

Recovering After a Stroke: A Patient and Family Guide

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Purpose of This Booklet

This booklet is about stroke rehabilitation. Its goal is to help the person who has had a stroke achieve the best possible recovery. Its purpose is to help people who have had strokes and their families get the most out of rehabilitation.

Note that this booklet sometimes uses the terms "stroke survivor" and "person" instead of "patient" to refer to someone who has had a stroke. This is because people who have had a stroke are patients for only a short time, first in the acute care hospital and then perhaps in a rehabilitation program. For the rest of their lives, they are people who happen to have had a stroke. The booklet also uses the word "family" to include those people who are closest to the stroke survivor, whether or not they are relatives.

Rehabilitation works best when stroke survivors and their families work together as a team. For this reason, both stroke survivors and family members are encouraged to read all parts of the booklet.

What is a Stroke?

A stroke is a type of brain injury. Symptoms depend on the part of the brain that is affected. People who survive a stroke often have weakness on one side of the body or trouble with moving, talking, or thinking.

Most strokes are ischemic (is-KEE-mic) strokes. These are caused by reduced blood flow to the brain when blood vessels are blocked by a clot or become too narrow for blood to get through. Brain cells in the area die from lack of oxygen. In another type of stroke, called hemorrhagic (hem-or-AJ-ic) stroke, the blood vessel isn't blocked; it bursts, and blood leaks into the brain, causing damage.

Strokes are more common in older people. Almost three-fourths of all strokes occur in people 65 years of age or over. However, a person of any age can have a stroke.

A person may also have a transient ischemic attack (TIA). This has the same symptoms as a stroke, but only lasts for a few hours or a day and does not cause permanent brain damage. A TIA is not a stroke but it is an important warning signal. The person needs treatment to help prevent an actual stroke in the future.

A stroke may be frightening to both the patient and family. It helps to remember that stroke survivors usually have at least some spontaneous recovery or natural healing and often recover further with rehabilitation.

Recovering From Stroke

The process of recovering from a stroke usually includes treatment, spontaneous recovery, rehabilitation, and the return to community living. Because stroke survivors often have complex rehabilitation needs, progress and recovery are different for each person.

Treatment for stroke begins in a hospital with "acute care." This first step includes helping the patient survive, preventing another stroke, and taking care of any other medical problems.

Spontaneous recovery happens naturally to most people. Soon after the stroke, some abilities that have been lost usually start to come back. This process is quickest during the first few weeks, but it sometimes continues for a long time.

Rehabilitation is another part of treatment. It helps the person keep abilities and gain back lost abilities to become more independent. It usually begins while the patient is still in acute care. For many patients, it continues afterward, either as a formal rehabilitation *program* or as individual rehabilitation *services*. Many decisions about rehabilitation are made by the patient, family, and hospital staff before discharge from acute care.

The last stage in stroke recovery begins with the person's return to **community living** after acute care or rehabilitation. This stage can last for a lifetime as the stroke survivor and family learn to live with the effects of the stroke. This may include doing common tasks in new ways or making up for damage to or limits of one part of the body by greater activity of another. For example, a stroke survivor can wear shoes with velcro closures instead of laces or may learn to write with the opposite hand.

What Happens During Acute Care

- The main purposes of acute care are to:
- Make sure the patient's condition is caused by a stroke and not by some other medical problem.
- Determine the type and location of the stroke and how serious it is.
- Prevent or treat complications such as bowel or bladder problems or pressure ulcers (bed sores).
- Prevent another stroke.
- Encourage the patient to move and perform self-care tasks, such as eating and getting out of bed, as early as medically possible. This is the first step in rehabilitation.

Stroke survivors and family members may find the hospital experience confusing. Hospital staff are there to help, and it is important to ask questions and talk about concerns.

Before acute care ends, the patient and family with the hospital staff decide what the next step will be. For many patients, the next step will be to continue rehabilitation.

Preventing Another Stroke

People who have had a stroke have an increased risk of another stroke, especially during the first year after the original stroke. The risk of another stroke goes up with older age, high blood pressure (hypertension), high cholesterol, diabetes, obesity, having had a transient ischemic attack (TIA), heart disease, cigarette smoking, heavy alcohol use, and drug abuse. While some risk factors for stroke (such as age) cannot be changed, the risk factors for the others can be reduced through use of medicines or changes in lifestyle.

Patients and families should ask for guidance from their doctor or nurse about preventing another stroke. They need to work together to make healthy changes in the patient's lifestyle. Patients and families should also learn the warning signs of a TIA (such as weakness on one side of the body and slurred speech) and see a doctor **immediately** if these happen.

How Stroke Affects People

Effects on the Body, Mind, and Feelings

Each stroke is different depending on the part of the brain injured, how bad the injury is, and the person's general health. Some of the effects of stroke are:

Weakness (hemiparesis--hem-ee-par-EE-sis) or paralysis (hemiplegia--hem-ee-PL EE-ja) on one side of the body.

This may affect the whole side or just the arm or the leg. The weakness or paralysis is on the side of the body opposite the side of the brain injured by the stroke. For example, if the stroke injured the left side of the brain, the weakness or paralysis will be on the right side of the body.

Problems with balance or coordination.

These can make it hard for the person to sit, stand, or walk, even if muscles are strong enough.

Problems using language (aphasia and dysarthria).

A person with aphasia (a-FAY-zha) may have trouble understanding speech or writing. Or, the person may understand but may not be able to think of the words to speak or write. A person with dysarthria (dis-AR-three-a) knows the right words but has trouble saying them clearly.

Being unaware of or ignoring things on one side of the body (bodily neglect or inattention).

Often, the person will not turn to look toward the weaker side or even eat food from the half of the plate on that side.

Pain, numbness, or odd sensations.

These can make it hard for the person to relax and feel comfortable.

Problems with memory, thinking, attention, or learning (cognitive problems).

A person may have trouble with many mental activities or just a few. For example, the person may have trouble following directions, may get confused if something in a room is moved, or may not be able to keep track of the date or time.

Being unaware of the effects of the stroke.

The person may show poor judgment by trying to do things that are unsafe as a result of the stroke.

Trouble swallowing (dysphagia--dis-FAY-ja).

This can make it hard for the person to get enough food. Also, care must sometimes be taken to prevent the person from breathing in food (aspiration--as-per-AY-shun) while trying to swallow it.

Problems with bowel or bladder control.

These problems can be helped with the use of portable urinals, bedpans, and other toileting devices.

Getting tired very quickly.

Becoming tired very quickly may limit the person's participation and performance in a rehabilitation program.

Sudden bursts of emotion, such as laughing, crying, or anger.

These emotions may indicate that the person needs help, understanding, and support in adjusting to the effects of the stroke.

Depression.

This is common in people who have had strokes. It can begin soon after the stroke or many weeks later, and family members often notice it first.

Depression After Stroke

It is normal for a stroke survivor to feel sad over the problems caused by stroke. However, some people experience a major depressive disorder, which should be diagnosed and treated as soon as possible. A person with a major depressive disorder has a number of symptoms nearly every day, all day, for at least 2 weeks. These always include at least one of the following:

- Feeling sad, blue, or down in the dumps.
- Loss of interest in things that the person used to enjoy.

A person may also have other physical or psychological symptoms, including:

- Feeling slowed down or restless and unable to sit still.
- Feeling worthless or guilty.
- Increase or decrease in appetite or weight.
- Problems concentrating, thinking, remembering, or making decisions.
- Trouble sleeping or sleeping too much.
- Loss of energy or feeling tired all of the time.
- Headaches.
- Other aches and pains.
- Digestive problems.
- Sexual problems.
- Feeling pessimistic or hopeless.
- Being anxious or worried.
- Thoughts of death or suicide.

If a stroke survivor has symptoms of depression, **especially thoughts of death or suicide**, professional help is needed right away. Once the depression is properly treated, these thoughts will go away. Depression can be treated with medication, psychotherapy, or both. If it is not treated, it can cause needless suffering and also makes it harder to recover from the stroke.

Disabilities After Stroke

A "disability" is difficulty doing something that is a normal part of daily life. People who have had a stroke may have trouble with many activities that were easy before, such as walking, talking, and taking care of "activities of daily living" (ADLs). These include basic tasks such as bathing, dressing, eating, and using the toilet, as well as more complex tasks called "instrumental activities of daily living" (IADLs), such as housekeeping, using the telephone, driving, and writing checks. Some disabilities are obvious right after the stroke. Others may not be noticed until the person is back home and is trying to do something for the first time since the stroke.

Deciding About Rehabilitation

Some people do not need rehabilitation after a stroke because the stroke was mild or they have fully recovered. Others may be too disabled to participate. However, many patients can be helped by rehabilitation. Hospital staff will help the patient and family decide about rehabilitation and choose the right services or program.

Types of Rehabilitation Programs

There are several kinds of rehabilitation programs:

Hospital programs.

These programs can be provided by special rehabilitation hospitals or by rehabilitation units in acute care hospitals. Complete rehabilitation services are available. The patient stays in the hospital during rehabilitation. An organized team of specially trained professionals provides the therapy. Hospital programs are usually more intense than other programs and require more effort from the patient.

Nursing facility (nursing home) programs.

As in hospital programs, the person stays at the facility during rehabilitation. Nursing facility programs are very different from each other, so it is important to get specific information about each one. Some provide a complete range of rehabilitation services; others provide only limited services.

Outpatient programs.

Outpatient programs allow a patient who lives at home to get a full range of services by visiting a hospital outpatient department, outpatient rehabilitation facility, or day hospital program.



Home-based programs.

The patient can live at home and receive rehabilitation services from visiting professionals. An important advantage of home programs is that patients learn skills in the same place where they will use them.

Individual Rehabilitation Services

Many stroke survivors do not need a complete range of rehabilitation services. Instead, they may need an individual type of service, such as regular physical therapy or speech therapy. These services are available from outpatient and home care programs.

Paying for Rehabilitation

Medicare and many health insurance policies will help pay for rehabilitation. Medicare is the Federal health insurance program for Americans 65 years of age or over and for certain Americans with disabilities. It has two parts: hospital insurance (known as Part A) and supplementary medical insurance (known as Part B). Part A helps pay for home health care, hospice care, inpatient hospital care, and inpatient care in a skilled nursing facility. Part B helps pay for doctors' services, outpatient hospital services, durable medical equipment, and a number of other medical services and supplies not covered by Part A. Social Security Administration offices across the country take applications for Medicare and provide general information about the program.

In some cases, Medicare will help pay for outpatient services from a Medicare-participating comprehensive outpatient rehabilitation facility. Covered services include physicians' services; physical, speech, occupational, and respiratory therapies; counseling; and other related services. A stroke survivor must be referred by a physician who certifies that skilled rehabilitation services are needed.

Medicaid is a Federal program that is operated by the States, and each State decides who is eligible and the scope of health services offered. Medicaid provides health care coverage for some low-income people who cannot afford it. This includes people who are eligible because they are older, blind, or disabled, or certain people in families with dependent children.

These programs have certain restrictions and limitations, and coverage may stop as soon as the patient stops making progress. Therefore, it is important for patients and families to find out exactly what their insurance will cover. The hospital's social service department can answer questions about insurance coverage and can help with financial planning.

Choosing a Rehabilitation Program

The doctor and other hospital staff will provide information and advice about rehabilitation programs, but the patient and family make the final choice. Hospital staff know the patient's disabilities and medical condition. They should also be familiar with the rehabilitation programs in the community and should be able to answer questions about them. The patient and family may have a preference about whether the patient lives at home or at a rehabilitation facility. They may have reasons for preferring one program over another. Their concerns are important and should be discussed with hospital staff.

Things To Consider When Choosing a Rehabilitation Program

- Does the program provide the services the patient needs?
- Does it match the patient's abilities or is it too demanding or not demanding enough?
- What kind of standing does it have in the community for the quality of the program?
- Is it certified and does its staff have good credentials?
- Is it located where family members can easily visit?
- Does it actively involve the patient and family members in rehabilitation decisions?
- Does it encourage family members to participate in some rehabilitation sessions and practice with the patient?
- How well are its costs covered by insurance or Medicare?
- If it is an outpatient or home program, is there someone living at home who can provide care?
- If it is an outpatient program, is transportation available?

A person may start rehabilitation in one program and later transfer to another. For example, some patients who get tired quickly may start out in a less intense rehabilitation program. After they build up their strength, they are able to transfer to a more intense program.

When Rehabilitation Is Not Recommended

Some families and patients may be disappointed if the doctor does not recommend rehabilitation. However, a person may be unconscious or too disabled to benefit. For example, a person who is unable to learn may be better helped by maintenance care at home or in a nursing facility. A person who is, at first, too weak for rehabilitation may benefit from a gradual recovery period at home or in a nursing facility. This person can consider rehabilitation at a later time. It is important to remember that:

- Hospital staff are responsible for helping plan the best way to care for the patient after discharge from acute care. They can also provide or arrange for needed social services and family education.
- This is not the only chance to participate in rehabilitation. People who are too disabled at first may recover enough to enter rehabilitation later.

What Happens During Rehabilitation?

In hospital or nursing facility rehabilitation programs, the patient may spend several hours a day in activities such as physical therapy, occupational therapy, speech therapy, recreational therapy, group activities, and patient and family education. It is important to maintain skills that help recovery. Part of the time is spent relearning skills (such as walking and speaking) that the person had before the stroke. Part of it is spent learning new ways to do things that can no longer be done the old way (for example, using one hand for tasks that usually need both hands).

Setting Rehabilitation Goals

The goals of rehabilitation depend on the effects of the stroke, what the patient was able to do before the stroke, and the patient's wishes. Working together, goals are set by the patient, family, and rehabilitation program staff. Sometimes, a person may need to repeat steps in striving to reach goals.

If goals are too high, the patient will not be able to reach them. If they are too low, the patient may not get all the services that would help. If they do not match the patient's interests, the patient may not want to work at them. Therefore, it is important for goals to be realistic. To help achieve realistic goals, the patient and family should tell program staff about things that the patient wants to be able to do.

Rehabilitation Goals

- Being able to walk, at least with a walker or cane, is a realistic goal for most stroke survivors.
- Being able to take care of oneself with some special equipment is a realistic goal for most.
- Being able to drive a car is a realistic goal for some.
- Having a job can be a realistic goal for some people who were working before the stroke. For some, the old job may not be possible but another job or a volunteer activity may be.

Reaching treatment goals does not mean the end of recovery. It just means that the stroke survivor and family are ready to continue recovery on their own.

Rehabilitation Specialists

Because every stroke is different, treatment will be different for each person. Rehabilitation is provided by several types of specially trained professionals. A person may work with any or all of these:

Physician.

All patients in stroke rehabilitation have a physician in charge of their care. Several kinds of doctors with rehabilitation experience may have this role. These include family physicians and internists (primary care doctors), geriatricians (specialists in working with older patients), neurologists (specialists in the brain and nervous system), and physiatrists (specialists in physical medicine and rehabilitation).

Rehabilitation nurse.

Rehabilitation nurses specialize in nursing care for people with disabilities. They provide direct care, educate patients and families, and help the doctor to coordinate care.

Physical therapist.

Physical therapists evaluate and treat problems with moving, balance, and coordination. They provide training and exercises to improve walking, getting in and out of a bed or chair, and moving around without losing balance. They teach family members how to help with exercises for the patient and how to help the patient move or walk, if needed.

Occupational therapist.

Occupational therapists provide exercises and practice to help patients do things they could do before the stroke such as eating, bathing, dressing, writing, or cooking. The old way of doing an activity sometimes is no longer possible, so the therapist teaches a new technique.

Speech-language pathologist.

Speech-language pathologists help patients get back language skills and learn other ways to communicate. Teaching families how to improve communication is very important. Speech-language pathologists also work with patients who have swallowing problems (dysphagia).

Social worker.

Social workers help patients and families make decisions about rehabilitation and plan the return to the home or a new living place. They help the family answer questions about insurance and other financial issues and can arrange for a variety of support services. They may also provide or arrange for patient and family counseling to help cope with any emotional problems.

Psychologist.

Psychologists are concerned with the mental and emotional health of patients. They use interviews and tests to identify and understand problems. They may also treat thinking or memory problems or may provide advice to other professionals about patients with these problems.

Therapeutic recreation specialist.

These therapists help patients return to activities that they enjoyed before the stroke such as playing cards, gardening, bowling, or community activities. Recreational therapy helps the rehabilitation process and encourages the patient to practice skills.

Other professionals.

Other professionals may also help with the patient's treatment. An orthotist may make special braces to support weak ankles and feet. A urologist may help with bladder problems. Other physician specialists may help with medical or emotional problems. Dietitians make sure that the patient has a healthy diet during rehabilitation. They also educate the family about proper diet after the patient leaves the program. Vocational counselors may help patients go back to work or school.

Rehabilitation professionals, the patient, and the family are vitally important partners in rehabilitation. They must all work together for rehabilitation to succeed.

Rehabilitation Team

In many programs, a special rehabilitation team with a team leader is organized for each patient. The patient, family, and rehabilitation professionals are all members. The team has regular meetings to discuss the progress of treatment. Using a team approach often helps everyone work together to meet goals.

Getting the Most Out of Rehabilitation

What the Patient Can Do

If you are a stroke survivor in rehabilitation, keep in mind that you are the most important person in your treatment. You should have a major say in decisions about your care. This is hard for many stroke patients. You may sometimes feel tempted to sit back and let the program staff take charge. If you need extra time to think or have trouble talking, you may find that others are going ahead and making decisions without waiting. Try not to let this happen.

- Make sure others understand that you want to help make decisions about your care.
- Bring your questions and concerns to program staff.
- State your wishes and opinions on matters that affect you.
- Speak up if you feel that anyone is "talking down" to you; or, if people start talking about you as if you are not there.
- Remember that you have the right to see your medical records.

To be a partner in your care, you need to be well informed about your treatment and how well you are doing. It may help to record important information about your treatment and progress and write down any questions you have.

If you have speech problems, making your wishes known is hard. The speech-language pathologist can help you to communicate with other staff members, and family members may also help to communicate your ideas and needs.

Most patients find that rehabilitation is hard work. They need to maintain abilities at the same time they are working to regain abilities. It is normal to feel tired and discouraged at times because things that used to be easy before the stroke are now difficult. The important thing is to notice the progress you make and take pride in each achievement.

How the Family Can Help

If you are a family member of a stroke survivor, here are some things you can do:

- Support the patient's efforts to participate in rehabilitation decisions.
- Visit and talk with the patient. You can relax together while playing cards, watching television, listening to the radio, or playing a board game.
- If the patient has trouble communicating (aphasia), ask the speech-language pathologist how you can help.



- Participate in education offered for stroke survivors and their families. Learn as much as you can and how you can help.
- Ask to attend some of the rehabilitation sessions. This is a good way to learn how rehabilitation works and how to help.
- Encourage and help the patient to practice skills learned in rehabilitation.
- Make sure that the program staff suggests activities that fit the patient's needs and interests.
- Find out what the patient can do alone, what the patient can do with help, and what the patient can't do. Then avoid doing things for the patient that the patient is able to do. Each time the patient does them, his or her ability and confidence will grow.
- Take care of yourself by eating well, getting enough rest, and taking time to do things that you enjoy.

To gain more control over the rehabilitation process, keep important information where you can find it. One suggestion is to keep a notebook with the patient. Some things to include are provided in the sample that follows.

Discharge Planning

Discharge planning begins early during rehabilitation. It involves the patient, family, and rehabilitation staff. The purpose of discharge planning is to help maintain the benefits of rehabilitation after the patient has been discharged from the program. Patients are usually discharged from rehabilitation soon after their goals have been reached.

Some of the things discharge planning can include are to:

- Make sure that the stroke survivor has a safe place to live after discharge.
- Decide what care, assistance, or special equipment will be needed.
- Arrange for more rehabilitation services or for other services in the home (such as visits by a home health aide).
- Choose the health care provider who will monitor the person's health and medical needs.
- Determine the caregivers who will work as a partner with the patient to provide daily care and assistance at home, and teach them the skills they will need.
- Help the stroke survivor explore employment opportunities, volunteer activities, and driving a car (if able and interested).
- Discuss any sexual concerns the stroke survivor or husband/wife may have. Many people who have had strokes enjoy active sex lives.

Preparing a Living Place

Many stroke survivors can return to their own homes after rehabilitation. Others need to live in a place with professional staff such as a nursing home or assisted living facility. An assisted living facility can provide residential living with a full range of services and staff. The choice usually depends on the person's needs for care and whether caregivers are available in the home. The stroke survivor needs a living place that supports continuing recovery.

It is important to choose a living place that is safe. If the person needs a new place to live, a social worker can help find the best place.

During discharge planning, program staff will ask about the home and may also visit it. They may suggest changes to make it safer. These might include changing rooms around so that a stroke survivor can stay on one floor, moving scatter rugs or small pieces of furniture that could cause falls, and putting grab bars and seats in tubs and showers.

It is a good idea for the stroke survivor to go home for a trial visit before discharge. This will help identify problems that need to be discussed or corrected before the patient returns.

Deciding About Special Equipment

Even after rehabilitation, some stroke survivors have trouble walking, balancing, or performing certain activities of daily living. Special equipment can sometimes help. Here are some examples:

Cane.

Many people who have had strokes use a cane when walking. For people with balancing problems, special canes with three or four "feet" are available.

Walker.

A walker provides more support than a cane. Several designs are available for people who can only use one hand and for different problems with walking or balance.

Ankle-foot orthotic devices (braces).

Braces help a person to walk by keeping the ankle and foot in the correct position and providing support for the knee.

Wheelchair.

Some people will need a wheelchair. Wheelchairs come in many different designs. They can be customized to fit the user's needs and abilities. Find out which features are most important for the stroke survivor.

Aids for bathing, dressing, and eating.

Some of these are safety devices such as grab bars and nonskid tub and floor mats. Others make it easier to do things with one hand. Examples are velcro fasteners on clothes and placemats that won't slide on the table.

Communication aids.

These range from small computers to homemade communication boards. The stroke survivor, family, and rehabilitation program staff should decide together what special equipment is needed. Program staff can help in making the best choices. Medicare or health insurance will often help pay for the equipment.

Preparing Caregivers

Caregivers who help stroke survivors at home are usually family members such as a husband or wife or an adult son or daughter. They may also be friends or even professional home health aides. Usually, one person is the main caregiver, while others help from time to time. An important part of discharge planning is to make sure that caregivers understand the safety, physical, and emotional needs of the stroke survivor, and that they will be available to provide needed care.

Since every stroke is different, people have different needs for help from caregivers. Here are some of the things caregivers may do:

- Keep notes on discharge plans and instructions and ask about anything that is not clear.
- Help to make sure that the stroke survivor takes all prescribed medicines and follows suggestions from program staff about diet, exercise, rest, and other health practices.
- Encourage and help the person to practice skills learned in rehabilitation.
- Help the person solve problems and discover new ways to do things.
- Help the person with activities performed before the stroke. These could include using tools, buttoning a shirt, household tasks, and leisure or social activities.
- Help with personal care, if the person cannot manage alone.
- Help with communication, if the person has speech problems. Include the stroke survivor in conversations even when the person cannot actively participate.
- Arrange for needed community services.
- Stand up for the rights of the stroke survivor.

If you expect to be a caregiver, think carefully about this role ahead of time. Are you prepared to work with the patient on stroke recovery? Talk it over with other people who will share the caregiving job with you. What are the stroke survivor's needs? Who can best help meet each of them? Who will be the main caregiver? Does caregiving need to be scheduled around the caregivers' jobs or other activities? There is time during discharge planning to talk with program staff about caregiving and to develop a workable plan.

Going Home

Adjusting to the Change

Going home to the old home or a new one is a big adjustment. For the stroke survivor, it may be hard to transfer the skills learned during rehabilitation to a new location. Also, more problems caused by the stroke may appear as the person tries to go back to old activities. During this time, the stroke survivor and family learn how the stroke will affect daily life and can make the necessary adjustments.

These adjustments are a physical and emotional challenge for the main caregiver as well as the stroke survivor. The caregiver has many new responsibilities and may not have time for some favorite activities. The caregiver needs support, understanding, and some time to rest. Caregiving that falls too heavily on one person can be very stressful. Even when family members and friends are nearby and willing to help, conflicts over caregiving can cause stress.

A stroke is always stressful for the family, but it is especially hard if one family member is the only caregiver. Much time may be required to meet the needs of the stroke survivor. Therefore, the caregiver needs as much support as possible from others. Working together eases the stress on everyone.

Tips for Reducing Stress

The following tips for reducing stress are for both caregivers and stroke survivors.

- Take stroke recovery and caregiving one day at a time and be hopeful.
- Remember that adjusting to the effects of stroke takes time. Appreciate each small gain as you discover better ways of doing things.
- Caregiving is learned. Expect that knowledge and skills will grow with experience.
- Experiment. Until you find what works for you, try new ways of doing activities of daily living, communicating with each other, scheduling the day, and organizing your social life.
- Plan for "breaks" so that you are not together all the time. This is a good way for family and friends to help on occasion. You can also plan activities that get both of you out of the house.
- Ask family members and friends to help in specific ways and commit to certain times to help. This gives others a chance to help in useful ways.
- Read about the experiences of other people in similar situations. Your public library has life stories by people who have had a stroke as well as books for caregivers.
- Join or start a support group for stroke survivors or caregivers. You can work on problems together and develop new friendships.
- Be kind to each other. If you sometimes feel irritated, this is natural and you don't need to blame yourself. But don't "take it out" on the other person. It often helps to talk about these feelings with a friend, rehabilitation professional, or support group.
- Plan and enjoy new experiences and don't look back. Avoid comparing life as it is now with how it was before the stroke.

Follow-up Appointments

After a stroke survivor returns to the community, regular follow-up appointments are usually scheduled with the doctor and sometimes with rehabilitation professionals. The purpose of follow-up is to check on the stroke survivor's medical condition and ability to use the skills learned in rehabilitation. It is also important to check on how well the stroke survivor and family are adjusting. The stroke survivor and caregiver can be prepared for these visits with a list of questions or concerns.

Where To Get Help

Many kinds of help are available for people who have had strokes and their families and caregivers. Some of the most important are:

Information about stroke.

A good place to start is with the books and pamphlets available from national organizations that provide information on this subject. Many of their materials are available free of charge. A list of these organizations starts on page 30.

Local stroke clubs or other support groups.

These are groups where stroke survivors and family members can share their experiences, help each other solve problems, and expand their social lives.

Home health services.

These are available from the Visiting Nurses Association (VNA), public health departments, hospital home care departments, and private home health agencies. Services may include nursing care, rehabilitation therapies, personal care (for example, help with bathing or dressing), respite care (staying with the stroke survivor so that the caregiver can take a vacation or short break), homemaker services, and other kinds of help.

Meals on Wheels.

Hot meals are delivered to the homes of people who cannot easily shop and cook.

Adult day care.

People who cannot be completely independent sometimes spend the day at an adult day care center. There they get meals, participate in social activities, and may also get some health care and rehabilitation services.

Friendly Visitor (or other companion services).

A paid or volunteer companion makes regular visits or phone calls to a person with disabilities.

Transportation services.

Most public transportation systems have buses that a person in a wheelchair can board. Some organizations and communities provide vans to take wheelchair users and others on errands such as shopping or doctor's visits.

Many communities have service organizations that can help. Some free services may be available or fees may be on a "sliding scale" based on income. It takes some work to find out what services and payment arrangements are available. A good way to start is to ask the social workers in the hospital or rehabilitation program where the stroke survivor was treated. Also, talk to the local United Way or places of worship. Another good place to look is the Yellow Pages of the telephone book, under "Health Services," "Home Health Care," "Senior Citizen Services," or "Social Service Organizations." Just asking friends may turn up useful information. The more you ask, the more you will learn.

Additional Resources**ACTION**

1100 Vermont Avenue, NW
Washington, DC 20525
(202) 606-4855 (call for telephone number of regional office)
Sponsors older American volunteer programs.

Administration on Aging

330 Independence Avenue, SW
Washington, DC 20201
Toll-free (800) 677-1116
(call for list of community services for older Americans in your area)

**AHA Stroke Connection (formerly the Courage Stroke Network)
American Heart Association**

7272 Greenville Avenue
Dallas, TX 75231
Toll-free (800) 553-6321 (or check telephone book for local AHA office) Provides prevention, diagnosis, treatment, and rehabilitation information to stroke survivors and their families.

American Dietetic Association/National Center for Nutrition and Dietetics

216 West Jackson Boulevard

Chicago, IL 60606

Toll-free (800) 366-1655 (Consumer Nutrition Hotline)

Consumers may speak to a registered dietitian for answers to nutrition questions, or obtain a referral to a local registered dietitian.

American Self-Help Clearinghouse

St. Clares-Riverside Medical Center

Denville, NJ 07834

(201) 625-7101

(call for name and telephone number of State or local clearinghouse)

Provides information and assistance on local self-help groups.

National Aphasia Association

P.O. Box 1887

Murray Hill Station

New York, NY 10156

Toll-free (800) 922-4622

Provides information on the partial or total loss of the ability to speak or comprehend speech, resulting from stroke or other causes.

National Easter Seal Society

230 West Monroe Street, Suite 1800

Chicago, IL 60606

(312) 726-6200 (or check telephone book for local Easter Seal Society)

Provides information and services to help people with disabilities.

National Stroke Association

8480 East Orchard Road, Suite 1000

Englewood, CO 80111

(303) 771-1700

Toll-free (800) STROKES (787-6537)

Rosalynn Carter Institute

Georgia Southwestern College

600 Simmons Street

Americus, GA 31709

Provides information on caregiving. Reading lists, video products, and other caregiver resources are available by writing to the address listed above.

Stroke Clubs International

805 12th Street

Galveston, TX 77550

(409) 762-1022 (call for the name of a stroke club located in your area)

Maintains list of over 800 stroke clubs throughout the United States.

The Well Spouse Foundation

P.O. Box 801

New York, NY 10023

(212) 724-7209 Toll-free (800) 838-0879 Provides support for the husbands, wives, and partners of people who are chronically ill or disabled.

Medicare Information

Consumer Information Center

Department 59 Pueblo, CO 81009 By writing to this address, you can receive a free copy of *The Medicare Handbook* (updated and published annually). This handbook provides information about Medicare benefits, health insurance to supplement Medicare, and limits to Medicare coverage. It is also available in Spanish.

[Figures] Figure: Sample Pages for Patient Notebook

For Further Information

Information in this booklet is based on *Post-Stroke Rehabilitation. Clinical Practice Guideline, Number 16*. It was developed by a non-Federal panel sponsored by the Agency for Health Care Policy and Research (AHCPR), an agency of the Public Health Service. Other guidelines on common health problems are available, and more are being developed. Four other patient guides are available from AHCPR that may be of interest to stroke survivors and their caregivers:

- *Preventing Pressure Ulcers: Patient Guide* gives detailed information about how to prevent pressure sores (AHCPR Publication No. 92-0048).
- *Treating Pressure Sores: Patient Guide* gives detailed information about treating pressure sores (AHCPR Publication No. 95-0654).
- *Urinary Incontinence in Adults: Patient Guide* describes why people lose urine when they don't want to and how that can be treated (AHCPR Publication No. 92-0040).
- *Depression Is a Treatable Illness: Patient Guide* discusses major depressive disorder, which most often can be successfully treated with the help of a health professional (AHCPR Publication No. 93-0053).

For more information about these and other guidelines, or to get more copies of this booklet, call toll-free: **800-358-9295** or write to:

- Agency for Health Care Policy and Research Publications Clearinghouse
P.O. Box 8547 Silver Spring, MD 20907
- U.S. Department of Health and Human Services Public Health Service Agency for Health Care Policy and Research
Executive Office Center, Suite 501
2101 East Jefferson Street Rockville, MD 20852
- AHCPR Publication No. 95-0664 May 1995