HOPE HELP GUIDE
published by
The Stroke of Hope Club, Inc.

The Stroke of Hope Club, Inc., a not-for-profit organization, was founded in October, 1984. Our mission is to work toward increased awareness of stroke prevention, improved community education, and –above all- to provide information, education and support to stroke "victors", their families and friends. The Stroke of Hope Club, Inc. provides services to all stroke "victors", their families and friends, recognizing that no two strokes are the same and no two families coping with stroke do so in the same way.

This "Hope Help Guide" is provided to you as an educational tool. The information to follow is designed to help you and your family better understand stroke and the process of rehabilitation. Stroke victors and their families have reported that the Hope Help Guide was instrumental in assisting them in their journey to the "new normal" of life after stroke.

Our volunteer "Rehab Buddies" are prepared to help you further. The "Rehab Buddy" program at the Stroke of Hope Club, Inc. involves a weekly telephone contact from a volunteer who provides support for a stroke victor and/or a family member. This program has made a huge impact in the lives of many stroke victors and their families.

If you would like to learn more about our Rehab Buddies program, or have any questions about life after stroke, please contact the Stroke of Hope Club, Inc. at: (561) 627-2202. This is our "virtual" phone number. Simply leave a message and we will return your call as soon as we are available.

We also invite you to visit our website: **www.strokeofhope.com.**

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COMMUNITY RESOURCES
For Stroke Victors and their Families

I. For information/education/literature regarding "Stroke", "CVA", "Brain attack", "TIA", "Transient Ischemic Attack", and/or "Cerebro-Vascular Accident":

American Stroke Association: 1-800-553-6321
www.strokeassociation.org

National Stroke Association: 1-800-STROKES
www.stroke.org

Stroke of Hope: 561-627-2202
www.strokeofhope.com

II. **Local agencies providing information and/or services important for Stroke Victors and their Families.**

For more information regarding local programs please contact Stroke of Hope, Inc. at 561-627-2202.

III. Additional support sources:

National Aphasia Association: www.aphasia.org

National Alliance for Caregiving: www.caregiving.org

Family Caregiving Alliance: www.caregiver.org

FACTS about STROKE

Did you know…..

- Stroke is the third leading cause of death in the United States today.
- Stroke is the leading cause of adult disability
- People with diabetes, heart disease, or over the age of 55 years are at the greatest risk
- Stroke is more accurately called "BRAIN ATTACK".
- There are warning signs of stroke (or brain attack), which can help prevent severe stroke or disability:
    - Sudden weakness in an arm, hand, or leg
    - Loss of sensation on one side of your body
    - Loss of vision
    - Difficulty speaking
    - Difficulty understanding of what others are saying
    - Dizziness
    - the "worst headache" of your life

Use **F-A-S-T** to remember the warning signs of stroke:

FACE: ask the person to smile. Does one side of the face droop?
ARM: ask the person to raise both arms. Does one arm drift downward?
SPEECH: ask the person to repeat a simple sentence. Is their speech slurred or strange?
TIME: if you noted any of the above, dial 9-1-1 immediately.

STROKE

The suddenness and severity of its symptoms led the ancients to call this illness “stroke”, believing it to be caused by a stroke of fate or by a stroke of God’s hand. Only in the last century have we discovered the true causes, parallel to those causing heart attacks, hence the more recent term “Brain Attack”.

Recent research has revealed that approximately 730,000 strokes occur in the United States every year. Stroke is the leading cause of adult disability in America. Stroke is the third leading cause of death in the United States, claiming nearly 160,000 lives annually. This fact is why individuals who survive stroke prefer to be called “Stroke Victors”.

Stroke occurs when there is disruption to the normal flow of blood in the brain. Most commonly it results from an obstruction in a blood vessel feeding the brain. These are called ISCHEMIC strokes or attacks. Less often a blood vessel (usually an aneurysm) ruptures, causing a HEMORRHAGIC stroke. Although outcomes may appear similar for both types, they require vastly different treatment. That is why immediate care by specially trained stroke-response terms is critical. CALL 911 at the first sign of any of the preciously-mentioned symptoms.

ISCHEMIC STROKE

An ISCHEMIC stroke occurs when blood flow is interrupted to a part of the brain. There are three types of ischemic stroke: *embolic* which means that a blood clot has formed somewhere in the body and traveled to the brain through the veins and arteries (accounts for 20% of all strokes); *thrombotic* which is a blood clot that forms within a vein or artery in the brain thereby causing reduced blood flow to the brain (Accounts for 60% of all strokes); systemic hypoperfusion (low blood flow) which occurs because of circulatory failure caused by the heart. This may occur during heart attack.

A TRANSIENT ISCHEMIC STROKE (TIA) is also referred to as a “mini-stroke”. Presently, physicians are recognizing that TIA is actually a real stroke event. A patient who experiences “TIA” exhibits some or all of the “warning signs” listed above. Often, these disappear are mysteriously as they occurred, hence the name “transient”. Diagnostic procedures often do not reveal evidence of a true “stroke”. In the past, this “TIA” s were treated

as warning signs themselves of a bigger stroke yet to dome and are therefore treating “TIA” aggressively as a “Stroke”.

Ischemic strokes are treated by surgery (endarterectomy), drugs (anticoagulants, antiplatelet agents, TPA, etc.), and/or rehabilitation.

HEMORRHAGIC STROKE

A hemorrhagic stroke occurs when a blood vessel or an artery ruptures in around the brain. These strokes are seen in 15 to 20% of all strokes. The fatality rate from hemorrhagic stroke is much greater. However, the recovery from hemorrhagic stroke is more typically better then from ischemic stroke. Younger people exhibit hemorrhagic strokes more frequently. These strokes typically occur along with exertion and are associated with nausea and severe headaches. There are two types of hemorrhagic stroke: *subarachnoid (SAH)*, which means a blood vessel at the surface of the brain ruptures and bleeds into the space between the skull and the brain (most often caused by high blood pressure, arteriovenous malformation <AVM>, or head injury); *intracerebral hemorrhage (ICH)*, which is caused by a deep bleed; aspirin must be avoided by those subject to or suffering from hemorrhagic strokes. Hemorrhagic strokes are treated by medication, surgery to repair ruptures or drain bleed area, and/or rehabilitation.

CAUSE of BRAIN ATTACK (Stroke)

This is the great unsolved mystery for many people. The obvious cases of high blood pressure, hypertension, heart disease, cancer, smoking, birth control pills, Lupus, and stress are causative factors for stroke. Recently, it has been determined that Atrial Fibrillation is one of the leading risk factors for stroke, resulting in a three to five fold increased risk. Approximately 15% of all strokes occur in people with Atrial Fibrillation. Symptoms of Atrial Fibrillation include heart palpitations, dizziness, and in some people there are no symptoms. Congenital defects of blood vessels in the brain are often an underlying cause of stroke in children and young adults. Trauma and migraine headache also have been closely identified as possible causes of stroke. Patients who experience stroke, however, will tell you that one or more, all or even NONE of these causes can be linked to their stroke. Thus, stroke continues to truly be a mystery.

Have you alerted other family members about traits or behaviors that might lead to having a stroke? Do they know the warning signs and what to do in case of an attack?

STROKE ALERTS

PRIMARY and COMPREHENSIVE STROKE CENTERS

In 2000, a multidisciplinary group of members from major professional organizations involved with the care of patients with stroke and cardiovascular disease known as the Brain Attack Coalition (BAC) discussed the concept of "stroke centers". The BAC proposed establishing two types of centers: primary and comprehensive.

A primary stroke center (PSC) is defined by the BAC as "having the necessary staffing, infrastructure, and programs to stabilize and treat most acute stroke patients". It was recognized that "although PSCs provide stroke patients with high-quality care, some patients with complex stroke types, severe deficits, or multi-organ disease may require and benefit from specialized care and technological resources not available in a typical PSC. Such patients often require advanced diagnostic and treatment procedures directed by specially trained physicians and other healthcare professionals". According to the Agency for Healthcare Administration (AHCA), the following hospitals are Primary Stroke Centers: Martin Memorial Hospital, Jupiter Medical Center, Palm Beach Gardens Medical Center, Columbia Hospital, Good Samaritan Medical Center, Bethesda Memorial Hospital, West Boca Medical Center, Wellington Regional Medical Center, and Palms West Hospital. (AHCA, 4/2/2012)

A comprehensive stroke center (CSC) is defined by the BAC as "a facility or system with the necessary personnel, infrastructure, expertise and programs to diagnose and treat stroke patients who require a high intensity of medical and surgical care, specialized tests or interventional therapies. The types of patient who might use and benefit from a CSC include (but are not limited to) patients with large ischemic strokes or hemorrhagic strokes, those with strokes from unusual etiologies or requiring specialized testing or therapies, or those requiring multispecialty management.

According to AHCA, there are four Comprehensive Stroke Centers in Palm Beach County: St. Mary's Medical Center, JFK Medical Center, Delray Medical Center and Boca Raton Regional Hospital (AHCA, 4/2/2012). There is not a CSC listed in the report for Martin or St. Lucie Counties.

Once 911 is called and rescue teams arrive at your home, they will stabilize the patient and if they establish that the patient has indeed had a stroke, they will send a "Stroke Alert" to the Primary Stroke Center (PSC) nearest to the patient's home. The rescue team will desperately want to know when the stroke patient or the caregiver believes the stroke has taken place. This is extremely important, as it will influence the care received. Recent developments in the field of heart attack and brain attack include development of the drug "TPA", which is known as "clot buster". If you arrive at the hospital and can establish that you know you have had your stroke within the three hour "window" and receive a CT-scan, at the hospital to verify that you indeed had an ischemic stroke, then you ***MAY*** be a candidate for TPA. Other drugs that prevent the "domino" effect of cell damage have been tested. They have a longer window of opportunity.

By alerting the receiving hospital of a "stroke alert" the rescue team is providing the hospital with the opportunity to assemble their stroke team. The team generally consists of specially trained doctors, nurses, and radiologists, who will prepare necessary equipment and service for the stroke patient's arrival.

Diagnostic tests that are completed upon arrival in the Emergency Room include CT-scan, laboratory tests, and complete physical neurological examination.

Further diagnostic tests that may follow after admission and diagnoses of a brain attack may include MRI (Magnetic Resonance Imaging), electroencephalogram (EEG), Evoked Response, and blood flow tests.

MRI uses a large magnetic field to produce an image of the brain. Like the CT-scan, it shows the location and extent of damage to the brain from the stroke. The image from the MRI is sharper and more detailed.

EEG and Evoked Response tests show the electrical activity in the brain. EEG records electrical signals which are printed out as brain waves. Evoked Response measures how the brain handles different sensory information.

Blood flow tests include ultrasound and angiography. Ultrasound tests (Doppler testing, duplex scanning, and B-mode imaging) give detailed information about the condition of the arteries. Angiography is a special

medical procedure. Dyes are injected into the blood vessels and an X-ray is taken. Angiography gives the picture of the blood flow through the vessels. This allows the size and location of blockages to be evaluated.

Transfer to a Comprehensive Stroke Center (CSC) is determined following consultation between the stroke teams at the PSC and the CSC. Determining factors for transfer include size and type of stroke, among others. The members of Palm Beach/Martin County Stroke Coalition work together to ensure that patients receive the best and most appropriate stroke care.

When a stroke occurs, the individual is first treated at a primary or comprehensive stroke center (see above). This is considered "acute care". A stroke victor does not typically receive acute care for very long. Each stroke patient should anticipate having an initial consult with each of the following services while in "acute care": physical therapy, occupational therapy, and speech therapy. Stroke patients often experience difficulty swallowing as a result of their stroke. This will be assessed by the speech therapist. The goal for each of these therapies at this point is to determine the patient's current level of function. This is vital information which, along with recommendations from the neurologist and/or physical medicine doctor, will help direct where the patient will be sent for rehabilitation. The stroke patient and/or his/her family will also meet with a discharge planner or social worker who will discuss the rehabilitation options. This will be dictated in part by the individual's insurance benefits, as well as the specific levels of function as determined by the therapists and doctors.

"Recommendations for Comprehensive Stroke Centers", Alberts, Latchaw, Selman, et.al., *Stroke*, July, 2005

AFTER THE DIAGNOSIS OF STROKE, THEN WHAT?

Our mantra at the Stroke of Hope Club is “NO TWO STROKES ARE THE SAME”. We cannot tell you for certain what to expect after STROKE (BRAIN ATTACK) has occurred to you or someone you love. Some of the common post-stroke difficulties and/or deficits are as follow:

- reduced motor function and/or loss of sensations one side of body
- difficulty with speech and/or language (aphasia, dysarthria, agraphia)
- impaired visual field and visual perception (NOT vision)
- increased emotionality and mood swings
- personality differences
- difficulty with memory, judgment, problem-solving (cognitive deficits)
- depression (a clinical side-effect)
- seizures
- bladder/ bowel problems
- seizures
- pneumonia (often due to swallowing difficulties)
- dysphagia (swallowing difficulties)

Recovery after stroke is again an individual thing. Unlike other parts of your body, brain cells do not regenerate. Thus it is up to you and your brain to train new areas to complete old tasks. The analogy often used in therapy is one of considering an island with three access bridges. If one of the bridges should go out-of-service, the other two bridges will still get you on and off the island. However, there will be much more traffic, it will take you longer, it will be confusing, and it will take some time to learn your new route. This is the case with recovery after stroke. The information is still within your brain. Your ability to access that information is impaired. Thus, given time and motivation you will slowly feel that improvement.

There is a period of “spontaneous recovery” immediately after stroke. This generally lasts six months, depending upon the severity of your stroke and how quickly you are able to begin rehabilitation. However, rehabilitation will continue for your lifetime after stroke. Do not believe that after just six months or a year there is no room for further gain. Members of the Stroke of Hope Club will testify to the fact that their recovery continues.
There is also medication available to help with many of the post-stroke deficits and disorders. Of particular interest are the new antidepressant treatments. If depression occurs for longer than 3 months post-stroke, see your doctor about medication to assist you in your rehabilitation.

Of course, rehabilitative therapies are available to stroke patients to assist them in their recovery. More on that will follow.

STROKE REHABILITATION DEFINED

It is important to remember that each stroke victor's rehabilitation is unique and specific to the needs of the individual. Some stroke victors are discharged to their home with therapy and nursing support. Most stroke victors, however, are discharged to a facility that offers rehabilitation. These include inpatient rehabilitation centers which may be affiliated with a hospital and short-term rehabilitation facilities located within a skilled nursing facility (SNF). The decision as to where an individual stroke victor will be sent for rehabilitation is dependent on the individual's level of function and his/her insurance benefits. Services at an inpatient rehabilitation center include all of the therapies and are typically described as intensive, meeting twice a day up to seven days a week. Patients must be able to tolerate this type of intensive therapy. Services at a short-term rehabilitation facility, usually as a part of a SNF, also include a wide range of therapies which meet once or twice during the day, 5 to 6 days a week. The length of stay at these rehabilitation facilities is determined by your insurance benefits and by the progress made in therapy. It is very important that you and your family are made aware of care plan meetings which are scheduled at the facility. During these care plan meetings, your goals are reviewed and your progress discussed.

Physical therapy, occupational therapy, and speech therapy are the most common services provided specifically for the stroke patient. As a consumer you should be certain that therapists are licensed and/or certified. Be sure and ask about the therapists' experience, interest in treating stroke patients, and continuing education received in order to remain current with diagnosis and treatment strategies in stroke rehabilitation. A brief description of these therapies is found below.

Physical Therapy and Occupational Therapy:

Physical Therapy (PT) and Occupational Therapy (OT) are often recommended by physicians after stroke, as many stroke victors have difficulty with their arms and/or legs. Walking, balance, use of arm/hand/fingers on one side of the body is often affected by stroke. PT and OT services can be offered in the hospital, rehabilitation center, and outpatient clinic or in your home through home health services. A licensed PT and/or OT should complete a comprehensive initial evaluation to determine the degree and type of deficits the stroke victor is experiencing. PT typically involves increased strength, movement, balance and coordination. OT typically involves use of the upper body, especially hands and arms, and can also

emphasize improved fine motor movements and cognitive skills. OT will also visit the patient's home to recommend adaptive equipment needed.

Speech and Language Therapy:

A wide variety of speech, language deficits and/or swallowing difficulties may be experienced after stroke. The Speech-Language Pathologist evaluates a patient to diagnose which deficit areas need to be addressed in therapy. Dysarthria, Apraxia, and Aphasia (see definitions section of this handbook) are some of the most common deficits. Severity levels between individuals vary greatly.

An important note of caution needs to be added at this point. The greatest factor in limiting success for stoke victors is frustration, especially in the area of speech and language. Acknowledging frustration and helping the stroke victor work through it is a real asset to continued rehabilitation. In addition, stroke victors report that fatigue plays a large role in their success in speaking. Victors note that they perform better first thing in the day and after a "rest".

Emotional liability is a fancy term for being unable to control one's emotions. Recent research has suggested that we control our emotions through "centers" in different parts of our brain. When stroke occurs, these "centers" become disrupted and stroke victors no longer have the control they once did. This adds to frustration and embarrassment. Victors may laugh inappropriately or cry often. Simply recognizing this is part of stroke is helpful to stroke victors. Eventually, control of the "centers" returns, but this takes time.

In recent years some medications have been found useful in enhancing the progress of therapy. Your physiatrist can advise you and/or write necessary prescriptions. Additionally, there are computer programs to assist with speech and cognitive impairments; water exercise programs at many area pools as well as therapy centers. Your therapists may be able to offer these services or help you find them.

As you approach discharge from the rehabilitation facility, you will again meet with a discharge planner who will discuss the specifics of what will follow. These recommendations will be determined by your insurance benefits and progress in previous therapy. This can include:

- home health therapy. Your doctor will order the necessary therapies and nursing care which will be sent to your home.
- Outpatient therapy. Your doctor will order the necessary therapies. You will need to go to an outpatient therapy center to receive this treatment, generally scheduled 3 times a week.

It will be important to know your insurance benefits in order that you can be aware of what services are covered. If ordered by your doctor, you can also pay out of pocket for services not covered by your insurance

You and your family will also need to discuss living options. This can be a very difficult process. The important part is that you are safe and able to continue your rehabilitation.

THE CAREGIVER

Giving care – loving help – to the patient is an essential part of recovery. Nurses, aides, therapists, family members and friends are all a part of the caregiving team. Yet there must inevitable be one primary caregiver, coordinating and direct the others, offering particular comfort and inspiration to the stroke survivor. That job usually falls to a spouse, parent, adult child or significant other. Lifetime roles are usually drastically altered and may create conflicts even as the caregiver strives to cope with the sudden change and to meet the needs of the patient.

Just as brain attacks vary widely in their effects, so do caregiving needs. Trust your own instincts for the most part, but allow the patient to regain as much independence as possible. Regaining old skills may take time, and participation in favorite activities may require some modifications but the results will be rewarding to both of you. We all think first of physical needs in relation to caregiving, but financial and legal affairs must be addressed, a residence may have to be modified to provide a safe and workable environment. Often the primary caregiver is also the primary source of emotional support of the entire family – a heavy load. It helps everyone if others can be involved in specific rolls, such as providing transportation to therapy, shopping, or arranging regular outings. In these days of better primary treatment, it only may be necessary for the caregiver to be aware of limitations the patient doesn't realize!

Stroke support groups offer a unique blend of compassion and practical guidance for the caregiver. Often, stroke victors will state thy do not "need" to attend a support group, but caregivers usually welcome such an opportunity. Thus, do not be afraid to take care of YOU and let your stroke victor know that you do indeed need to and intend to go to a support group. If the victor cannot be left alone, he will simply need to come with you.

Stroke support programs usually offer varied activities for stroke victors to enrich their lives while allowing caregivers the comfort and help of others who have found solutions to problems common to us all (and some not so common!) Informal group therapies foster camaraderie while developing skills; monthly luncheons in fine restaurants restore self-esteem and build new friendships.

CAREGIVER GUIDE

I Have the Right…

- To take care of myself. This is not an act of selfishness. It will give me the capacity to take better care of my relative.
- To seek help from others even though my relative may object. I recognize the limits of my endurance and strength.
- To maintain facts of my own life that does not include the person I care for, just as I would if he/she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things just for myself.
- To get angry, be depressed, and express other difficult feelings occasionally.
- To reject any attempt by my relative (either conscious or unconscious) to manipulate me through guilt, anger, or depression.
- To receive consideration, affection, forgiveness, and acceptance for what I do for my loved one for as long as I offer these qualities in return.
- To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my relative.
- To protect my individuality and my right to make a life for myself that will sustain me in the time when my relative no longer needs my full-time help.
- To expect and demand that as new strides are made in finding resources to aid physically and mentally impaired older persons in our country, similar strides will be made toward aiding and supporting caregivers.

THINK “S T R O K E” ANOTHER WAY

This STROKE has CHANGED your life! Understatement, to be sure!

Changes are scary, partly because things are DIFFERENT now. Maybe you're the person who has experienced the stroke; perhaps you're the loved one--the caregiver. Life that seemed so predictable and so planned, when you were managing it fairly comfortably, somehow does not feel under CONTROL now.

CHANGE brings LOSS (and it can bring some GAINS, too—but in the initial impact, the LOSS often seems overriding and sometimes over powering—that's what you want to know about.)

--and with LOSS comes DEPRESSION -- that dreaded condition. A most common occurrence after a stroke is depression--bringing with it those feelings that range from a general sense of sadness to utter despair and often hopelessness over the real and/or the perceived losses.

Be aware that DEPRESSION is a very natural, and really a very necessary part of your experience and adjustment process right now. It is one of those "steps along the path" in your journey through the changes, losses, and accompanying emotions brought about by this event.

We will re-write STROKE for you, first to clarify for you something you need to KNOW about DEPRESSION, and secondly, to inform you of some thing you can DO about DEPRESSION.

THINGS YOU MUST KNOW ABOUT DEPRESSION AND STROKE

Symptoms especially common in depression are the following:

Tearfulness, crying jags	Difficulty in concentrating
Irritability	Disturbance in sleep/eating habits
Indifference, withdrawal	Fatigue, lethargy
Pervasive anxiety	Low self esteem
Restlessness	Physical complaints

Turmoil in emotional affect is especially typical after a stroke. Organic damage to that part of brain which controls emotions may cause them to seem unmanageable and different.

Reactions to the loss of independence--physically, mentally, and socially—are quite realistic and contribute to very legitimate reasons for depression. Vast readjustments with an accompanying emotional upheaval may occur in lifestyle.

Overwhelmingness of the accumulated circumstances may cause severe immobilization and inability even to begin pulling out of depression toward rehabilitation after a stroke.

Keeping in mind that distorted reality may exist for the depressed person, know that reassurances such as “everything will be ok” or “snap out of it” are not appropriate, and serve only to convince the depressed that he/she is not understood. Keep in mind, also, that living with and caring for a depressed person can be exhausting and very difficult, causing your own depression.

Emotions commonly give rise to these feelings in depression:

Sadness	Guilt and self-reproach	Helplessness
Emptiness	Rejection, loneliness	Hopelessness

Anger often lies beneath these more obvious feelings. Anger is very natural, though often unexpressed and frightening and it can result from any loss

THINGS YOU CAN DO TO TURN YOUR “STROKE” REACTIONS INTO PRO-ACTIVE BEHAVIORS

Share yourself with others. Turn your interest to other people and other activities to alleviate some of the preoccupation with yourself and your own circumstances. We all thrive on attention and you will be pleased and surprised at what you "get back" from "giving of yourself" to others who will cherish your attention and interest.

Talk with others. Let them know how you are FEELING. Talking really helps, especially when emotions are rampant—and they will be while you are experiencing the effects of this stroke. Being able to "vent", just to talk with others who truly listen, can do much to relieve stresses. Support groups, stroke clubs, hotlines may provide understanding, compassionate, safe and encouraging resources. When verbal communication capabilities are very limited, rely on and encourage non-verbal means of expression.

Rehabilitate positively, rejoicing in each small step of progress, patiently recognizing that good days and bad days are a part of any experience.

Open yourself to others as you seek and gain emotional support and understanding from friends, family and professionals; you will not feel so alone. Open yourself to learning as much as you can about strokes and its ramifications to reduce fear or misunderstanding about the unknown.

Know yourself, your limitations, and your resources to guide you in re-establishing a meaningful and manageable life again. Experience your problems as opportunities for growth; know that the pain of grieving your losses and doing your "grief work" are part of the bigger picture, and that, although life will never be the same again, times can be happy once more.

Exercise frequently. Physical and psychological benefits of exercise are well documented. Any sort of physical movement—"a doing activity"—(whatever is most feasible for your circumstances and condition) is more easily under your control than either feelings or thoughts. This can provide a sense of "control" and "mastery" for you.

Keep in mind that people can help themselves most effectively when

encouraged, supported and allowed to reach their own decisions, to do their own work, and to arrive at their own solutions, rather than to have others take over completely.

Regaining some control in your life, whether you are the person who experienced the stroke, or you are a caregiver, is essential. A better understanding of typical emotional reactions and awareness of positive "doing" behaviors—described above—can help you on your way.

Remember, however, that there may be times when professional help is indicated. Self –help is valuable and powerful, but sometimes the most effective stepping stone in working one's way through depression, especially if it is immobilizing, is with professional guidance.

If you need "sometime to listen", or want to know "where to turn", contact a member of your local stroke club, or call your local crisis hotline. Caring, understanding, and help—just a phone call away!

Submitted by Anne Stelter, MSW, Training Coordinator, CRISIS LINE INFORMATION AND REFERRAL SERVICES, INC., former Advisory board member, STROKE OF HOPE CLUB.

NUTRITIONAL GUIDELINES FOR STROKE VICTORS

When we think about diet we too often think in terms of preventing a stroke by reducing the intake of sodium or fat as well as controlling weight through diet and exercise and keeping blood pressure within acceptable limits. However, proper nutrition is also important after a stroke for restoration of previous health and to compliment the rehabilitation. The need for nutrients is increased by the extra demand for energy production and tissue maintenance.

RESTORING HEALTH: Adequate nutrition is important throughout life but the period after stroke may make achieving these goals more difficult to accomplish at a time when normal requirements are altered by illness.

Some areas of concerns are:

CHEWING AND SWALLOWING DIFFICULTIES: It may be necessary to modify the texture of foods offered to improve the ability to consume the high level of nutrients required. Frequently, early in the recovery, modification of texture (such as semi-solid foods and thickened liquids as opposed to thin liquids) may be necessary to assure adequate intake. As the patient progresses, additional foods should slowly be added to include foods form all of the food groups (e.g. milk, meat, fruits/vegetables, and grains)

APPETITE: Encouraging intake is important as well as providing food that can be eaten in frequent small servings to help stimulate an appetite dulled by illness, inactivity, or depression.

VISION: Arrange all food items so that they are in the field of vision. Some assistance may be needed.

SLOW EATING: Serving smaller amounts of food more often as well as using foods of mostly high nutrient concentration is of help. Also a warming dish of insulated glass will keep foods at the proper temperature.

OTHER MEDICAL CONDITIONS: High blood pressure, diabetes, etc. may make it necessary to make additional modifications in the food plan. Consult your doctor or a dietitian if help is needed in this area.

REHABILITATION: the nutritional status of the patient will have a direct effect of the course of the rehabilitation.

MALNUTRITION: the patient who shows little interest in therapy or who tires very quickly should be investigated for possible malnutrition. Adequate calories as well as nutrients are required to fully co-operate with intensive therapy.

OBBESITY: Extra weight makes transfers and mobility much more difficult and so a reduced calorie intake is recommended, however the calorie intake must be high enough to assure adequate intake of needed nutrients. Do remember that is it possible to be overweight AND malnourished so it is not acceptable for an overweight person not to eat for several days just because they need to lose weight anyway.

TO IMPROVE NUTRITIONAL CARE

-adapt food plan to individual needs and abilities
-take patients' preferences as well as social/cultural needs into account.
-keep a record of patient's intake as well as tolerance of food served.
-make sure the patients are aware of the modifications that are necessary in the food plan.

Submitted by Ann Large, R.D., former Advisory Board Member, STROKE OF HOPE CLUB

OTHER LIFE CHANGES

LIVING OPTIONS

The first thoughts of most stroke victor's center around returning home, to familiar surroundings. Managed care is accelerating that process, often overwhelming the caregiver, who wonders how to cope with the disability as well as all the special equipment needed. Therapists will advise of structural changes required (ramps, doors widened, etc.) and order appropriate equipment for the patient. If feasible, returning home is an excellent choice, causing the least disruption to both lives. To lighten the load on the caregiver, there are generally community resources available such as Meals on Wheels, wheelchair transport, day care center, companion service or respite care in your home or at a local nursing home are other options to consider. Check with your social worker, health care professional or local library for phone numbers.

If the caregiver is physically unable to cope, an assisted-living facility nearby should be considered. Although they may sound expensive, their all-inclusive nature makes such facilities a good bargain in many instances. A very important consideration is staying as near as possible to friends, family and social groups of long standing. Stroke is a condition that usually causes the caregiver to become isolated also. Joining a stroke support group can give both a new set of very understanding friends, also.

Finally, some very debilitating strokes may make placement in an extended-care. (nursing home) necessary, if not immediately, then certainly before the caregiver "gives out". Careful financial planning is indicated in all theses situations, but especially the last. Talk to your accountant, lawyer or financial consultant before deciding to sell your home and plunge into a change.

DRIVING

Driving a car is a highly cherished symbol of freedom in our society, so minimally-affected stroke victors are usually insistent about returning to that quickly. Even those more seriously impaired will often set driving as their most important goal. Having that goal is good if they recognize the discipline and work required to achieve it. Driving is a privilege and a responsibility, also, one that must not be taken lightly for one's own good as well as the good of those others on the road.

Some changes that a stroke victor may not notice are those in cognitive and communication impairments. These affect a person's ability to follow verbal directions or interpret a map, for instance. Impaired mobility is more obvious in terms of the victor's ability to make turns, complete stops and contributes to slower acceleration. The one-sided deficits also affect the way a stroke victor views the world, with visual "cuts" that prevent seeing the improvement in these areas as well as the ones you can readily see. It will take time; a year is the minimum recommended interval.

Your physician may not be the best judge of your driving competence. There are driver's training programs available that can assess and help you overcome or compensate for the deficits. Adaptive equipment may help you overcome or compensate for the deficits. Adaptive equipment may help you make the most of the "good" limbs. Your therapist or rehabilitation center can refer you to appropriate help; otherwise check with rehabilitation centers near you.

Public transportation, taxis, friends and especially the transport services set for the disabled offer a safe, reasonably priced alternative to driving. Don't be too proud to accept the rides that will allow you to "Arrive Alive!"

PREVENTION

Prevention is certainly preferable to treatment if you have had a brain attach, even the "mild" TIA, a few lifestyles changes will result in an improved quality of life and better health. Just as importantly, urge family members – especially your children and sibling – to join you, as they are often as much at risk as you. You have heard the litany many times, but it should hold great importance for you now:

- Reduce and control your blood pressure as you
- Get regular aerobic exercise and take blood pressure meds.
- Reduce extra weight with the help of a
- Low-sodium, low fat diet (read those labels!
- Quit smoking (the hardest) with the help of a support group
- Reduce the stress in your life; get a good night's sleep

As Floridians, we live in the "stroke belt" of the United States, an area comprising 12 contiguous states where stroke deaths are significantly higher than the national average. Contributing causes include the high population of elderly; with declining levels of activity and rising levels of eating out, where dietary fats and sodium are seldom controlled. Another large group with special risk factors of diabetes, hypertension, and sickle cell anemia is African-Americans. Our love affair with fast-food outlets (foods inevitably high in fat and sodium) especially puts us at risk. Even our beautiful Florida climate is a contributing factor, as it entices many young people to participate in sports – especially water sports – where trauma-induced stroke occur.

In summary, stay well and take care. Know your risk factors for stroke. And go back to page 5 and get very familiar with the "warning signs" of stroke.

STROKE DICTIONARY

Commonly used Terminology in Stroke Rehabilitation

acalculia: impairment of the ability to manipulate numerical symbols; due to brain damage.

agnosia: impairment of the ability to perceive and differentiate stimulus patterns, although the sensory mechanisms is intact.

1. Auditory agnosia: inability to differentiate sounds.
2. Auditory verbal agnosia: inability to differentiate spoken words.
3. Visual agnosia: inability to differentiate visual stimuli.
4. Visual verbal agnosia: inability to differentiate written words.
5. Tactile agnosia: inability to differentiate the shape of objects through the sense of touch.

agraphia: impairment of the ability to express ones self through writing; due to brain damage and not as a result of neuromuscular impairment.

alexia: a form of aphasia: impairment of the ability to comprehend written verbal stimuli due to brain damage. Sometimes this term is used to denote complete impairment, the term dyslexia being reserved for partial impairment.

aneurysm: a sac formed by the dilation of the walls of an artery or of a vain and filled with blood.

anomia: a symptom of expressive aphasia characterized by loss of the ability to use nouns

aphasia: impairment of language functioning associated with localized cerebral pathology

apraxia: an impairment of the ability to carry out voluntary movements of the mouth.

arteriosclerosis: a condition marked by loss of elasticity, thickening and hardening of the arteries

auditory memory span: the number of separate auditory stimuli successfully presented that can be accurately recalled immediately

after presentation. The stimuli presented to determine auditory memory span are usually spoken words or numbers.

CVA: (cerebral vascular accident) a lesion of the brain resulting from internally caused blockage of or damage to the blood vessels supplying it.

diplopia: the seeing of single objects as double or two; double vision.

dysarthria: the imperfect articulation of speech.

dysphagia: disturbance of the ability to swallow.

edema: the presence of abnormally large amounts of fluid in the intercellular tissue spaces of the body.

embolism: the sudden blocking of an artery or a vein by a clot or obstruction which has been brought to its place by the blood current.

expressive aphasia: a form of aphasia in which the ability to produce oral, written and/or gesture language is impaired.

functional performance: a patients ability to respond to everyday situations; distinguished from clinical performance.

global aphasia: a form of aphasia in which impairment in all language modalities appears complete. This term is sometimes used to denote severe impairment in all modalities as well.

hematoma: a cyst or swelling caused by a shedding of blood under conditions that prevent its escape from the site of the hemorrhage.

hemianopsia: blindness in one half the field of vision in one or both eyes.

hemiplegia: paralysis of one half of the body:
"right hemi" on right side of the body
"left hemi" on the left side of the body
bilateral or double: paralysis of both sides of the body resulting from two separate lesions occurring either simultaneously or at different times.

Interventional Radiology: Interventional radiology assesses what caused the a blood clot in the brain, such as a clogged carotid or other artery,

	and can correct the underlying problem to prevent future strokes from occurring.
jargon:	attempts at oral or written language which carry no meaning to the listener or reader. Jargon may be interspersed with meaningful words. Oral jargon may be emitted with meaningful inflection but meaningless content.
lability:	excessive laughing or crying; associated with brain damage.
orthotics:	that area of rehabilitation concerned with the design, adaptation and fitting of self help devices.
paralysis:	loss or impairment of motor function due to a lesion of the neural or muscular mechanism; also by analogy, impairment of the sensory mechanism. (sensory paralysis)
paresis:	a partial or incomplete paralysis
perseveration:	1. inappropriate oral or graphic repetition of a response. 2. production of a response that was previously appropriate and reinforced when it is no longer appropriate
Stroke Teams:	Stroke teams generally consist of emergency room physicians, neurologists and interventional radiologists.
tPA:	Tissue plasminogen activator (abbreviated **tPA** or **PLAT**) is a protein involved in the breakdown of blood clots. Because it works on the clotting system, tPA is used in clinical medicine to treat embolic or thrombotic stroke. Use is contraindicated in hemorrhagic stroke and head trauma. Must be administered within 4 hours of the onset of a stroke.