

# PATIENT & FAMILY STROKE EDUCATION HANDBOOK

# **Welcome/Overview**

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The experience of having a stroke can be overwhelming. The emergency room, the medical procedures, and just being in the hospital can be traumatic. The unknowns are frightening. “Will I feel like this forever?” “Will I walk again?” “Will I talk again?” “Will I be able to care for myself again?” “Will I have another stroke?”. The list of questions and confusions can seem endless.

We have put this handbook together to give you and your family answers to the questions you already have, and even some you haven’t thought of yet. For many stroke survivors, the road to recovery may take quite a long while and you will have to navigate through various health care systems. This handbook can guide you through your stroke recovery while you are with us at Jewish Hospital and Frazier Rehab Institute and beyond. We wish you good health and the best recovery possible. We are committed to giving you outstanding care.

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# **What Exactly Is A Stroke?**

## What Exactly Is A Stroke?

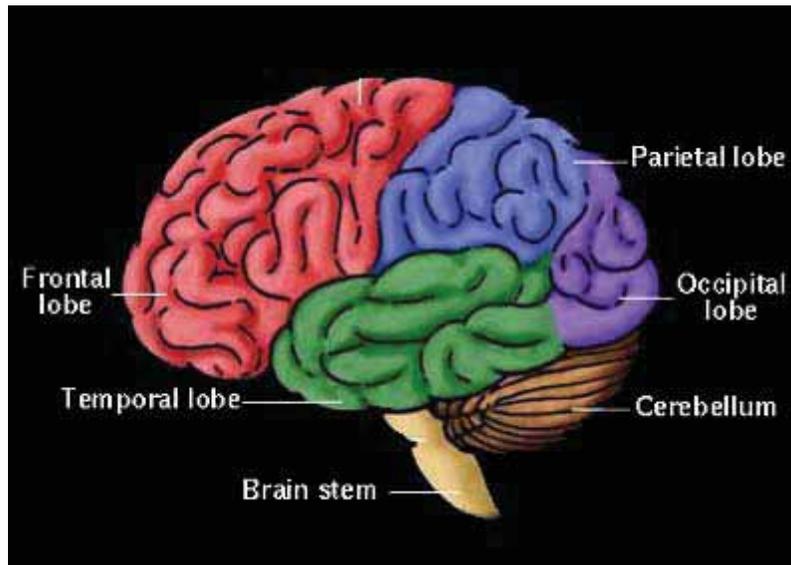
One term that is becoming common in describing stroke is “brain attack”. Just as a heart attack is caused by disrupted blood flow to tissue in the heart, a stroke consists of disrupted blood flow to the brain. When oxygen rich blood is unable to reach tissue, the result is cell death. Another term you may hear is “CVA”, which stands for *cerebral vascular accident*. 750,000 Americans suffer from stroke each year. Of this number, 160,000 persons will die. There are currently about 4 million stroke survivors in the United States today.

It’s important to remember that no two brains are alike. Stroke causes cell death or damage to the brain. Because no two brains are alike, no two strokes are alike. However, research has found that there are similarities in how each of the different parts of our brains function. By knowing the location of damage to the brain, your treatment team may be more prepared to assist you in your recovery process.

**Right-Brain Injury:** The right side of the brain controls motor function on the left side of the body. Therefore difficulty with movement is typically seen on the left side of the body. The right side of the brain also controls emotions, thinking skills, nonverbal communication, and spatial orientation (sense of body position). Attention, memory, and judgment for safety could be affected as well.

**Left-Brain Injury:** The left side of the brain controls motor function on the right side of the body. Difficulty with movement is typically seen on the right side of the body. Language is controlled by the left side of the brain. Therefore, there may be language problems present. Mood and behavior may be affected as well.

## Basic Brain Functions



**Frontal lobe:** Initiation of activities, problem-solving, judgment, inhibition of behavior, planning movements of the body, personality/emotions, awareness of abilities/limitations, organization, concentration, expressive language

**Temporal lobe:** Memory, hearing, understanding language, organization and sequencing

**Parietal lobe:** Sense of touch, differentiation of size/shape/color, spatial awareness, ability to perceive visual information

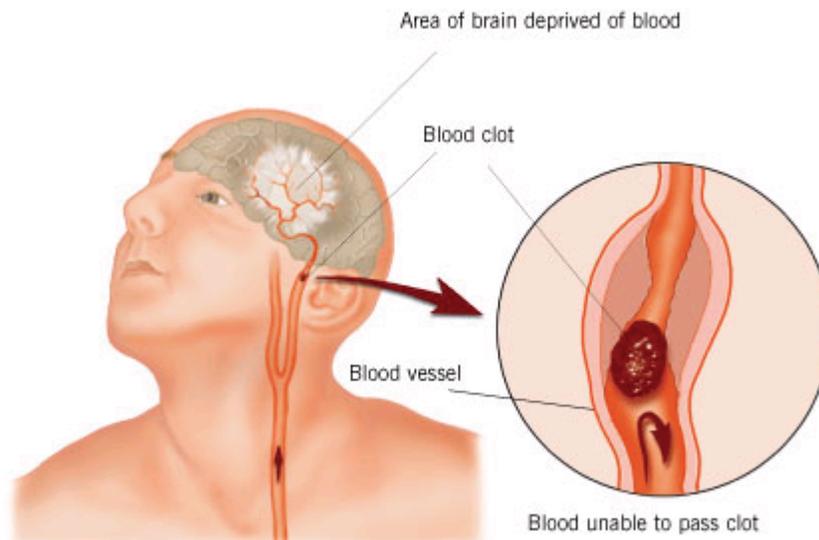
**Occipital lobe:** Vision

**Cerebellum:** Balance, coordination, skilled movement activities

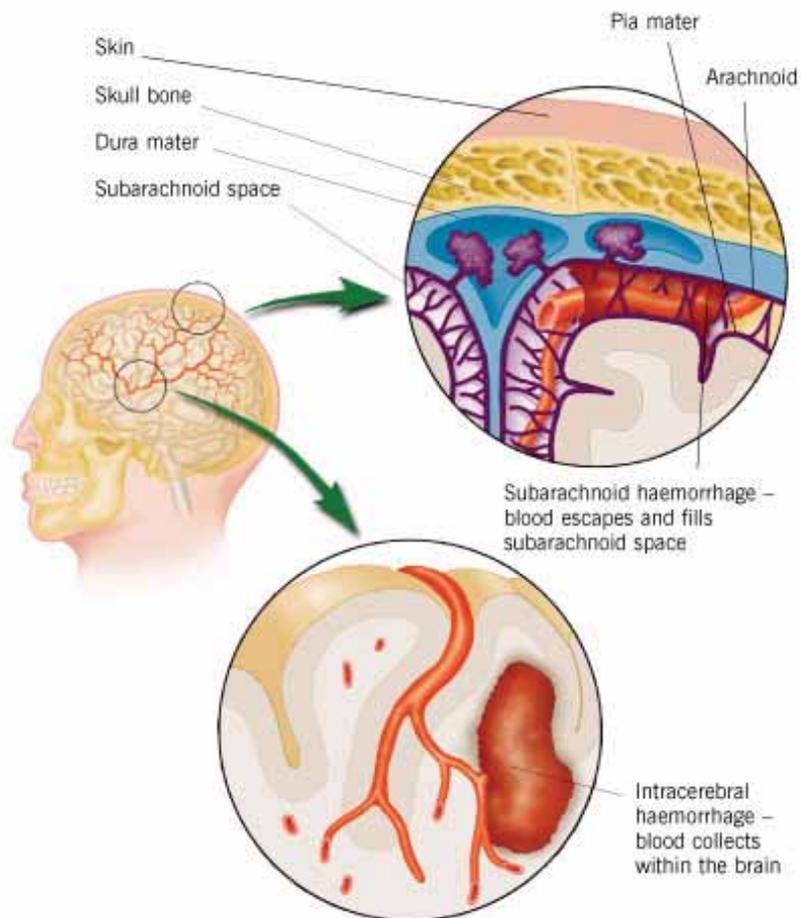
**Brain Stem:** Breathing, heart rate, consciousness/arousal, sleep/wake functions, attention/concentration

## Major Types of Stroke

- 1. Ischemic:** An *ischemic* stroke occurs when there is a blockage in a blood vessel. This causes tissue death, or what is also called a cerebral infarct. 85% of all strokes are *ischemic*. When the blood clot is still and narrows the artery, it is termed thrombotic. When a piece of blood clot breaks off and travels in the blood stream until it becomes stuck, it is termed embolic.



**2. Hemorrhagic:** A *hemorrhagic* stroke occurs when there is bleeding in or around the brain. 15 % of all strokes are *hemorrhagic*. However, 30% of all stroke deaths are *hemorrhagic*. In this type of stroke, the blood vessel may rupture and cause limited blood flow in or around the brain. A clot can also form and move brain tissue disrupting brain function. If there is a *subarachnoid hemorrhage*, this means that the bleeding is occurring in the space between the brain and the skull. If there is an *intracerebral hemorrhage*, this means that the bleeding is within the brain tissue itself.



**3. TIA:** You may have also heard the term “*TIA*”. This stands for a transient ischemic attack, and it is sometimes called a “mini-stroke”. During a *TIA*, there are temporary interruptions in the blood supply to the brain. This causes temporary stroke symptoms. A *TIA* can last anywhere from a few minutes to several hours, but less than 24 hours. Statistics show that 1/3 of all persons who have experienced a *TIA* will have a stroke at some time. There is also high risk for stroke survivors to have another stroke at some point in their lives.

**Stroke or TIA Warning signs and symptoms to watch for:**

- sudden weakness, numbness, or paralysis of the face, arm or leg (especially on one side)
- loss of speech or trouble talking or understanding language
- sudden loss of vision (especially in one eye)
- sudden severe headache with no apparent cause
- unexplained dizziness, loss of balance, or coordination (especially with the above symptoms)
- partial or total loss of consciousness
- vomiting or severe nausea (when other symptoms are present)

**It is ideal to get treatment immediately after the symptoms begin. If symptoms last greater than 10-15 minutes, appear frequently, or seem to get worse, call -911. When a stroke occurs, time is extremely valuable.**

**Every minute you waste could be the minute that saves your brain!**



# **Levels Of Care Throughout Stroke Recovery**

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Recovering from a stroke is typically not an “overnight” process. There are several stages of recovery, and many different levels of care to accommodate these stages. This section provides you with a brief description of each.

### **Acute Care:**

The purpose of an acute care hospital is to provide medical treatment at the beginning of an illness or accident. The responsibility of that hospital is to diagnose the problem and then to ensure that the patient is medically stable before discharge. Much of a patient’s time is spent having tests run to determine the cause or current status of a medical problem. Treatment may also consist of medical procedures necessary to manage symptoms or complications. For a person who has had a stroke, the primary goal is to diagnose the stroke and to find the cause of the stroke as soon as possible. Therapy may begin during acute care if it is deemed appropriate by the physician. This may be a good time to discuss power of attorney issues with the case manager/social worker, sick leave or disability benefits with your employer, and available insurance benefits with your medical insurance carrier.

## **Inpatient Rehab:**

This level of care is common following acute care. Inpatient Rehab allows stroke survivors to increase their independence level prior to returning home. It also provides family and/or caregiver training to assist with a successful daily routine upon return home. The main focus during an inpatient Rehab stay is therapy. Therapy is extremely important following a stroke. Stroke causes some brain cells to die, but it is possible to teach the remaining brain cells how to take over and perform the skill that was lost. However, the amount of return in previous skills varies. Therefore, Rehab focuses both on recovering lost skills and learning how to compensate for lost skills when needed.



**Frazier Rehab Institute** has been providing skilled care and therapy since 1954. The goal at Frazier is to help each individual and family reach their full potential. The mission of Frazier has been, and continues to be, helping people disabled by illness or injury to achieve the highest possible level of independence and to live life to the fullest with dignity, purpose, and pleasure. **Frazier Rehab Institute** meets the requirements for the Commission on the Accreditation for Rehab Facilities (CARF) and the Joint Commission on the Accreditation for Health Organizations (JCAHO).

The **Frazier Rehab Institute** stroke program consists of daily therapy as recommended by your physician and the treatment team. Therapies available at Frazier are physical therapy, occupational therapy, speech therapy, recreational therapy, and pulmonary therapy. Assistance is also available from the following departments: psychology, nutrition, case management, and nursing. More specific information as to how each of these specialists can assist in your recovery can be found in the section of this handbook titled “Individuals Involved In My Care”. Frazier offers stroke groups to enhance stroke education to each survivor, as well as to provide a peer group for learning and support. Frazier also provides a daily dining group, if necessary, to assist with feeding and swallowing issues.

### **Home Health:**

This level of care is provided in the home. Home health agencies can offer nursing needs, an aide for basic self care skills, and therapies. Medicare requires that a person be “home-bound” in order to receive these services. Home health is often recommended to a person going home from acute care or inpatient Rehab. It serves as transitional care to ensure safety and success in the home, and it allows evaluation of a person’s capabilities in his/her familiar home environment.

### **Skilled Nursing:**

These facilities offer skilled nursing care. Therapy, however, is most often still provided. This level of care is often recommended for persons who have trouble with a full day of therapy, as is offered in an inpatient Rehab hospital. Also, length of stay is typically longer than in inpatient Rehab, which allows the person who improves more slowly the opportunity to work at his/her own pace.

### **Outpatient Therapy:**

Therapy is provided in an outpatient clinic, which may or may not be affiliated with a hospital. Persons come from home and participate most often in an hour treatment for each therapy they attend. Outpatient therapy is an excellent opportunity for community re-entry as well as greatly improving overall endurance. Because the person must leave the home for therapy, they are more likely participating in activities that were routine prior to the stroke (grooming, getting dressed, getting in/out of the car).

**Frazier Rehab Institute** offers outpatient therapy at the downtown location within the hospital, as well as a number of satellite clinics throughout the region. Frazier also offers outpatient services specific to work/community re-entry and return to driving.

**Assisted Living:**

This is an alternative to return to complete independence in the home. Assisted living communities often offer various levels of assistance. However, these communities focus on meeting the needs of persons who are fairly independent in their self-care skills, but require assistance for cooking and cleaning. They also target those persons who may need physical assist for safety from time to time. Each assisted living community is different, so it is best to discuss needs with your case manager and ask various questions when interviewing these communities.

# **Medical Management**

## Medical Management

Following a stroke, the numerous medical concerns that must be discussed with your doctor can be overwhelming. The purpose of this section is to help make clear some medical terminology that may have been used during the early stages of stroke. It may also be helpful when discussing the management of any potential problems to be addressed after the stroke.

**Medical Treatment:** Possible medical treatment for the early stages of stroke consists of the following:



- manage blood pressure
- manage swelling or pressure on the brain
- manage blood sugar levels
- evaluate and manage the person's airway, breathing, and circulation
- determine whether the stroke is *ischemic* or *hemorrhagic*
  - if the stroke is *ischemic*, treat with the drug TPA (tissue plasminogen activator) within the first 3 hours
  - if the stroke is *hemorrhagic*, find the cause of the bleeding
- use of clinical research study drugs
- surgery to remove a blood clot, clip an *aneurysm* (ballooning of a blood vessel), or remove malformed blood vessels in the brain
- revascularization of blood supply -- which means to re-route blood for a new source of blood flow to the brain

- use coils for *aneurysm* to create a clot for the bleeding
- use “super glue” type substance for malformed blood vessels in the brain
- use *angioplasty* to open partially blocked vertebral and carotid arteries in the neck and vessels in the brain

use *stenting* in the vessels of the neck and brain: stents use fine, tubular wire mesh to hold the vessel open

- perform intra-arterial thrombolysis: a catheter is inserted in the brain during *angioplasty* to deliver clot dissolving medications directly into the blocked vessel
- evaluate swallowing and manage diet or place feeding tube if necessary

**Tests:** Many tests may be performed either following a stroke or prior to stroke for prevention efforts. Here is an overview of these medical tests:



- 1. Computed tomography scan (CT scan)** -- This is a low dose x-ray used to visualize the brain. It is used to determine whether the stroke is *ischemic* or *hemorrhagic*. However, it is often inconclusive for *ischemic* strokes.
- 2. Magnetic resonance imaging (MRI)** -- This test provides a high level of anatomic detail for location of the stroke and the extent of the damage.
- 3. Electrocardiogram (EKG)** - This test evaluates the heart's rhythm.
- 4. Echocardiogram** -- This is an ultrasound "video" of the chambers and valves of the heart in action.
- 5. Blood tests** -- These rule out clotting disorders, measure levels of enzymes and/or other metabolic factors, and monitor thickness of blood.
- 6. Video Swallow study** (done by a speech-language pathologist and radiologist) -- This is a video x-ray procedure which views the inside of the mouth and throat while swallowing liquids and foods.
- 7. Magnetic resonance angiography (MRA)** -- This is a noninvasive technique for looking at neck and brain blood vessels.
- 8. Computed tomography angiography (CTA)** -- This is a noninvasive test that demonstrates 3-D views of blood vessels and aneurysms.

**9. 3 Dimensional Transcranial doppler (TCD)** -- This is an ultrasound procedure that assesses blood flow through cerebral vessels using a small probe against the skull.

**10. Xenon CT scanning** -- This is inhalation of the gas Xenon to measure blood flow.

**11. Carotid duplex scanning** -- This test diagnoses blockage in the carotid arteries by recording sound waves.

12. Cerebral angiography (angiogram) -- This test involves the injection of contrast dye into major arteries for evaluation of blood flow.

**13. Transesophageal echocardiography** -- A tube is inserted into the stomach to image the heart.

# **Nursing And Nutrition Needs**

## **Nursing And Nutrition Needs**

Nurses and dietitians will become an extremely important part of your recovery process. Whether you are in acute care, inpatient Rehab, or skilled nursing, nurses and dietitians will serve and educate you to ensure a safe and speedy recovery process. This section will outline the topics they will focus on in your recovery and the ways in which they may assist you with these needs.

### **Skin:**

Your skin is one of the most important organs of your body. It regulates body fluids and temperature, protects the body, and provides sensation for touch, temperature, and pain. After a stroke, your skin is at risk for breaking down, and it may become unable to perform the vital function of protecting the body. This can be due to the following reasons: weakness or inability to move, loss of feeling, damp skin due to urine or stool against the skin, possible presence of diabetes, and use of anticoagulents (blood thinning medicine).

Therefore, the main goal for nursing in regards to skin care is to prevent possible pressure sores or skin breakdown. Nurses perform preventative skin care and educate caregivers on the following:

- daily skin observation
- daily skin care
- weight shifting for relief of pressure on the bottom
- turning in bed
- diet/proper hydration
- avoidance of skin injuries
- wearing of well fitted clothing/shoes
- ensuring correct donning of braces and splints

## **Bladder:**

Following a stroke, it may be difficult to pass urine or there may be difficulty with incontinence (control). This may be due to neurologic changes from the stroke or due to urological problems, such as infection or obstruction. Other factors that can cause bladder problems are impaired mobility to get to the bathroom, impaired cognition or thinking, aphasia or language difficulties, and pre-existing urinary problems.

There are many ways in which bladder problems are managed. Here are some possibilities:

- time voids -- a set schedule is used to allow the patient to empty his/her bladder at regular intervals
- use of a medication which contracts the bladder to assist with retention
- use of an indwelling or intermittent catheter to empty the bladder
- use of an external condom catheter for incontinence
- use of an adult brief for incontinence

## **Urinary Tract Infections:**

Urinary Tract Infections (UTI) are primarily caused from bacteria. Use of indwelling catheters or intermittently catheterizing to empty the bladder can introduce bacteria in to the urinary tract.

Changes in bladder function can lead to UTI's. Infections are caused by bacteria entering the urinary tract. Using catheters, poor hygiene, and incomplete emptying of the bladder can introduce bacteria into the bladder.

## **Signs and Symptoms**

cloudy or foul smelling  
bloody urine  
pain or burning  
increased frequency of urination or incontinence  
chills, nausea, temperature

## **Preventing UTI's**

drink adequate fluids  
routinely empty bladder – time void  
appropriate hygiene  
proper catheter care when applicable  
call your doctor

## **Bowel:**

Following a stroke, a person may have difficulty with constipation or incontinence/diarrhea. Again, factors from a stroke which may affect this are an inability to get to the bathroom, difficulty thinking, difficulty communicating, and/or pre-existing bowel problems. Possible ways to manage bowel problems include:

- cleaning out the bowels by using an enema
- adjusting frequency for use of the bathroom
- altering diet or fluid intake
- providing privacy for toileting
- managing body positioning when needed to assist with bowel management
- use of medications when necessary

## **Prevention of blood clots:**

Sometimes after a stroke or with impaired mobility, a blood clot (also called a *DVT* - deep vein thrombosis) may form in one of the limbs. Because the nursing staff is aware of this possibility, they may monitor for any of the following symptoms: redness, swelling, increased warmth along the path of the vein, and increased oral temperature. Upon noting these symptoms, the doctor may order what is called a “doppler study” to investigate whether or not there is a clot. Possible prevention and treatment approaches include:

- adequate fluid intake
- wearing compression stockings
- daily range of motion to the immobile limb or limbs
- use of anticoagulant medications (blood thinning medicine such as coumadin)
- bedrest with affected limb elevated
- IV blood thinning medications (heparin)

## Treating or controlling diabetes:



Many persons who have had a stroke have also been diagnosed with diabetes. Diabetes is an illness in which the body has difficulty changing food properly into energy that the body can use. Persons who suffer from diabetes are unable to control the amount of glucose (or sugar) in their blood. The majority of people with diabetes are non-insulin dependent. This type of diabetes occurs most often in people over the age of 40 and who are overweight. Persons diagnosed with insulin dependent diabetes are most often diagnosed during childhood or adolescence.

Common symptoms of diabetes include:

- increased glucose (blood sugar) levels
- fatigue
- often overly thirsty
- increased frequency of urination
- weight loss
- slow healing sores
- blurred vision

The nursing staff will assist with monitoring blood-glucose levels. Most common treatments are diet, exercise, use of medications, and use of insulin. Complications of diabetes may be early development of plaque build-up in the blood vessels, difficulty with vision due to retinal disease or cataracts, and kidney or bladder infections.

Although the symptoms stated above may be a sign of diabetes, there are also symptoms for both low and high blood sugars. Low blood sugars can be caused by taking too much insulin, not eating enough food, strenuous exercise, or alcohol consumption. Symptoms of low blood sugar are: sweating, shakiness, tremors, nervousness, dizziness, pale skin, headaches, hunger, blurred vision, clumsiness, numbness, and tingling of the lips. Treatment involves taking 10-15 grams of carbohydrates. High blood sugars can be caused by decreased amounts of insulin, increased food consumption, illness, infection, or stress. Symptoms of high blood sugar are: dry mouth, thirst, excessive urination, blurred vision, fatigue, hunger, weight loss, and vaginal itching in women. Treatment involves taking insulin, increasing fluids without sugar, and use of an insulin pump if necessary.

## Nutrition

In the early stages following a stroke, the nutrition goal is to provide adequate energy and protein from well-selected foods to increase energy level for daily activities, keep muscles strong and working well, allow the body to fight infection, and to feel well, both in mind and body. Good nutrition following a stroke improves a stroke survivor's ability to benefit from therapy.

Immediately following a stroke, several impairments can occur that may impact a patient's ability to consume adequate nutrition. Some of the potential impairments include: chewing and/or swallowing problems, reduced appetite, change in sense of taste or smell, and inability to feed self. Others may include ill-fitting dentures, memory loss, and communication difficulty, which can make menu selection/food preferences more difficult to convey to caregivers. Due to these impairments, stroke patients often require altered texture diets that are easier to swallow, and assistance with eating and completing menu selection may also be needed. Nutritional supplement beverages and snacks may also help the patient meet their nutritional needs until they are able to consume enough of their regular meals. Be sure to ask the dietitian about specific issues related to nutrition that you or your family member are experiencing.

Following a stroke, research indicates that a low fat, low salt, low cholesterol, low sugar, high fiber diet can help prevent a recurrent stroke. High blood pressure, high cholesterol, diabetes, and obesity are risk factors, and may increase the chances of experiencing another stroke. Healthy dietary modifications may help control blood pressure, cholesterol levels, weight, and reduce complications from diabetes.

A balanced diet is important for people of all ages. Eating at least five servings of fruits and/or vegetables daily may help to reduce your risk of a stroke. Also, eating a lower fat, lower saturated fat diet can help control weight and reduce risk of stroke and heart disease. Small changes in your eating habits can make a big difference in your health. Please discuss any drastic changes in your diet or any vitamin and mineral supplementation with your doctor.



## Nutrients

Nutrients are essential for your body to function well. Protein, carbohydrate and fat contribute calories to the diet and therefore must be thoughtfully integrated into a meal plan. Vitamins, minerals and phytochemicals are substances found within food that permit what we eat to be digested well and help the body run smoothly. Water is essential, as it is needed for complex chemical processes to take place, affecting overall body stability and health.

Protein repairs and builds body tissues, affects stamina and vitality, is essential for healthy muscles and skin, and helps the body fight infection. Carbohydrates are the body's chief source of fuel, and are key regulators in digestion. Fats may be a problem, noting that overindulgence can contribute to obesity and blocked blood vessels; however some fat is important in your diet.

It is important to strike a good balance in fat intake. There are four types of fatty acids that you should be aware of: polyunsaturated, monounsaturated, saturated and trans fats. All of these fatty acids are different chemically and found in different types of foods.

Polyunsaturated and monounsaturated fats are “good fats”, and tend to move along in the bloodstream. Polyunsaturated fats are found in liquid vegetable oils such as safflower, sunflower, corn, soybean, and cottonseed oils. They are also found in some fish. These fats help to lower total and LDL cholesterol, but too much may lower “good” or HDL cholesterol as well. Monounsaturated fats are found in liquid vegetable oils such as peanut, olive and canola oils. They are also found in avocados, olives and some nuts. These fats help to lower total and LDL cholesterol, while maintaining and possibly raising HDL cholesterol.



Saturated and trans fats are “bad fats” and can raise blood cholesterol and contribute to heart disease. They are found in meat and dairy products and some vegetable fats such as coconut, palm, and palm kernel oils. Saturated fats are solid at room temperature and can cause blood cholesterol levels to go up. You should limit your intake of saturated fat to less than one half of your total fat grams. Trans fats are found in baked goods, snack crackers, some fried foods, shortening, some margarines, cookies, and many other foods. These fats tend to increase total and LDL cholesterol and may decrease HDL cholesterol. Trans fats are required to be listed on the nutrition food label.



## **Cholesterol**

Cholesterol is a wax-like substance that may cause hardening of the arteries. Cholesterol is found in animal products such as egg yolks, organ meats like liver, and to a lesser degree in meat, poultry, seafood, and whole milk products. You can keep your blood cholesterol low by eating less fat, especially saturated fat and cholesterol. Plants do not contain cholesterol.

Total cholesterol is a measure of both HDL (good) and LDL (bad) cholesterol in the blood. In the past, health professionals used this number to estimate cardiovascular health. Now scientists know that looking at HDL and LDL separately, as well as looking at triglyceride levels in the blood, gives a more accurate picture of cardiovascular health.

HDL (high-density lipoprotein) cholesterol is the “good” blood cholesterol. HDL transports cholesterol in your blood back to the liver to get rid of it. Higher levels of HDL are associated with heart health. (Above 45 is best.)

LDL (low-density lipoprotein) cholesterol is the “bad” cholesterol. You want low levels of LDL circulating in your blood. LDL cholesterol is associated with an increased risk for cardiovascular disease. (Below 100 is best.)

Triglyceride level is a measure of the amount of circulating fat in the blood. This is an emerging risk factor for heart disease. A high level of triglyceride, or a lot of fat circulating in the blood, is associated with an increased risk for cardiovascular disease. (Below 150 is best.)

## **Vitamins, Mineral and Phytochemicals**

There are virtually dozens of vitamins and minerals that serve your body. Phytochemicals, a vast group of chemicals found in plants, are being studied to identify their roles in preventing and treating various diseases. A one-a-day type supplement may be of value when you are not eating well. Foods are the ideal sources of vitamins and minerals since phytochemicals that help with their uptake in the body usually are also naturally found inside the food. A bottled supplement cannot contain all of these additional substances.



## **Sodium**

Sodium is a naturally occurring substance in foods. Sodium, in the form of salt, can also be added to foods for flavor and preserving. Sodium can increase blood pressure. The low sodium diet limits processed foods with a high salt or sodium content and the use of salt in cooking or at the table. Sodium intake should be limited to 2,300 mgs a day.



## **Diabetes**

A carbohydrate-controlled diet is suggested for diabetics, people with high triglycerides, and those desiring weight loss. This diet limits sweets and simple sugars.

## **Fiber**

Fiber is one way to prevent constipation. It is beneficial in helping to control high cholesterol and diabetes. Fiber only comes from plants. Fiber is the part of the plant that remains undigested and unabsorbed as it passes through your intestines. There are two basic categories of fiber. Insoluble fiber, referred to as roughage, includes structural parts of plants such as vegetable skins and the outer covering of grains called bran. Soluble fibers are substances that dissolve in water to form gels, and include oats, barley and citrus fruits.



Your daily intake of fiber should be about 25 grams per day. Since fiber absorbs water in order to “work well,” fluid intake should be increased by about two cups per day (total 8-10 cups daily on average). Note: check with your physician for any fluid restrictions.

## **Dehydration**

Water is the largest single component of the body, but decreases with age because of diminished muscle mass. Water underlies all the functions of the other nutrients, and next to air, is the most essential substance to our survival. Estimated daily fluid consumption should equal 6 to 8 cups.

Thirst drives a person to seek water, but it lags behind the body's need. Thirst sensation can be diminished in the elderly, and if fluids are not replaced promptly, serious dehydration may occur.

Difficulty swallowing can be a result of having a stroke. To prevent liquids entering the lungs, thickened liquids may be prescribed. Thickened liquids are digested and used by the body in the same manner as water. That is, a cup of thickened liquid provides the same amount of fluid as a cup of thin liquid. A suggestion to ensure adequate fluid intake is to mark a line on a pitcher to show 6 to 8 cups, and fill with water to that line. Each time you drink water or a thickened liquid, pour that amount of water out of the pitcher. At the day's end, the amount of water removed from the pitcher will equal the amount of water/thickened liquid you have consumed. This allows you to track how much water is taken daily.



## **Dysphagia**

Following a stroke, a person may have difficulty swallowing liquids and/or solids. The medical term for this is dysphagia. This problem may be due to weakness and/or poor coordination of the muscles used for swallowing, and an altered diet may be needed.

## **Frazier Water Protocol**

The Frazier water protocol allows patients on thickened liquids, the ability to drink water between meals. This allows for increased fluid consumption and decreased risk for dehydration. Water is permitted until you take your first bite of food. No water is allowed during a meal or for 30 minutes following the meal.

# **Individuals Involved In My Care**

## Individuals Involved In My Care

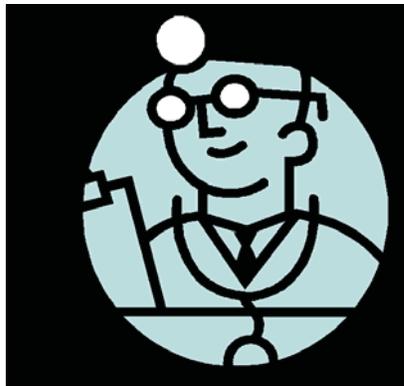
You meet a lot of new faces during a hospital stay. Although it's difficult to keep a name with all of these new faces (from doctors to therapists to nursing aides....), this section will help describe the role that each person plays in your recovery process. The staff that will be working with you understands how overwhelming it can be to meet all these new people. Don't be afraid to ask each person for clarification on what they do and how they can help you achieve the highest level of recovery possible!



You'll meet a number of different doctors during your hospital stay. Each may have a different specialty area. Your admitting doctor typically requests consults from other specialty doctors as needed. Here are the main doctors who may be involved in your care:

- **Primary Care Physician:** This is your family doctor. When you are admitted to the hospital, your doctor should be notified. Your doctor will either visit you personally in the hospital or will receive records pertaining to your admission. Plan on following up with your primary care physician after discharge from the hospital.

- **Neurologist:** This doctor specializes in disorders or traumas involving the nervous system. A neurologist will consult with other physicians to review tests and determine more information regarding the diagnosis of stroke. A neurologist may help determine what part of the brain has been damaged and to what extent.
- **Physiatrist:** This doctor specializes in Rehab. Once he/she evaluates the patient, he/she determines whether the patient has Rehab needs. If so, then the physiatrist will make a referral to the appropriate setting (i.e. inpatient, outpatient, home health, skilled nursing care). Once the patient is receiving therapy, the physiatrist receives reports from the therapists and nurses and works with the staff to manage any medical concerns that may be affecting your rehab. The physiatrist may also order specific positioning devices, therapeutic modalities, adaptive or durable medical equipment, and assessments or evaluations. It is important to follow up with your physiatrist upon discharge from the hospital when recommended.



## **Other persons who may be involved in your care include:**

**Nurse (LPN or RN):** Typically a different nurse will be assigned to you each shift. This person provides your basic daily care. He/she dispenses medications (including use of IV's), assists patients with positioning needs, assists patients with any feeding needs (feeding tubes), monitors bowel and bladder function, monitors blood pressure, monitors integrity of the skin, and manages any other medical complications that need to be communicated to the doctor. The nurse also educates caregivers when necessary about the above information.



**Nursing Aide:** This person assists the nurse in providing basic daily care. The aide also helps position the patient to prevent skin problems, improve correct alignment of the body, and provide comfort to the patient.

**Case Manager:** You will be assigned a case manager upon admission to the hospital. This person coordinates your overall care, with a strong focus on discharge planning. The case manager deals closely with you and your family, your doctors, nurses, therapists, and insurance company to ensure that all persons are working together for the best recovery process possible. Your case manager is also responsible for assisting in getting the necessary equipment recommended for home use. They also have great knowledge in community resources that may be available to you upon discharge. At **Frazier Rehab Institute**, the case manager coordinates team and family meetings requested by either the rehab team or the family.

**Registered Dietitian:** This person ensures adequate nutrition is being provided for all patients. When necessary, an individualized nutrition plan of care is developed with appropriate education to the patient and/or family.

**Physical Therapist:** Physical therapists work with patients to improve balance, movement of the arms and legs, strength, and mobility. Building control of the patient's body starts in the bed, then progresses to sitting, and then to standing -- with the hopeful goal of eventually walking. The goal is to achieve the highest level of function possible for each individual. If needed, the physical therapist may also recommend devices to help with mobility, such as walkers, wheelchairs, or braces. When working with a stroke survivor who has lost use of one side of the body, the physical therapist practices movement involving use of the affected side.



**Occupational Therapist:** Occupational therapists work with patients on performing everyday life skills independently. Basic skills involve self care needs such as dressing, bathing, grooming, and toileting. Advanced skills that may be necessary for independent living or return to roles include kitchen or homemaking tasks, money management, community re-entry activities, driving, or work skills. It is important to think about previous roles and what activities are most important to the patient when developing goals with the occupational therapist. Occupational therapists analyze activities and work with the patient on skills needed to complete these activities. They may also work with the patient to learn new techniques, change the environment, or recommend equipment that may be helpful.



**Speech Therapist:** Speech therapists work on improving the intelligibility of a person's speech so that speech can be understood. They also work with patients to improve language skills, which may include talking, writing, reading, comprehending, or using gestures. Speech therapists may also work on cognitive skills, or thinking skills. Cognition can be broken down into orientation, attention, memory, problem solving, reasoning, and sequencing. Speech therapists are also skilled in evaluation and treatment of swallowing problems.

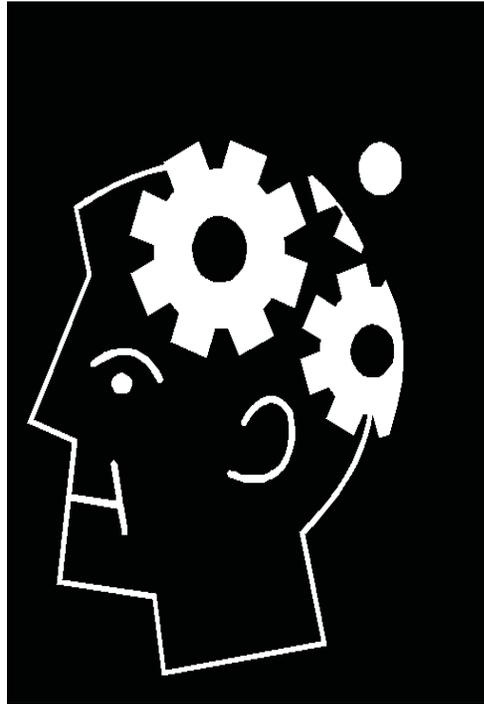


**Recreational Therapist:** Recreational therapists work with patients on leisure skill development. This person assists the patient in learning techniques that will enable the stroke survivor to continue past interests as well as an opportunity to learn new skills. The recreational therapist works on the following areas: community mobility skills, leisure education and awareness, time management skills, transportation options and modifications, health and wellness, and community re-integration. At **Frazier Rehab Institute**, the therapeutic recreation department offers animal assisted therapy. The recreational therapy staff also leads a stroke support group for stroke survivors to attend while staying in the hospital or while living at home.



**Psychologist:** The psychologist deals with any mood or behavioral issues that may be affecting the patient's recovery process. This person is available to work with the patient, their family, and the therapy staff to help the stroke survivor focus on therapy activities.

**Neuropsychologist:** This is a psychologist who specializes in diagnosing and treating behavioral, social, and emotional problems that result from neurological illness or injury. The neuropsychologist may perform an assessment that looks at a variety of thinking, memory, sensory, intellectual, academic, and vocational skills, as well as emotional functioning.



# **Common Changes Following Stroke**

## Common Changes Following Stroke

As was discussed earlier, no two strokes are the same. However, there are certain changes that occur in stroke survivors that are common. Many changes are dependent on the severity of the stroke and where the stroke occurred in the brain. This section will describe the various changes that may be seen following stroke.

### **Physical changes:**

Most people experience loss of movement or weakness on one side following stroke. This is because of how our brain works. The left side of our brain controls movement on the right side, and the right side of our brain controls movement on the left side. When a stroke occurs, it typically happens to one area of the brain. Therefore, it is most common to see loss of movement on one side only.

Here are some common physical changes that you or your loved one may be going through:

- Inability to move the affected arm or leg at all, especially early in recovery
- Loss of feeling in the affected arm or leg (touch, pain, temperature, or position)
- Swelling in the affected arm or leg
- Weakness in the entire body, making it difficult to sit, stand, or walk
- Difficulty overall with balance
- Difficulty perceiving position of the body in space (a person's body may feel so different that he/she cannot tell where his/her "middle" is, or where his/her arm or leg is positioned)
- Difficulty with coordination -- controlling the direction, force, or speed of movement that his/her body or limbs perform

- Imbalance of muscle activity in the affected arm or leg (as movement returns, some muscles may involuntarily work too hard and cause pain or stiffness in the joints)
- Tightness in all joints throughout the affected arm or leg may occur if movement does not return
- Inability to move the affected arm, as well as the weight of a person's arm, may cause a condition known as shoulder subluxation. This means that the shoulder becomes separated or dislocated and is not in its normal position. It is commonly managed by proper positioning of the shoulder in relation to the body.
- Pain may or may not be experienced after a person suffers a stroke. Often times pain can be prevented by proper positioning, range of motion, and overall mobility. If pain is present, it will be managed by both the physician and therapy team.

### **Cognitive changes:**

Some people experience changes in cognition, or thinking, following a stroke. Because the stroke occurs in the brain, it is only logical that there may be some change in how the person thinks following the stroke. However, some problems are very mild and resolve fairly quick, while other problems may persist and cause difficulty in even basic daily activities. Your therapists will try to be very thorough to assess any difficulty with cognition following the stroke to ensure a safe transition home.

Here are some common cognitive changes that you or your loved one may be going through:

- Difficulty with orientation to self, place, time, or situation
- Limited attention to an activity either in an isolated or a distractible environment
- Limited ability to switch attention between two or more tasks (for example, answering the phone while in the middle of cooking, but being able to return to cooking activity)
- Limited ability to attend to two or more things at once (for example, holding a conversation while driving)
- Limited attention to details (for example, when filling out a form a person may miss a question or section without realizing it)
- Difficulty with long term, short term, or immediate memory
- Difficulty solving either routine daily problems or high level problems related to time management or work skills

- Difficulty with reasoning skills (drawing conclusions, understanding the rationale for doing something)
- Difficulty with sequencing, or putting things in order
- Impaired insight (the person does not believe he/she is having difficulty with things that seem to be apparent problems to others)

### **Speech changes:**

Some people may experience difficulty with speech production following a stroke. The medical term for this is dysarthria. This typically involves changes in the muscles of the lips, tongue, and throat. It can also be caused by weakness in the muscles used for breath support.

Here are some common speech changes that you or your loved one may be going through:

- Slurred speech
- Unintelligible speech, or speech that is not able to be understood
- Slow or uncoordinated speech
- Extremely soft speech

Another cause of impaired speech production is termed verbal apraxia. This is the inability to plan the movements required to make a certain sound or word. Severity can range from occasional sound substitutions to complete inability to make a sound. The person may be able to say “hi” or “how are you” automatically when seeing someone. If asked to say these words or phrases though, the person may not be able to do so.

### **Language changes:**

Language problems typically appear in persons whose stroke occurred on the left side of the brain. The medical term for a difficulty with language is aphasia, which can be defined as a total or partial loss of the ability to use words. It can affect someone’s ability to speak, write, read, gesture, and/or understand spoken, written, or gestural language. There are two main types of aphasia.

1. *Fluent aphasia*: A normal rate of speech may be present, but the person may use words that don't make sense or that are not actually words. The person sometimes has more difficulty understanding what is said and also has difficulty realizing that his/her speech is not being understood by others.
2. *Nonfluent aphasia*: Generally the person has more effortful, hesitant speech. The person often understands much of what is being said and is more aware of his/her errors. Therefore, this individual tends to get frustrated.

### **Swallowing changes:**

Following a stroke, a person may have difficulty with swallowing. The medical term for this is dysphagia. A person may have difficulty swallowing liquids and/or solids. This problem may be due to weakness and/or poor coordination of the muscles used for swallowing. A person with swallowing difficulties may be placed on an altered diet or tube feedings. The altered diet may include a change in the consistency of the food or in the thickness of the liquid. Food may need to be pureed or chopped, and liquid may need to be thickened like nectar, honey, or pudding. A person may also learn different techniques to assist with swallowing, such as tucking the chin or taking small bites. A person with dysphagia is at risk for aspiration pneumonia if food, liquid, or saliva containing bacteria enters the lungs. Good oral care is essential to aspiration pneumonia prevention. Small sips and bite size allowing time between swallows also cut down pneumonia risk.

The Frazier Water Protocol allows patients on thickened liquids to drink water between meals. This promotes increased fluid consumption and decreases risk for dehydration. Water is permitted until you take your first bite of food. No water is allowed during a meal or for 30 minutes following the meal. People drinking thickened liquids often report the thickened liquids do not quench their thirst. Fewer glasses of liquid are consumed which can lead to serious health consequences. Water does quench most people's thirst. A person taking thickened liquids should be encouraged to drink water to meet the body's daily fluid requirements for health.

Individuals receiving their nutrition through tube feedings may have water anytime.

## **Visual changes:**

Some stroke survivors experience visual changes. However, it is important to understand that most often the changes are in visual perception vs. visual acuity. Because a stroke causes damage in the brain, the changes in vision occur where the sensory information is gathered. Therefore, the person may be able to see things in his/her environment, but the way that he/she sees the environment may be altered. This does not rule out visual acuity as a problem following stroke, but it is important to realize that some visual changes after stroke are not able to be corrected by traditional glasses. If acuity is a problem, it is typically due to impaired motor control of one of the eyes.

Here are some common visual changes that may occur after stroke:

- Difficulty visually attending to the affected side. The person may look briefly to that side when encouraged to do so, but most often holds head in the other direction. This causes problems finding items in his/her environment, avoiding obstacles during mobility, and performing reading and writing activities.
- Difficulty seeing things on one side of the environment. This can be due to a limited visual field since the stroke. When a person turns the head, he/she is able to seek and find an object on the impaired side. But without turning the head, that visual information is not there. Again, problems may be encountered when finding things, avoiding obstacles, and performing reading and writing activities.
- The person may see double. This is typically due to weakness in one of the eyes. Because one of the eyes is weak, it is unable to focus with the other eye to receive a clear image. This is more typical in near activities.
- Limited visual attention to details. The person may “skip over” small visual information that may be of importance. For example, the person may misread simple directions on a package when cooking (using 2 teaspoons water vs. 1 tablespoon).
- Inability to find objects in clutter. The person may have difficulty locating objects in a drawer when looking for something.
- Difficulty organizing the position of an object in space. The person may turn his/her shirt several times when donning, with problems finding the top or realizing that it is inside out.

## **Daily living changes:**

Following a stroke, life becomes very different if there are changes in how a person walks, talks, moves, eats, or sees. Mundane daily activities do not seem as easy as they once were. They can even be extremely challenging. Getting dressed, bathing, going to the bathroom, brushing teeth, managing hair, and shaving are all activities that were once taken for granted. All areas of life are affected. Work roles, family roles, and other responsibilities may be difficult or impossible for the time being. However, with the help of skilled therapy, the impossible may become possible. There are techniques, equipment, and technology available to assist stroke survivors with becoming more independent in their daily activities. There is also the potential for return of lost skills. It is extremely important for the stroke survivor to participate in these familiar activities. These activities provide rehearsal for all problem areas, and they also allow the person to begin taking part in old routines. A person is unable to know current abilities unless the opportunity has been given to show his/her abilities.

## **Leisure changes:**

Not only have basic daily activities been affected by a stroke, there are also significant changes in leisure activities. Leisure activities provide an outlet for stress relief and relaxation. Following a stroke, this outlet is desperately needed. However, there are often changes that may occur.

- Inability to pursue leisure activities of interest due to physical or cognitive changes
- Inability to use one side of the body for activities
- Inability to socialize due to speech or language problems
- Frustration over lack of leisure options
- Inability to problem solve or find resources for participation in leisure activities
- Lack of transportation for leisure activities
- More time spent on daily activities, leaving no time for leisure

## **Mood and psychosocial changes:**

Life can change quickly and drastically following a stroke. This life change is often difficult to manage emotionally. Here are some common problems that can occur following stroke.

- Depression or grief over the loss of old abilities
- Language problems, creating a lack of adequate communication which can put a distance between the patient and family or friends
- Dealing with the social stigma of having a disability
- Lack of or altered sexual intimacy
- Denial of disability
- Anxiety over current situation and future
- Lessened self-esteem due to loss of control over situation

# **How Can Family Members Or Loved Ones Help?**

## **How Can Family Members Or Loved Ones Help?**

It is impossible to recover from a stroke without support from others. Although your treatment team will provide support while you are staying in the hospital, unfortunately (or fortunately) they cannot go home with you! Therefore, it is very important for family members or other loved ones to learn how to assist you in your recovery process. Family members or loved ones should take an active role in learning the needs of a stroke survivor. The purpose of this section is to provide some helpful hints for assisting you in order to achieve your maximum potential.

### **Physical changes:**

- Be sure to follow any recommended positioning needs. Wearing of splints for the hand or foot may be recommended. Be sure to go over the proper fit with the therapist.
- In some instances, a person who has suffered a stroke will exhibit increased muscle tone, or spasticity, in the affected arm or leg. This occurs when the brain involuntarily sends a signal to make the muscles contract, and the stroke survivor is unable to voluntarily relax those muscles. This spasticity is commonly managed by positioning, range of motion exercises, or medication.
- The following diagrams are common bed positioning needs for persons who have hemiplegia or lack of movement on one side.

## Lying On The Back (Supine)



1. Head on pillow.
2. Place corner of head pillow under involved shoulder to prevent retraction. Shoulder blades coming forward.
3. Place affected arm and hand on a pillow, arm slightly away from the body, the upper arm turned away from body, elbow straight, forearm and palm turned up, palm up (o.k. for wrist to fall into extension.)
4. Place corner of arm pillow under affected hip, to prevent pelvic retraction (falling back toward bed).
5. May need to place folded towel under affected thigh, so that the leg is not suspended (do not want knee flexion in supine).

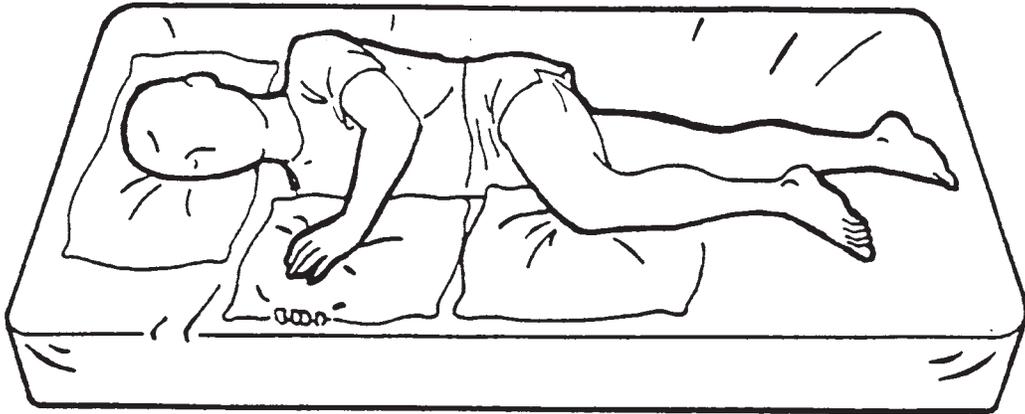
Foot boards cause positive supporting reaction, keep feet and ankles in proper positioning.

## Lying On Affected Side



1. Pillow underhead, which allows for a slight stretch to neck flexors on affected side.
2. Get elongation (lengthening of muscles) of trunk on affected side.
3. Scapula (shoulder blade) on affected side must be well forward; arm slightly away from body, and turned out. Forearm and palm turned up towards the ceiling.
4. Non-affected leg forward on a pillow, with hip and knee bent; be sure foot is supported.
5. Back and affected hip in extension (straight) with knee flexed (bent).

## Lying On Non-Affected Side



1. Pillow underhead.
2. Top leg forward on pillow, foot and leg supported.
3. Enough flexion (bend) of top leg to prevent falling onto prone (stomach).
4. Underneath leg back.
5. Towel under waist to prevent shortening of muscles of affected side.
6. Affected arm flexed (bent) to 90 degree at shoulder, with scapula forward; arm extended (straight) on a pillow with forearm in pronation (palm down toward pillow).
7. Make sure waist is not hanging in over edge of pillow.

Encourage a symmetrical posture (both sides being held in the same position with the middle of the body centered) whenever possible. This includes when laying in bed, when sitting in a chair or wheelchair, when standing, etc...

- Encourage sitting up and getting out of bed to improve balance and endurance.
- Encourage any possible movement in the affected side. Encourage use of this movement with all activities ranging from moving in bed to getting dressed.
- Assist in range of motion exercises to the affected side. Your therapist should educate you in these. However, range of motion is merely taking the arm or leg through movements that were normal prior to the stroke in order to keep all joints flexible.
- Give sensory input to the affected side. Be sure to rub and handle the affected side to assist with any changes in sensation. Be careful, though, to make sure the affected side is safe if there is difficulty feeling hot/cold, pain, and/or position of the extremity in space.
- If there is swelling, the key is to position the swollen body part above the heart. Also, be diligent with range of motion exercises.
- Always encourage full concentration and focusing on controlled movements when attempting to use the affected side. Sometimes it is helpful to “tell” the affected side what to do by breaking it down into parts (i.e. ‘lift wrist, straighten elbow, open hand, now grasp object’).

### **Cognitive changes:**

- Assist in orientation to the date, time, place, and situation daily. Point out the clock or calendar when needed.
- If attention is a problem, reduce distractions when conversing or doing other activities.
- Encourage the person to re-check his/her work when completing paperwork or filling out his/her daily menu.
- Give hints to assist with remembering information. Also, encourage the person to write down important information when needed. Using a memory board, journal, or daily calendar is helpful in remembering information.
- Give the person extra time to solve problems. If there is still difficulty, help the person talk through the problem in order to help solve it.
- Have the person explain his/her reasoning with certain activities. If it does not appear logical, talk gently and patiently with the person about it.
- Be sure to point out unsafe behaviors to the person. Calmly explain why the behavior was unsafe and what the correct or safe method would have been.
- Provide repetition of activities for new learning. It may take much longer to pick up on new ways of doing things. Be patient and allow this practice.

### **Speech changes:**

- Encourage the person to talk slow, open his/her mouth wide, and repeat or rephrase the message if necessary.
- Encourage the person to sit up straight and take a deep breath before speaking.
- Encourage the person to complete any recommended exercises to increase the strength and coordination of the muscles needed for speech.

**Language changes:**

- Simplify information using shorter sentences and repeat or reword ideas until he/she understands. You can also try gesturing to assist in getting your idea across.
- Be patient. Allow time for the person to understand and respond.
- Be clear and say “I’m sorry; I didn’t understand you,” when necessary and try again.
- Try to eliminate distractions when trying to communicate.
- Keep in mind that the person is an adult who is quite aware of his/her surroundings even though language function is impaired. Unless the person has difficulty hearing, do not attempt to speak louder. Language is the issue, not hearing
- Respect the person and include him/her in conversations with family and friends.

**Swallowing changes:**

- Follow the diet and swallow techniques recommended by your speech therapist. Encourage the person to be independent following those recommendations.
- Be sure to drink lots of liquids, at least 6-8 cups per day. Water is the best liquid of all and can be taken between meals if the person is taking thickened liquids.

## **Visual changes:**

- Encourage the person to look towards his/her affected side. This may involve a strong head turn in that direction, taking the non-affected hand and following it into that side of the environment, someone assisting the person to turn his/her head or move his/her non-affected hand into that side of the environment, or using bright colors to draw attention to that side of the environment.
- Help the person maintain normal range of motion at the neck. Practice turning it each direction daily and holding it toward the affected side for an extended amount of time.
- Encourage the use of an organized search pattern to find objects. For example, always start by looking in the same area when trying to find something and then follow a consistent pattern, like left to right and top to bottom.
- Rid the environment of visual distractions. This may include using a white piece of paper to cover unnecessary visual clutter on a piece of paper, or it may include keeping drawers and closets highly organized in order to find items easily.
- Highlight the affected side of paper when reading in order to complete the entire line of reading instead of skipping words.
- Read information twice to make sure that all visual details were noticed the first time.
- Magnify reading information when necessary.
- Encourage use of the person's finger to follow across the line when reading.
- Discuss with your doctor when a visual consult may be necessary

### **Daily living changes:**

- Encourage the person to attempt previous activities before asserting that he/she is unable to do them. The person may be pleasantly surprised at what he/she is able to do.
- Encourage the person to assist with getting dressed. When doing so, the general rule of thumb is to dress the affected side first. It is typically easier when dressing on a lower chair with a back. Also, practice using adapted equipment if it is recommended, and elastic shoelaces or velcro fasteners to eliminate tying.
- Encourage the person to assist with bathing. Follow recommendations from the occupational therapist on any bath equipment. Sit when necessary. It may help to cross the affected leg to reach the foot. Also, the non-affected arm can be washed by rubbing it against the non-affected leg. Long sponges or brushes can also help getting “hard to reach” areas.
- Encourage the person to assist with grooming. The affected hand can be used to help stabilize a container while opening with the other hand. Be cautious with shaving, as many persons are on blood thinners following stroke.
- Include the person in conversations or activities involving previous roles. For example, continue to ask “fatherly” advice, have intimate “husband-wife” conversations, share opinions, talk about hobbies, etc...

### **Leisure changes:**

- Help to identify available resources and programs within the community.
- Work as a team with the person to become involved in leisure activities.
- Motivate and encourage the person to explore and use modified options and equipment for leisure activities.
- Encourage independence with leisure activities.
- Attend the monthly educational support group meetings for stroke survivors and their families presented by the recreational therapy department from **Frazier Rehab Institute**.

## **Mood and psychosocial changes:**

- Be supportive. No one can understand how difficult it is to recover from a stroke unless he/she has been through it. Be encouraging and motivating to the stroke survivor to assist in the Rehab process.
- Do not take the person's change in moods personally. The stroke survivor is attempting to process what has happened, learn what he/she needs to know from therapists, and become less modest toward the nursing staff. Also, he/she may be unable to control his/her emotions. Big changes mean a big change in moods. Go with the flow and make the person realize that you are available if he/she would like to talk.
- Encourage the person to focus on his/her improvements since the stroke, rather than comparing his/her abilities to those before the stroke.
- Encourage speaking to other stroke survivors about feelings and recovery.
- Encourage return to community activities in order to experience life in his/her new situation. Assist in making this a smooth transition by being well prepared to assist when needed.
- Speak to the doctor or psychologist regarding sexual intimacy issues.
- Allow the person to regain control over situations when possible.
- Discuss the future with hope, but also in realistic terms.

# **Community Resources**

## Community Resources

Life after a stroke is different than before. No matter how much a person recovers, that person is forever changed by the experience. This section will help identify resources in the community to provide support. Both patients and family members or caregivers can benefit from these resources.

### **Local Stroke Support Groups:**

- **Frazier Stroke Support Group** (in partnership with Louisville Metro Parks - Adapted Leisure Activities)  
Time: 3rd Wednesday of each month from 12:00 - 1:30 p.m.  
Location: Douglass Community Center (off Bardstown Road)  
Contact: (502) 582-7411
- **St. Mary & Elizabeth Hospital Friendly Folks Stroke Club**  
Time: 2<sup>nd</sup> Wednesday of each month at 12:00 noon  
Location: Caritas Hospital 1850 Bluegrass Ave.  
Contact: (502) 361-6585
- **SIRH Stroke Support Group**  
Time: 2nd Tuesday of each month from 1:00-2:30 p.m.  
Location: Southern Indiana Rehab Hospital  
Contact: (812) 941-8300

### **Stroke Associations:**

- **National Stroke Association**  
1-800-STROKES (1-800-787-6537)  
(502) 896-7221  
[www.stroke.org](http://www.stroke.org)
- **Kentucky and Southern Indiana Stroke Association**  
(502) 894-8213  
[www.strokekyin.org](http://www.strokekyin.org)
- **American Stroke Association**  
1-888-4-STROKE (1-888-478-7653)  
[StrokeAssociation.org](http://StrokeAssociation.org)

\*\*\*These associations typically have brochures, publications, and/or magazines that discuss specific stroke issues. They are written for the stroke survivor and his/her family. Helpful hints and feedback from other stroke survivors is often available.\*\*\*

## **Other Agencies and Associations that may be helpful:**

- **American Association of Retired Persons (AARP)**  
1-800-424-2277  
[www.aarp.org](http://www.aarp.org)
- **American Heart Association**  
1-800-242-8721  
[www.americanheart.org](http://www.americanheart.org)
- **Americans with Disabilities Act information**  
**National Organization on Disability**  
(202)293-5960  
<http://nod.org>
- **American Society of Hypertension**  
(212) 644-0650  
[www.ash-us.org](http://www.ash-us.org)
- **Center for Accessible Living**  
(502) 589-6620
- **Children of Aging Parents**  
(215) 945-6900  
[www.experts.com](http://www.experts.com)  
[www.careguide.net](http://www.careguide.net)
- **Consumer Information Center/Medicare Information**  
(719) 948-3334  
[www.pueblo.gsa.gov](http://www.pueblo.gsa.gov)
- **Eldercare Locator**  
1-800-677-1116  
[www.eldercare.gov](http://www.eldercare.gov)
- **Family Care Giver Alliance**  
(415) 434-3388  
[www.caregiver.org](http://www.caregiver.org)
- **Help for Incontinent People, Inc.**  
1-800-252-3337  
[www.nafc.org](http://www.nafc.org)
- **Medicare Hotline**  
1-800 MEDICARE (1-800-633-4227)  
[www.medicare.gov](http://www.medicare.gov)
- **NARIC (references related to disability and Rehab)**  
1-800-346-2742  
[www.naric.com/naric](http://www.naric.com/naric)
-

**National Aphasia Association**

1-800-922-4622

[www.aphasia.org](http://www.aphasia.org)

- **National Council on the Aging, Inc.**

(202) 479-1200

[www.ncoa.org](http://www.ncoa.org)

- **National Council on Disability**

(202) 272-2004

[www.ncd.gov](http://www.ncd.gov)

- **National Family Caregiver Association**

1-800-896-3650

[www.nfcacares.org](http://www.nfcacares.org)

- **National Institute of Neurological Disorders and Stroke (NINDS)**

1-800-352-9424

[www.ninds.nih.gov](http://www.ninds.nih.gov)

- **National Insurance Consumer Helpline**

1-800-942-4242

[www.iii.org](http://www.iii.org)

- **National Rehab Information Center**

1-800-346-2742

- **Social Security Administration**

1-800-772-1213

[www.ssa.gov](http://www.ssa.gov)

- **Vocational Services for the Disabled**

1-800-222-JOBS (1-800-222-5627)

[www.vesid.nysed.gov](http://www.vesid.nysed.gov)

- **Vocational Rehab (local)**

(502) 588-4235

- **The Well Spouse Foundation**

1-800-838-0879

[www.wellspouse.org](http://www.wellspouse.org)

**Local Rehab Services:**

- **Frazier Rehab Institute (Inpatient)**  
(502) 582-7476
- **Frazier Rehab Institute (Outpatient)**  
(502) 582-7486
- **Visiting Nurse Association (Home health)**  
(502) 584-2456
- **Four Courts Senior Center (Skilled Nursing Care)**  
(502) 451-0990

**For More Information:**

It is impossible to list all available resources for you and your family. Often local churches and/or community centers offer programs or services for persons with disability. You may want to contact them to explore available assistance. However, your case manager is an excellent resource for questions and information regarding assistance in the community. Your case manager may be able to assist you with investigating funds or programs available to you, attaining a handicap parking permit, applying for TARC 3 for transportation, day programs within your area, and agencies providing assistance with daily living care. Don't hesitate to ask questions regarding this information.

# **Preventing Recurrence/ Health and Wellness**

## Preventing Recurrence/Health and Wellness

Although Rehab of problems following stroke is an important process, it is of equal (if not greater) importance to address stroke prevention following a stroke. Statistics show that stroke risk increases after a first stroke with time. Therefore, it is important to understand risk factors that can be changed. Compliance with a healthy lifestyle and medications prescribed by your doctor is critical!

### **“To-Do” list for stroke prevention:**

- **Do attend regular medical check-ups**
- **Do control high blood pressure** - This is the single most important risk factor for stroke. Know your blood pressure and have it checked at least once every two years. If it is 140/90, it's high. Talk to your doctor about how to control it.
- **Do stop smoking**
- **Do treat heart disease** - Heart disease can cause blood clots in the brain causing stroke.
- **Do manage A-fibrillation** - A-fib (an irregular heartbeat rhythm) can cause the blood to pool and clot, increasing the risk of stroke. Talk to your doctor about how to manage this.
- **Do improve your diet and monitor cholesterol** - Get rid of excess fat and excess sodium in your diet. Also, avoid excessive alcohol intake. Drinking an average of more than one drink per day for women and more than two drinks per day for men raises blood pressure.
- **Do maintain a healthy weight** - This reduces the risk of heart disease.
- **Do exercise regularly** - Exercising 20 minutes at least 3-4 times per week also reduces the risk of heart disease.
- **Do treat Diabetes** - Work with your doctor to manage diabetes.
- **Do reduce stress** - High stress leads to an increase in blood pressure.
- **Do manage circulation problems and blood disorders**
- **Do avoid illegal drug use** - Intravenous drug abuse carries a high risk of stroke. Cocaine use also has been linked to stroke.

## **Uncontrollable Risk Factors:**

- **Increasing age** - Stroke affects people of all ages. But the older you are, the greater your stroke risk.
- **Gender** - In most age groups, more men than women have strokes. However, more women die from strokes than men.
- **Heredity and race** - People whose close blood relations have had a stroke have a higher risk of stroke themselves. African Americans have a higher risk of death and disability from stroke than whites. Hispanic Americans are also at a higher risk of stroke.
- **Prior stroke** - Someone who has had a stroke is at higher risk for having another stroke.

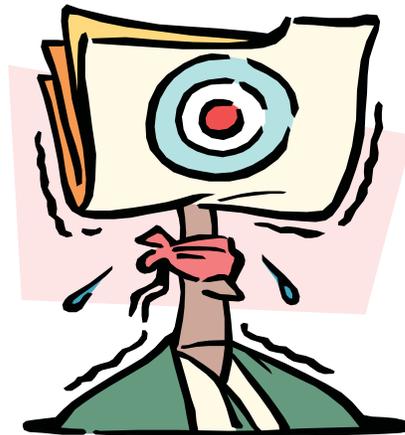
## **High Blood Pressure and Stroke**

### **What is High Blood Pressure?**

High blood pressure means that the pressure in your arteries is consistently in the high range. It can lead to stroke, heart attack, heart failure or kidney failure.

Blood pressure results from the force of blood pushing against blood vessel walls. Two numbers represent blood pressure. The higher (systolic) number represents the pressure while the heart is beating and the lower (diastolic) number represents the pressure when the heart is resting between beats. The systolic number is always listed first and the diastolic number is second.

A blood pressure of less than 120 over 80 is considered normal for adults. A blood pressure reading equal to or higher than 140 over 90 is considered high. Blood pressure between 120-139/80-89 is considered “prehypertension” and requires lifestyle modifications to reduce the risk of cardiovascular disease.



## **Who is at a Higher Risk for High Blood Pressure?**

- People with a family history of high blood pressure
- African Americans
- People 35 years old or older
- People who are overweight or obese
- People who smoke
- People who eat too much salt
- People who drink too much alcohol
- Women who use birth control pills
- People who are not physically active
- Pregnant women

## **Controlling High Blood Pressure**

Lose weight if you are overweight.

Eat a healthy diet that is low in salt, saturated fat, and cholesterol.

Eat enough fruits and vegetables and fat-free or low-fat dairy products.

Enjoy regular physical activity.

Limit alcohol to no more than two drinks a day if you're a man and one drink if you're a woman. Check with your doctor regarding alcohol consumption.

Take medicine as prescribed.

Know what your blood pressure should be and try to keep it at that level.

# **Frequently Asked Questions**

## **Frequently Asked Questions**

Our hope is that this handbook has successfully answered the majority of your questions. However, there are always going to be questions that you may have that have been left unanswered. This section will answer some questions that may be common following stroke.

### **Will I ever be back to normal? How will I know when I have reached my potential?**

A stroke affects everyone differently. There are various factors that affect recovery. These include mental readiness for recovery, family support, medical management, Rehab efforts, the amount of brain tissue damaged, the ability to learn new information, environmental factors, and previous body type or medical history. Most persons never recover from a stroke feeling “the same” as they did before. This may be due to changes in one’s physical capabilities, but most often it is due to the experience of having had a stroke. Your treatment team will discuss your recovery progression with you. They will determine treatment needs and length of stay based on clinical judgment, as well as discussing when discharge may be appropriate. It is important to know that research is showing changes in function from up to 2-5 years following stroke. Therefore, even upon discharge from Rehab, it is important to continue with a home exercise program that addresses any remaining problem areas.

### **How long will I need therapy?**

This is dependent on the factors discussed above. Again, your treatment team will take all of these factors into consideration and determine an appropriate length of stay. The need for outpatient therapy may not be necessary for some, or it may go on for months for others. When being discharged from outpatient therapy, it is important to know that recovery does not necessarily end at that time. If positive changes occur during your home exercise program, it may be appropriate to ask for a referral from your doctor to return to therapy for an evaluation.

## **What kind of changes need to be made to my home?**

This is dependent on your level of functioning upon return to your home. It is important to know whether the therapists think you will go home using a wheelchair or a walker. If going home at a wheelchair level, you may need to have a ramp installed for access to the home. If there are major concerns regarding your home environment, discuss them with your therapists. It may be necessary to do an evaluation of the home in order to make specific recommendations for safety. Your occupational and physical therapists should be discussing home considerations during treatment. They will recommend any necessary equipment or home modifications.

## **Where can I get resources after my insurance is gone?**

If insurance is a problem, it is important to discuss this with your case manager. Your case manager will try to help guide you toward any available funding or assistance necessary to assist you in your recovery.

## **When can I drive again?**

It is necessary to get approval from your doctor prior to driving again. If there are concerns regarding your safety, a driver's evaluation may be recommended. Driver's evaluations are completed at one of the Frazier outpatient satellite clinics. Recommendations and training (if necessary) are provided by the occupational therapist who is a certified driving instructor.

## **What type of transportation is available for persons with a disability?**

Depending on your physical functioning, you may be able to ride in a typical vehicle. Your physical and/or occupational therapist can practice getting in and out of your vehicle with you and your caregiver. If this is not a possibility, or if you have been dependent on public transportation in the past, TARC in Louisville provides a special service for transportation of individuals with a disability. This service is called TARC 3 and it requires an application process for use. Your case manager has more information regarding the application process.

## **I was told I would need supervision in my home. What does that mean?**

There are several different levels of supervision that may be recommended to you upon return home. Your treatment team should specify the level of supervision that is required to maintain safety in the home. Supervision is sometimes recommended for physical reasons, but it may also be recommended due to difficulty with thinking skills or vision. You may need someone to care for you 24 hours per day, or you may simply need someone to check in on you one or two times per day. Recommendations are based on your problems since your stroke, and they are made to ensure a safe and successful return home.

## **As a family member or caregiver, should I be attending therapy with my loved one?**

Most often the answer is “YES”! However, several factors need to be considered. The treatment team may recommend that your attendance at therapy is limited based on the responses of your loved one. Some people do better when left on their own, and others do better surrounded by their family and friends in therapy. It is important though to try to attend fairly consistently. You will be able to help your loved one carry over new things learned in therapy, and you may even be educated with “hands-on” ways of assisting with the recovery process.

## **Once I return home, how do I know what medical problems need reported to my doctor and what may be just common side effects from my stroke?**

If any symptoms of stroke occur (refer to the list in the beginning of the handbook), go the emergency room immediately! Other symptoms that you want to report to your doctor include:

- new onset of swollen or painful arm or leg
- chest pain or shortness of breath
- bleeding of gums, skin, or in urine
- severe indigestion
- presence of a seizure or loss of consciousness
- decreased responsiveness
- change in urinary functioning (burning)
- long lasting depression that affects eating and/or sleeping
- fainting when standing up or dizziness

## **I have so many medications to take. How do I keep track of them all?**

First, it is important to understand what each medication is for. So be sure to ask your doctor if you do not understand. Next, keep a list of all current medications (including over the counter). This is very important in case you need to go to the emergency room or a new doctor. Anyone caring for you medically needs to know what medications you are on. Third, use a pill organizer to dispense your medication daily. They can be found at most any drug store. Fourth, keep a consistent schedule for taking your medications. Last, use visual reminders to make sure you have taken all your medications for the day.

## **As a family member or caregiver, I feel so helpless. What are some things I can do to help with the recovery process?**

Refer to the section on “How can family members help?” in this stroke handbook. Also, attend therapy and ask the therapist for specific suggestions or things to do to help with recovery. Keep a positive attitude and watch your word choice when discussing your loved one. It is important to keep a mindset that there is an “affected side” and a “non affected” side in stroke vs. a “bad” side. Also, do not victimize your loved one, yet empower him/her to regain self confidence by increasing independence. Finally, be sure to discuss progress in relation to where the person started after the stroke. Try not to compare to function prior to the stroke.

## **As a family member or caregiver, I am overwhelmed. What are some ways that I can stay on top of everything I need to, but maintain my sanity?**

Take notes during your loved one’s hospital stay, and get things in writing from others when needed. You can put all this information in one place such as a box or folder. It may be helpful later when this information is needed. Make the hospital room environment as cheery as possible. You may be spending a lot of time there, and it helps to have pictures or flowers to make it seem less like a hospital. Request a pass home prior to discharge if your insurance allows. This will help uncover any unforeseen problems and allow time to review them prior to discharge. As a caregiver, don’t try to do it all!!! You may need to attend support groups, ask for help from others, get time away, and attend to your own physical and mental health. It’s important to maintain a balance of organized yet “go with the flow” attitude.

## **How do other people deal with having a stroke? I'd like some suggestions from stroke survivors on how to handle this difficult time.**

“When I look back at my experiences in rehab, especially in speech therapy, I think the most important suggestion I could offer a person in similar circumstances would be to listen to your therapist and do all they ask no matter how silly or trivial it seems at the time. You are not in the right frame of mind to evaluate the benefit of the work you are being asked to do while you are actually involved with it. I can recall now things that, at the time, seemed so foolish and beside-the-point, but in looking back were of great value. Most of these things dealt with improving cognitive and reasoning skills. Of course, it is certainly as important to respond in the same way to all those who are trying to improve your quality of life. Keep an open mind. Most patients have never had to experience this kind of ordeal before. Don't set or allow anyone else to set unrealistic expectations for you. Rehab is a process that will require you to be committed to a long-term goal.”

Bill Fleming

“At the beginning of my recovery, I felt as though I was on the outside of my life looking in. I was unable to do all of those things that had once been so easy. However, after a great deal of hard work, I am now able to feel in control of my life again. You must be persistent with your therapy program, and never lose hope.”

Dr. Rafiq Rahman

“You've just gotta do the best you can with it. Try to live the best you can and do the best you can. You can't ask 'why me' or cry over it, because then it will just be worse. You've got to accept it and move on!”

George Mosley

# Glossary

## Glossary

**Abnormal muscle tone** - A disturbance in the amount of tension normally found in a muscle. It may be too high (tight) or too low (floppy).

**Active range of motion** - The amount of movement in a joint that a person can achieve by using their own muscle strength.

**Activities of daily living (ADL's)** - Activities include feeding, dressing, personal care, homemaking, and community reintegration.

**Adaptive equipment** - Any device used for the purpose of improving one's ability to perform a task.

**AFO** - Ankle foot orthosis; any brace which controls the ankle and foot.

**Aneurysm** - A weakness in the wall of an artery which balloons out in a bubble-like protrusion.

**Anoxia** - An absence or lack of oxygen.

**Aphasia** - A loss or reduction of language skills due to damage in the brain.

**Apraxia** - A movement planning problem involving a disruption in sequencing of voluntary muscle movements. A transmission problem between the brain and the muscle.

**Aspiration** - The passage of foreign material, such as food and liquid, into the lungs.

**Ataxia** - A muscle incoordination problem which results in a jerky pattern of movement. This movement pattern can interfere with walking or daily living functioning.

**Atherosclerosis** - An abnormal condition of the arteries in which a thick, rough, fatty deposit forms on the inner wall of the arteries and gradually narrows the passageway so that the blood flow is slowed.

**Auditory Comprehension** - The ability to understand what is heard.

**Carryover** - Refers to the ability to retain newly learned skills or information and apply them from situation to situation.

**Catheter** - Thin tube which may be placed in several parts of the body to put material in, drain body fluid out, or take samples or measurements.

**Cognition** - Mental ability to attend, concentrate, learn, remember, organize, and process information in to a logical progression for solving problems.

**Compensation** - Learning to use other than normal means to achieve a goal.

**Continence** - Ability to control bowel and bladder functions.

**Contracture** - Loss of range of motion in a joint due to insufficient movement.

**Craniotomy** - An operation removing a portion of the skull to allow surgical access to the brain.

**Deficit awareness** - A desirable learning and appreciation of the problems caused by the stroke.

**Dysarthria** - Difficulty with talking due to weakness or poor coordination of the muscles of the lips, tongue, or jaw. Speech may sound “slurred”.

**Dysphagia** - Inability or difficulty in swallowing.

**Edema** - Swelling caused by extra fluid in the tissues.

**Embolism** - The sudden blocking of an artery by a blood clot or foreign material which originated elsewhere in the body and was carried by the blood stream to the site of blockage.

**Fine motor activities** - Activities involving small complex movements such as writing and manipulating small objects.

**Fluent aphasia** - A type of aphasia where verbal expression remains normal in speed, but is lacking content. The person is unaware of the language problem.

**Gastrostomy Tube** - A tube placed into the stomach through the abdominal wall. Used for feeding directly into the stomach when the person is unable to eat by mouth.

**Gross Motor Activities** - Large movements of body parts that are involved in rolling, sitting up, and standing.

**Hematoma** - A collection of blood in an organ, space, or tissue.

**Hemianopsia** - A loss of visual recognition and possibly vision itself to one side of space due to brain injury/stroke.

**Hemiparesis** - Weakness of one side of the body.

**Hemiplegia** - Paralysis of one side of the body.

**Hemisphere (brain)** - Relating to one side of the brain, as in right or left hemisphere.

**Hemorrhage** - The escape of blood from the vessels; bleeding into the delicate brain tissue (cerebral hemorrhage).

**Impulsive** - Rapid movement or decision making without using judgment. Hasty, rash.

**Incontinent** - Inability to control bowel and bladder functions.

**Infarct** - A tissue area deprived of blood flow.

**Initiation** - The ability to start an activity or conversation with little or no prompting.

**Insight** - Understanding and integrating factors of a situation.

**Intention tremor** - A tremor that occurs only with voluntary, planned movements.

**Jargon** - Nonsensical words or sounds used in place of real words.

**Judgment** - An evaluation or decision.

**Lability** - The sudden appearance of uncontrolled crying or laughing that is inappropriate to the situation. This is an impairment of emotional control due to brain injury/stroke.

**Long term memory** - The ability to remember things over a long period of time.

**Motor control** - The ability to selectively contract or relax a muscle or group of muscles at will for a purposeful movement.

**Muscle tone** - The amount of tension (continuous contraction) in a muscle at rest. It is felt when a muscle is moved. The quality or quantity of muscle tone has an effect on the efficiency of voluntary muscle contraction.

**N.P.O.** - Nothing per oral or nothing by mouth. A description of the feeding status of persons not allowed by their physician to have food or liquid by mouth.

**Nasogastric tube (NG tube)** - A feeding tube inserted into the nose running down the back of the throat, into the esophagus (food tube) and then into the stomach. Used for people unable to eat by mouth.

**Neglect or hemi-inattention** - Severe lack of awareness of the side of the body or environment opposite the side of the brain injury/CVA.

**Non-fluent aphasia** - A type of aphasia in which there is relatively better auditory comprehension than verbal expression. Use of correct grammar is reduced to its simplest forms. The person may only be able to use one or two words in all situations.

**Orientation** - The ability to know one's location in time, space, and relationship to other people.

**Paralysis** - Inability to move a muscle or group of muscles voluntarily.

**Paresis** - Lack of control of a muscle or group of muscles; partial or incomplete paralysis.

**Perception** - The brain's interpretation of what the senses (sight, hearing, touch, taste, smell) tell it.

**Perseveration** - Continuation of an action that was once appropriate and now has stopped being appropriate. Example: repeating the same word over and over.

**Problem solving** - The ability to logically think one's way through a problem to arrive at a reasonable and acceptable solution.

**Range of motion** - Refers to the specific angles of movement that a joint is capable of.

**Seizure** - A disturbance in the electrical activity of the brain due to damage or electrolyte imbalance.

**Shunt** - A procedure to drain off excessive fluid in the brain.

**Social Security Disability** - Monthly income granted to persons who have paid into the social security system and are confirmed disabled and unable to work for at least one year. Coverage also provides health insurance through the Medicare program if the disability continues beyond two years.

**Spasm** - A sudden involuntary contraction in muscles or blood vessels which disrupt function.

**Splint** - An external device applied to an extremity to provide positioning to help prevent or correct contracture.

**Subluxation** - A partial or incomplete dislocation of a joint.

**Thrombosis** - The development of a blockage within an artery caused by a clot or atherosclerotic material forming at the site.

**Tracheostomy** - A surgical procedure used to make an external entrance to the airway (windpipe) through the neck. Used to aid breathing.

**Tracking** - The ability to follow moving objects with the eyes.

**Transfer** - To move from one place to another.

**Trunk control** - The ability of a person to maintain proper alignment of the trunk and pelvis with movement and at rest.

**Verbosity** - Inability to control the amount of verbalization. Verbalization is often disorganized.

**Vestibular system** - This system is responsible for maintaining balance and equilibrium. Information is gathered from the inner ear, eyes, and sensory receptors of the joints. Dysfunction will result in unsteadiness.

**Visual field deficit** - The inability to visually perceive information in a specific area of the visual field. This may involve left, right, one half or one quarter of the visual field.

**Word finding** - The ability to search for and locate words from the learned vocabulary when they are needed.