HOPE
A Stroke Recovery Guide

RELATIONSHIPS
MOVEMENT
RESOURCES
RELATIONSHIPS
EXERCISE

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>
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</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>
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<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>
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<tr>
<td>Long-term 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>
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<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>
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<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>
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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>
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<tr>
<th><strong>Rehabilitation Team</strong></th>
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<tbody>
<tr>
<td><strong>Physiatrist</strong></td>
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<tr>
<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>
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<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>
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<td><strong>Case Manager</strong></td>
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<tr>
<td><strong>Recreation Therapist</strong></td>
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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-handled 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 (eg, 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 of 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.
Aphasia

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

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

**Types of Communication Problems Resulting from Aphasia**

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

People with “word-finding” problems may frequently pause during 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
APPENDIX

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.
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