokes, many recurrent strokes and TIAs can be prevented through lifestyle changes, surgery, medicine, or a mix of all three.

Your Lifestyle Choices

Everyone has some stroke risk. But, there are two types of stroke risk factors. One type you can’t control. The other you can.

Stroke risk factors you can’t change include:

- Being over age 55
- Being a man
- Being African American
- Someone in your family has had a stroke
- Having diabetes

Having one or more of these factors doesn’t mean you will have a stroke. By making simple lifestyle changes, you may be able to reduce the risk of a first or recurrent stroke.

These simple lifestyle changes can greatly reduce your chance of having a stroke:

[www.stroke.org](http://www.stroke.org)
Control your blood pressure
Find out if you have atrial fibrillation (an irregular heartbeat which allows blood to pool in the heart and cause blood clots)
Quit smoking
Limit alcohol
Monitor your cholesterol levels
Manage your diabetes
Exercise often
Eat foods low in sodium (salt) and fat
Monitor circulation problems with the help of your doctor

**Monitor Your Blood Pressure**

High blood pressure is one of the most important and easily controlled stroke risk factors. So it’s important to know your blood pressure range!

Blood pressure is given in two numbers, for example 120/80. The first number, the systolic blood pressure, is a measurement of the force your blood exerts on blood vessel walls as your heart pumps. The second, diastolic blood pressure, is the measurement of the force your blood exerts on blood vessel walls when your heart is at rest.

- For people over age 18, normal blood pressure is lower than 120/80. A blood pressure reading consistently 120/80 to 139/89 is pre-hypertension. If yours falls in this range, you are more likely to progress to high blood pressure. Also called hypertension, high blood pressure is a reading of 140/90 or higher.

- Have your blood pressure checked at least once each year — more often if you have high blood pressure, have had a heart attack or stroke, are diabetic, have kidney disease, have high cholesterol or are overweight. If you are at risk for high blood pressure, ask your doctor how to manage it more aggressively.

Often blood pressure can be controlled through diet and exercise. Even light exercise — a brisk walk, bicycle ride, swim or yard work — can make a difference. Adults should do some form of moderate physical activity for at least 30 minutes five or more days per week, according to the Centers for Disease Control and Prevention. Regular exercise may reduce your risk of stroke. Before you start an exercise program, check with your doctor.
Your Blood Pressure is High

What do you do if you still have high blood pressure, even though you have made an effort to eat healthy foods and exercise? Then it’s time to talk to your doctor.

A doctor can advise you about better lifestyle choices. Medicine may also be needed.

Many drugs can help treat high blood pressure. The most common are calcium channel blockers or ACE-inhibitors. You may have to try several different drugs before you find one that works for you. This is common. So, try not to be discouraged if it happens. Once you find a drug that works, take it as directed and exactly as prescribed, even when you feel fine.

Medicines

Medicine may help reduce stroke risk. In addition to those that treat high blood pressure, drugs are also available to control high cholesterol and treat heart disease. There are also drugs that can interfere with the blood’s tendency to form potential stroke-causing blood clots.

Heart Disease

Many forms of heart disease can increase your stroke risk. One form — known as atrial fibrillation or AF — causes blood to form clots that can travel to the brain and cause a stroke. AF is an irregular heartbeat.

Warfarin (Coumadin®) and aspirin are often prescribed to treat AF. People taking warfarin should be monitored carefully by a doctor. Also, people taking this drug should limit foods rich in vitamin K, which in large quantities may offset the drug’s effects. Examples of these foods include green leafy vegetables, alfalfa, egg yolks, soy bean oil and fish livers.

High Cholesterol

High levels of cholesterol may also increase stroke risk by not letting blood move freely through the arteries. Cholesterol build-up can break off. This can cause a clot to form or a stroke to occur. A few drugs, such as statins, may help lower cholesterol. Some statins have helped reduce the risk of stroke or TIA in people who have had a heart attack. They have even helped some with average or only slightly high cholesterol.
Blood Clotting

There are also a few drugs that can prevent clots, helping reduce risk of a second stroke.

Aspirin is the least costly and longest lasting of these drugs. A newer, more effective option is a combination of aspirin and extended-release dipyridamole, called Aggrenox®. Or, your doctor might choose to treat you with Clopidogrel (Plavix®). Warfarin is often prescribed to prevent clots from forming in those with atrial fibrillation.

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 another stroke.

During surgery, blockages and build-up in the arteries are removed to restore the free flow of blood. Your doctor is the best judge to decide if this is a good option for you.

Compliance is Critical

The key to preventing recurrent stroke is simple: follow your doctor’s suggestions about diet, exercise and weight loss, and take any medicine as directed. Your doctor will decide what’s best for you based on your general health and your 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.

Rehabilitation is a lifetime commitment and an important part of recovering from a stroke. Through rehabilitation, you relearn basic skills such as talking, eating, dressing and walking. Rehabilitation can also improve your strength, flexibility and endurance. The goal is to regain as much independence as possible.

Remember to ask your doctor, “Where am I on my stroke recovery journey?”

Note: This fact sheet is compiled from general, publicly available information and should not be considered recommended treatment for any particular individual. Stroke survivors should consult their doctors about any personal medical concerns.
Recovery After Stroke:  Health Insurance

Stroke recovery can require lots of time and medical attention. Ideally, some of that medical care is covered by health insurance. Dealing with health insurance companies, however, can be a challenge. But, taking the time to understand the specific benefits of your health care plan will help you manage your stroke recovery.

Dealing with Insurance Companies

Rehab programs can be costly. So it is important to know what portion of the bill your health insurance will pay and what you will have to pay “out-of-pocket.” It is also good to know if you can choose any doctor you want. Some plans require that you choose a doctor or specialist in a particular “network.”

There are two main types of health plans: Indemnity plans and managed care plans.

Traditional “Indemnity Insurance”

This type of health insurance usually:

- Involves a deductible, or amount you must pay toward your medical expenses before the insurance company will pay anything at all on your behalf.
- Pays part of your expense (usually 80%), once your deductible is met.
- Pays only for “covered” services listed in material sent by the insurance company.
- Allows you the flexibility to go to any doctor or rehab facility you choose.
- Requires more paperwork than other plans because you have to fill out and submit claim forms to receive your insurance benefits.
- Involves higher payments by you.

Managed Care

Managed care plans provide complete health services at reduced prices for their members, who agree to use doctors and facilities that belong to their plan. Under managed care plans:

- All medical costs are covered except for a small co-payment that you have to pay each time...
you are seen by a doctor or therapist.

- Your out-of-pocket expenses are often less.
- Your choice of providers, facilities, and services is usually limited to those within the network of health care providers. If you see a doctor or therapist that is not in the network, you may have to pay full price.

There are different kinds of managed care plans. The two most common are:

- Health maintenance organization (HMO). With an HMO, you usually have to get a referral from your doctor in order to see a specialist.
- Preferred provider organization (PPO). With a PPO, no referrals are necessary. You can go to any specialist in the network or pay more to go to a specialist that is not in the network.

**Settings and Services**

Stroke recovery may require extensive rehabilitation. This may include many services in different settings. Check with your health insurance company to make sure you are covered under the following settings and services.

- **acute care (inpatient) and rehab hospitals** – provide 24-hour medical care and a full range of rehab services in a hospital setting.
- **sub-acute facilities** – provide daily nursing care and a fairly wide range of rehab services.
- **long-term care facilities or “skilled nursing homes”** – provide rehab services several times per week to long-term and short-term residents.
- **outpatient facilities** – provide a wide range of rehab services for people who live at home and can come to the center for treatment several times a week.
- **home health agencies** – provide rehab services to stroke survivors in their own homes.

It is important to remember that there are inpatient and outpatient settings and services.

Inpatient services are those that are given to hospital residents who get treatments while they are staying in the hospital. Outpatient services are those given to patients who live in their own homes. These patients come into an office to see a doctor or therapist. Insurance companies...
sometimes pay different rates/benefits for these two types of services.

**Key Questions on Coverage**

Figuring out what your insurance plan pays for requires that you ask a lot of questions. Examples include:

- Does the plan cover rehabilitation services? Which services?
- Does the plan require me to pay more for rehab services than for regular doctor visits?
- Are my doctors and facilities in the provider network?
- Does the plan require my primary care doctor to give me a referral to see a specialist?
- Does the plan provide coverage for prescription drugs?
- What medical equipment is covered by the plan (power wheelchair, adaptive equipment, braces, equipment to continue therapy at home)? How much of the equipment cost is paid by health insurance? How much do I pay?
- Does the plan limit the number of days for rehab program visits (either inpatient days in a facility or outpatient days/doctor visits, or combined)?
- If days are limited, are they renewed from year to year?
- Does the plan limit coverage, or require special referrals for treatment of a pre-existing condition or a repeat experience, such as a stroke?
- Does the plan require me to have speech therapy in order to receive occupational therapy (help with performing daily activities)?
- Does the plan cover outpatient speech therapy?
- Does the plan limit the dollar amount it will pay for a particular setting or service?
- Can the plan suddenly remove my doctor or therapist from the network, leaving me without coverage to continue with them? Can the plan decide I will no longer be covered? In either situation, how much advance notice would I receive?
- What are the procedures to appeal a decision made by the health insurance plan? Does the insurance company or an independent reviewer handle an appeal?
- Does the plan exclude “cognitive therapy” (a form of treatment used to change...
patterns of thinking, such as depression)?

- What type of home care is covered? What do I pay for home care?

**Disability Benefits**

If you are working in a place where you are covered by the Family Medical Leave Act (FMLA), you must apply as soon as possible. For one, FMLA will protect your job. Also, you often have to apply for FMLA before you can apply for short-term and long-term disability from an employer-sponsored plan.

It is important that you apply for disability benefits shortly after your stroke. These benefits can assist you financially until you are able to go back to work.

There are several types of disability benefits that 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 on your own. If you have private disability insurance, take these steps to apply:

- If your disability insurance is through your employer, contact human resources to assist you in applying for benefits.
- Check with your employer to see if you will have to pay taxes on the money received.
- If you have your own disability insurance policy, call your insurance agent to help you apply for benefits.
- Not all disability plans are the same. Some will pay if you cannot do your current job. Others will only pay if you cannot do any job at all. Check to see which applies to your situation.
- Check your life insurance policies because they may pay your premiums while you are disabled.

**Government Disability Benefits**

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)
- Supplemental Security Income (SSI)

You can learn more about Social Security programs on the web at [www.ssa.gov](http://www.ssa.gov) or by calling (800) 772-1213. There are a few things to consider:
If you are already retired and receive a Social Security benefit, you will not be eligible to receive additional benefits.

SSA’s definition of disability is a physical or mental condition that lasts for at least 12 months and keeps you from working.

Apply for benefits even if you plan to go back to work.

You will need to describe to them the impact the stroke has had on you physically – they need to know why you can’t work.

Because of the time needed to process the paperwork, be sure to contact them as soon as possible. Also, make and keep copies of all the documents you send to them and letters they have sent to you. Keep track of the names of all the people you talked to, dates and what they told you.

Changes in Your Abilities

After stroke, what you are able to do may change many times. For example, you may start walking after years of using a wheelchair. Or you may regain sensation in an arm or leg. You may even lose the ability to do something that you once could do. Changes may happen shortly after stroke or take place years later. Either way, they generally require new rehab treatments.

Under Medicare and many private health plans, you are entitled to “re-enter” the system at any time if you experience a change in your abilities. This means that you can re-apply for added rehab benefits based on the change.

What Can Help

Every health insurance plan has coverage limitations. But you may have options for getting the rehab services you need.

- Try contacting the “exceptions” department of your health plan.
- Ask to work with a case manager for chronic or catastrophic illness.
- Seek help from your employer in dealing with the plan.
- Trade inpatient rehab days for outpatient days. Some plans have short inpatient coverage but longer home care/outpatient coverage.
- File an appeal if you feel you are being denied payment or a medical service to which you are entitled.
- If you need help talking to your insurance company about your health care and recovery, consider contacting resources

www.stroke.org
in your community, including vocational rehabilitation services, aging agencies, disability law/elder law projects and the Social Security Administration Office of Disability (http://www.ssa.gov/disability).

- For more information on Medicare coverage for stroke rehab, call (800)-MEDICARE or visit www.medicare.gov
- For information on your specific private health insurance plan, contact your insurance company or your employer’s benefits administrator.

Rehabilitation is a lifetime commitment and an important part of recovering from a stroke. Through rehabilitation, you relearn basic skills such as talking, eating, dressing and walking. Rehabilitation can also improve your strength, flexibility and endurance. The goal is to regain as much independence as possible.

Remember to ask your doctor, “Where am I on my stroke recovery journey?”

NSA publications are reviewed for scientific and medical accuracy by the NSA Publications Committee.

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About Skilled Nursing Facility Discharge

How do I make a decision about short-term or SNF rehab after stroke?
The healthcare team recommends a discharge and rehab plan based on your medical needs, activity tolerance, degree of deficit from the stroke, as well as your personal resources. You will not be discharged from the hospital until your doctor feels you are medically stable. However, the team will work to have a discharge plan in place so you can leave the hospital when the doctor feels you are ready.

Who pays for rehab services in a SNF?
Medicare pays 100% for the first 20 days, then 80% through the 100th day. Secondary insurance may pay the remaining 20 percent. Medicaid does NOT pay for the rehab. Other types of insurance usually follow Medicare guidelines. You should verify rehab benefits with your insurance. The facility also verifies your insurance coverage and notifies you of any out-of-pocket expense. However, insurance will only pay for rehab services as long as measurable gains in recovery are made.

What is the difference between short-term rehab and long-term SNF admission?
Individuals who are admitted for short-term rehab are expected to leave the facility at the end of rehab. If the stroke survivor cannot return to his/her prior living arrangements, he/she may be able to transition to long-term care in the same facility. Long-term care insurance is the only type of insurance that pays for this level of care. Long-term care is usually paid for privately, unless the person has Medicaid.

How is a referral or request made for a SNF?
The case manager/social worker will ask you to select at least two facilities you prefer and then will fax information to them. The SNF then has a very short time to review the information and make a bed offer based on bed availability and its ability to meet your needs. If the first two facilities of your choice do not offer a bed, Medicare guidelines require the hospital to send your information to all facilities within a 50-mile radius. Any offer from these other facilities should be seriously considered as there is a risk that insurance will not continue to pay for hospitalization once you are ready for discharge.

Should I contact the SNF myself?
Because each SNF receives many bed requests, you can bring your name to the attention of the facility’s admission coordinator by contacting them directly. When contacting a facility make sure to ask if any short-term beds are available. The facility will need to know the discharge plan when rehab is completed. If transition to a long-term care bed is expected, they will ask what the plan is for payment.

What happens after a facility offers a bed?
As soon as a facility offers a bed, the case manager/social worker will notify the patient/family and the doctor will determine the day of discharge. The patient’s family must complete paperwork at the facility before patient transfer. On the day of
discharge, the healthcare team will prepare hospital documents and arrange for patient transportation. The patient and/or family should be notified of the scheduled time for transport to the facility.
Get Involved

In addition to your personal preparedness, consider getting involved in neighborhood and community emergency preparedness activities. Assist emergency planners and others in considering the preparedness needs of the whole community, including people with disabilities and others with access and functional needs. Communities are stronger and more resilient when everyone joins the team. People with disabilities often have experience in adapting and problem solving that can be very useful skills in emergencies. To find out more about potential volunteering and emergency response training opportunities, go to http://www.ready.gov/volunteer.

This information was developed by the U.S. Department of Homeland Security in consultation with AARP, the American Red Cross and the National Organization on Disability and updated by the FEMA Office of Disability Integration and Coordination.

Prepare for Emergencies Now: Information for People with Disabilities

Your ability to recover from an emergency tomorrow may depend on the planning and preparation you do today. This guide provides tips which individuals with disabilities and others with access and functional needs, and the people who assist and support them, can take to prepare for emergencies before they happen.

1. Be Informed

It is important to know what types of emergencies are likely to affect your region. For more information about specific types of emergencies, visit www.ready.gov/be-informed.

Be prepared to adapt this information to your personal circumstances and make every effort to follow instructions received from authorities on the scene. Above all, stay calm, be patient and think before you act. With these simple preparations, you can be ready for the unexpected.

2. Make a Communications Plan

A disaster can interfere with your ability to communicate with your family, friends and coworkers. It is vital to have backup plans for staying in touch with your support network, and for your network to be aware of where you will shelter or evacuate.

Create a Personal Support Network

Everyone should make a list of family, friends and others who will be part of your plan. Include a relative or friend in another area who would not be affected by the same emergency, and who can help if needed. Make sure everyone knows how you plan to evacuate your home, school or workplace, and where you will go in case of a disaster. Make sure that someone in your personal support network has an extra key to your home and knows where you keep your emergency supplies. Teach them how to use any lifesaving equipment or medicine in case of an emergency. If you use a wheelchair, oxygen or other medical equipment, show friends how to use these devices so they can move you or help you evacuate. Practice your plan with your personal support network.

If you undergo routine treatments at a clinic or hospital, or if you receive regular services at home such as home health care, meals, oxygen, or door-to-door transportation, talk to your service provider about their emergency plans. Work with them to identify back-up service providers within your area and the areas you might evacuate to. If you use medical equipment in your home that requires electricity to operate, talk to your health care provider about a back-up plan for its use during a power outage.

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Build an Emergency Kit

The reality of a disaster situation is that you will likely not have access to everyday conveniences. To plan in advance, think through the details of your everyday life. You should include the following in your planning:

Basic Supplies
Think first about survival basics - food, water, first aid, and tools. Plan to make it on your own for at least three days. Consider two kits. In one kit put everything you will need to stay where you are and make it on your own for a week. The other kit should be smaller - lightweight, smaller version you can take with you if you have to leave your home. For more information on what should be included in a basic kit, please refer to the National Household Preparedness Guide at www.ready.gov/basic-disaster-supplies-kit.

The second step is to consider how an emergency might affect your individual needs. During emergencies, you may not have access to disaster assistance, a medical facility or even a drugstore. It is crucial that you and your family think about what kinds of resources you use on a daily basis, and what you might do if those resources are limited or not available.

Include Important Documents in Your Kit
Include copies of important documents in your kit, such as family records, medical records, wills, deeds, social security cards, bank account and insurance information, and tax records. Also be sure you have cash or travelers checks in your kits in case you need to buy supplies. It is best to keep these documents in a waterproof container. If there is any information related to operating equipment or life-saving devices that you rely on, include those in your emergency kit as well. Even if you do not use a wheelchair or other aid, consider putting important information onto a portable thumb drive for easy transport in an evacuation.

Finances
Signing up for direct deposit or the Direct Express card is a simple but important step that can help protect your family’s access to funds in case an emergency happens. If you or those close to you are still receiving Social Security or other federal benefits by check, please consider switching to one of these safer, cheaper options:
• Arrange electronic payments for your paycheck and federal benefits.
• The Direct Express® prepaid debit card is designed as a safe and easy alternative to paper checks for people who don’t have a bank account. Sign up is easy, call toll-free at (877) 212-9951 (phone), (866) 569-0447 (TTY) or sign up online at www.USDirectExpress.com.

Depending on your needs, additional items for your Go Kit might include:
• Copies of medical prescriptions, doctors’ orders, and the style and serial numbers of the assistive devices you use.
• At least a week’s supply of any medication or medical supplies you use regularly, or as much as you keep on hand.
• Medical alert tags or bracelets written descriptions of your disability and support needs, in case you are unable to describe the situation to an emergency responder.
• A list of the local non-profit or community-based organizations that know you or assist people with access and functional needs similar to your own.
• Extra eyeglasses; backup supplies for any visual aids you use.
• Extra batteries for hearing aids; extra hearing aids if you have them (or if you have insurance coverage for them).
• Battery chargers for motorized wheelchairs, or other powered medical/assistive technology devices.
• Supplies for your service animal. You can find more information at www.ready.gov/animals.
• A laminated personal communication board, if you might need assistance with being understood or understanding others.
• If you use a motorized wheelchair, have a light weight manual chair available for emergencies. Know the size and weight of your wheelchair, in case it is collapsible, in case it has to be transported.
• If you have allergies or chemical sensitivities, be sure to include items that are available for personal hygiene and for cleanup.

Create a Personal Support Network (con’t)
Talk to your employer and co-workers about the assistance you might need in an emergency. This is particularly important if you need to be lifted or carried. Talk about any communication difficulties, physical limitations, or special medical procedures that might arise during an emergency. Always participate in exercises, trainings and emergency drills offered by your employer or in your community.

Develop a Family Communications Plan
Your family may not be together when disaster strikes, so plan how you will contact one another and review what you will do in different situations. For more information on the family communications plan, visit http://www.ready.gov/family-communications.

Deciding to Stay or Evacuate
Depending on your circumstances and the nature of the emergency, the first important decision is whether to stay or go. The second step is to understand and plan for both possibilities. Use common sense and available information to determine if there is immediate danger. In any emergency, local authorities may not immediately be able to provide information on what is happening and what you should do. However, you should monitor television, radio, Internet, or social media news reports for information or official instructions as they become available. If you’re specifically told to evacuate or seek medical treatment, do so immediately. Check for items such as bookcases, hanging pictures, or overhead lights that could fall and block an escape path. For more fire safety tips, go to http://www.usfa.fema.gov/citizens/disability/.

Fire Safety
Plan two ways out of every room in case of fire. Check for items such as bookcases, hanging pictures, or overhead lights that could fall and block an escape path. For more fire safety tips, go to http://www.usfa.fema.gov/citizens/disability/.

Staying Put
Whether you are at home or elsewhere, there may be situations where you choose to stay put, even where you are and avoid any uncertainty outside. Consider what you can do to safely shelter-in-place alone or with friends, family or neighbors. Also consider how a shelter designated for the public would meet your needs. Work with local emergency managers and others in your community on preparing shelters information to a registry, be sure you understand your needs. Work with local emergency managers in emergencies. If you add your name and how a shelter designated for the public would meet information; others may be used to offer assistance or with friends, family or neighbors. Also consider Some registries are only used to collect planning what you can do to safely shelter-in-place alone maintain registries for people with disabilities.

Consider Your Service Animal and Pets
Whether you decide to stay put or evacuate, you will need to make plans in advance for your service animal and pets. Keep in mind that what’s best for you is typically what’s best for your animals. If you must evacuate, take your pets with you if you can. However, if you go to a public shelter, it is important to remember that by law only service animals must be allowed inside. Plan in advance for shelter alternatives that will work for both you and your animals. For more information about service animal/ pet preparedness, visit http://www.ready.gov/animals.

Evacuation
There may be situations in which you decide to leave, or are ordered to leave. Plan how you will get away and anticipate where you will go. Choose appropriate destinations in advance that you and others in your community understand you have options in an emergency. Ask about evacuation plans at the places where you spend time including work, school, community organizations, and other places you frequent. If you typically rely on elevators, work with others to develop back-up plans for evacuation in case they are not working. When traveling, consider alerting hotel or motel workers if you will need help in a disaster situation. Keep your equipment with you in an evacuation, if at all possible. If you must leave your wheelchair, bring your cushion.

Contact Your Local Emergency Information Management Office
Some local emergency management offices maintain registries for people with disabilities. Some registries are open to all individuals seeking information; others may be used to offer assistance in emergencies. If you add your name and information to a registry, be sure you understand with whom a registry is NEVER a substitute for personal preparedness. Even if the registry may be linked to first responders, assistance may not be available for hours or days after a disaster. Contact your local emergency management agency to see if these services exist where you live, or visit www.ready.gov/ to find links to government offices in your area.