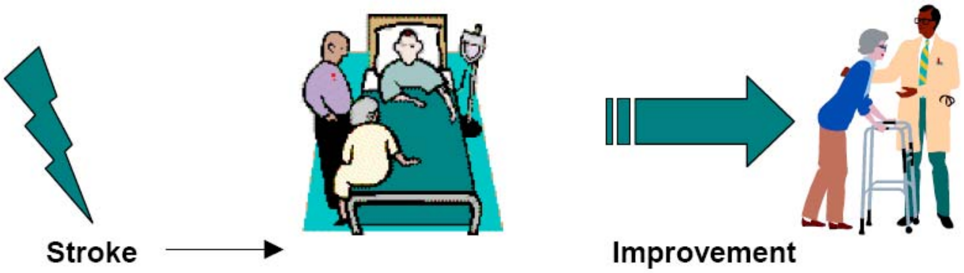
STROKE CAREGIVERS

HANDBOOK

"What do I do and how do I do it?"



Acute Care **Rehabilitation**

Written by: Experienced stroke caregivers for the inexperienced stroke caregiver.

The handbook was a project by members of the Stroke Network.

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We would like to acknowledge the many people responsible for making the Stroke Caregiver Handbook happen. Many members of The Stroke Network, mainly lots of experienced stroke caregivers and a few stroke survivors were responsible for contributing, writing, editing and typing; everyone collaborated. Below are listed some of the people that people that made significant contributions:

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We want to acknowledge these members' efforts and thank them very much for their valued contributions to the Handbook.

Thank You!

The Stroke Network

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Disclaimer:

We are not medical professionals, but only seek to share our experiences and opinions. Always confirm specific suggestions with your doctor.

You can register with our organization and ask stroke caregiver questions by asking them in our caregiver forums, either on the message board or mailing list.

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CHAPTER 1

Stroke: An Equal Opportunity Attack

Who? Where? When? Why?

Many questions … few answers in common Stroke … cerebra-vascular accident … brain attack! You can be anywhere, doing anything and Stroke can attack. Stroke doesn't discriminate. It has NO regard for where you are or what you are doing. In a matter or seconds you can go from being as next to perfect as one can be to being encased in a body that no longer is able to perform life's most basic functions and everything in between. Various physical and mental abilities leave – sometimes temporarily, sometimes forever.

Stroke has NO regard or respect for age, race, creed, color, intelligence, accomplishments, or the lack thereof. You and those around you may not even be aware of what is happening nor know what to do in this most critical of times. You may have a warning in the form of a TIA (transient ischemic attack, a brief occlusive circulatory event similar to stroke, but usually with no permanent in effect) or a "small stroke," then you may have THE BIG ONE; or you may have THE BIT ONE, with little warning, followed by TIAs. It's a very individualized experience:

> *Stroke is the #1 disabler of Americans, yet seldom two people are affected the same way.*

All strokes are caused by an interruption of blood to the brain, so there may be symptoms in common, but since everyone's brain is different, so is practically every stroke. In general, each journey down the road to recovery is different too, and no one can predict at the beginning how rocky or smooth it will be, how long it's going to take, and what lies beyond. The situation may seem quite dark and bleak at the onset, but that may only be because you feel as if you're in a tunnel! Don't give up! A sunny day may be just a short distance down the track.

Different for all Folks but only 2 Kinds of Strokes

While, typically, neither two strokes nor their resulting effects will appear to be the same, there are really only two only two basic kinds of stroke causing these highly diverse problems. The blood supply to the brain is disrupted or diminished, and that situation comes about because of:

1. blockage (a "block")
2. bleeding (a "bleed")

The "block" can be a blood clot, fatty material or any foreign matter getting stuck in an artery like debris-laden water through a clogged pipe: at most, only a trickle of blood can get through, and the brain needs more then a trickle to deliver the required amount of oxygen to function properly. These strokes can also be called thrombolic (cerebral thrombosis, a clot formed at the site of blockage), embolic (embolism, a clot, air or foreign object formed elsewhere that travels to the site of blockage) or ischemic (a catchall word for any type of blockage).

There is also some evidence, though rare, that vessels can spasm or contract and shut off blood flow, causing a blockage of blood to the brain. A "bleed" occurs when a blood vessel bursts, allowing blood to flow into the brain or its surrounding area. Other terms associated with bleeds are hemorrhage and ruptured aneurysm.

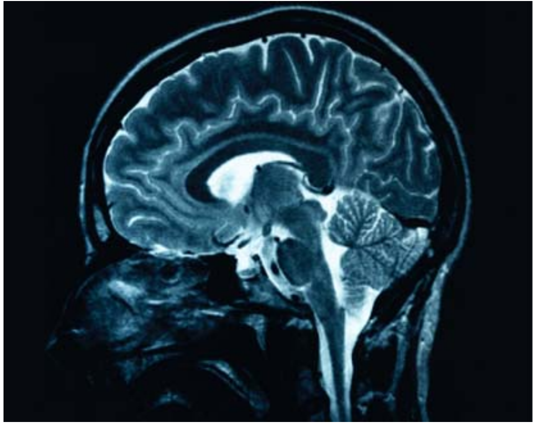
The diagnosis doctors will generally write on the patient's chart that it was a CVA, or cerebrovascular accident. The description of the CVA includes location of the stroke: cerebrum (right and left hemispheres), brainstem or cerebellum. Though all these and other parts of the brain operate symbiotically and to some degree share functions, there are usually distinct problems associated with each section, where typically, like snowflakes, no two persons are alike. .An injury in the right hemisphere will affect the left side of the body, quite often causing total paralysis (right – sided hemiplegic) or partial paralysis (right sided hemiparesis), and vice versa for the left hemisphere.

Because often, the left hemisphere handles language skills, frequently those stricken in the left hemisphere have speech and/or comprehension problems. The brainstem controls the vita autonomic human survival functions, so there may be paralysis on both sided and/or a coma, low level of consciousness or impaired breathing. Most balance and coordination is controlled in the cerebellum so abnormal reflexes and balance problems will result from an injury there.

While a stroke is a problem by whatever name you call it, it's important to know what kind of stroke your loved one has had, what the probable cause was, and what symptoms can generally be expected. Early on, have a doctor highlight on a drawing of the brain exactly where the problem occurred and the fancy name assigned to it. Have the doctor explain what body functions are controlled in that part of the brain that has been damaged. You'll have enough problems without having to appear dumb every time a new doctor, nurse, or therapist asks the inevitable: *"And what kind of stroke did we have?"*

How Do MDs Know It's a CVA?

Its alphabet soup times in the emergency room. A CAT (often called just a CT scan) or MRI scan will usually confirm the diagnosis. Whether CAT or CT, it is pronounced *"cat"* and stands for Computerized Axial Tomography or just Computed Tomography. MRI is pronounced *me-are-eye* and stands for Magnetic Resonance Imaging either will help diagnose a hemorrhagic stroke. But in the case of ischemic stroke, often CAT scans are inconclusive, whereas in an MRI, a clot will show up nice and clear, such that a doctor will know if they can safely administer tPA, *tissue plasminogen activator*, the clot-busting drug. If deemed apropos, it must be administered within three hours of the onset of the stroke, and if mistakenly given to a victim of a bleed-type stroke, death can occur. But, if given quickly under the correct circumstances, tPA can greatly reduce damage from stroke, and even save a life. Therefore, it's important that the ABCs of stroke be followed in order.



Later on, the MDs will go about the business of finding out if the stroke was caused by a blood clot, why it happened, and how does the problem get fixed (if it can be fixed). Another stroke is a possibility if the underlying problem isn't solved. Blood clots from the heart, for instance, may be investigated via electrocardiograms (*EKG)* and echocardiograms (ultrasonic *"videos"* of the chambers and valves in action, to uncover places where a clot might form).

There will be many blood tests: some to rule out clotting disorders, some to measure levels of various enzymes and other metabolic factors and others to monitor the thickness of the blood. Medications may be given to thin the blood and correct irregular heartbeats. Decisions might need to be made as to whether surgery will be required and when. If possible, it's often best to put off surgery until significant recover from stroke can be affected.

Although there are just two basic types of stroke, there are many causes from stroke, and many tests to determine cause. However, because the brain is so complex, there will be situations where the doctors simply cannot determine the cause, and will treat the patient according to best judgment. BUT, particularly if the stroke victim is not elderly (and more then on-third are not), a diagnosis should be determined and given, and – if the cause is not readily evident – the patient should be undergoing a battery of tests to determine cause. If you are being told that no one knows why your loved one had the stroke, and no diagnostic tested are being performed beyond the CT and MRI, ask why further tests are not being administered.

Keeping Hope Alive for the Challenges Ahead

One thing all stroke victims have in common is that life will forever be changed in some way. In addition, everyone close to the victim will experience a life-altering adjustment. No family member or good friend escapes the reach of this paralyzing agent. In addition, the degree of recovery can be in direct proportion to the amount of support put forth by the family-and-friend network.

Once you've been assured that the stroke's threat to life has waned, be wary of statements from people (often medical professionals) who say there is no recovery after **"x"** amount of time. For many, recovery continues for years, and sometimes a lifetime. Recovery usually comes more quickly during that first year, but seldom ceases. The brain continues to form new pathways as it heals, and there will be times when recovery is great and times when it slows.

If you are facing a situation where your loved one has been felled by stroke, it is very important to understand that, in most cases, nobody (not even the most experienced medical professionals) can really predict how much the survivor will or will not recover. No matter what you are told, stroke recovery is very unpredictable and varies with each individual. Try to take each day one at a time. Take job in each moment of progress, and know that there is always room for hope. Sometimes neurologists and other doctors, even though knowing their territory very well, will communicate through statistics, and their talent in understanding the complexities of the brain does not necessarily extend to understanding the emotional needs of the new survivor and their family. We're complex too! In addition, we don't need to be frightened by someone rattling off the statistics of average recovery or possibility of recurring stroke. As we said, every stroke is different. And we certainly don't want to be thrown into a head called "*average*".

Stroke Care: An Unwelcome Job Opportunity

It's not a job you apply for. Chances are, if you already employed; you don't need or want another job, much less this one. Usually you have no prior experience, you don't know the language, you don't have the proper tools to do it, the pay isn't compensatory to the task, it may come at a time in your life when you don't have the energy required to do the job well, you may be expected to do it without giving up all the other jobs you may have, but there IS job security – as it may last forever!

It's like you're on your way to the restroom at the theater on opening night, and someone says, "*YOU!*" The star is sick, the conductor hasn't shown up, the stagehands have gone on strike, and you've been tapped to step in and make sure the show goes on for 20 years. If you don't, someone dies (or so you're led to believe). Caregiving isn't like parenthood where you have had nine months to prepare. You were once a kid, and you've seen millions of parents in the act of doing decisions you can just say no to, like when you were threatened with not having your kid in Scouts unless you became the scout leader. So? The kid can play soccer and not be a Scout. This is a bigger deal. Stroke offers few options.

Suddenly you're front and center stage in the wrong outfit and totally clueless. Quick, someone give that person a handbook!

CHAPTER 2

Acute Care

Emergency Room – A Matter of Life or Death

Checklist

✓ Within 3 hours of onset of stroke, get CT & MRI scans and c evaluation for possible treatment with tPA (clot buster drug) – if this treatment is appropriate and given, this can save a life, or save the survivor from a lifetime of disability.

✓ Be certain of drugs and dosages being taken by victim and take steps to verify medical history as accurately as possible.

✓ Call a friend to be with YOU. Realize you are in shock and two pairs of ears are better then one. Someone (preferably one with a clear head) must take notes.

When the new stroke victim is in the hospital, probably first in intensive care and then in regular care, that is when the designated caregiver has to step to (or be pushed up to) the plate so the game can go on. In this age of insurance cutbacks and managed health care, every hospital patient needs an advocate to help look out for their well-being. A stroke victim, because they have suffered an attack to the brain, may have more than the usual amount of difficulty with communication, comprehension and of course, mobility. A team of advocates is needed!

First job assignment: Delegate assistant advocates.

Intensive Care – Be Faithful

Checklist

✓ Take care of yourself first.

✓ Take mountains of notes.

✓ Keep ALL records in a safe and easy-to-find location.

✓ Contact victim's employer to determine benefits.

✓ Don't pay any bills yet, other then meeting required deductibles.

Chances are that during this stage, friends and family will come to your aid. There are cards, flowers, concern, attention, food, visitors, and offers of help. TAKE IT ALL! Especially the offers of help. Line up people to be with the patient, in shifts, to take notes when doctors appear, to remind nurses and aides that if they had read the chart, they'd know this patient cannot more one side, etc. Do NOT try to do it all yourself. This is going to be a long haul. You'll need to conserve your energy and get plenty of sleep (ask your doctor about drugs to assist in sleep, if necessary, to insure this happens). Don't allow someone to get rid of his or her guilt and sense of duty by just dropping off the lasagna. The answer to *"Is there anything I can do?"* is ALWAYS *"Yes."* (Freeze the lasagna for use later. You may get ten the first week, but chances are you won't see another one for the next ten years). Don't forget to thank profusely as you come up with another small task to be done. *"Pick up stamps at the post office, and take in dry cleaning, etc. PLEASE!"*

Keep a notebook. Better, keep two notebooks. Label them appropriately. Caregiving 101, which will be the toughest course you'll ever study. Invest in a three-hole punch if you don't have one, a couple of tab separators. Save every scrap of paper and document. Use one notebook for notes (with names, dates, and times) from every encounter with any and all medical personnel. You may also want to utilize a tape recorder (ask permission to use it – *"Can I record this? I always get things mixed up!"*) to have a more accurate record of doctors' orders or answers to questions you ask. It can also save a lot of grief when coming home with a survivor who "remembers exactly" what the doctor said.

Use the other notebook for all medical records and correspondence, insurance receipts and medical bills. You are entitled to copies of all test results and medical records. Sign a release and keep them in the notebook. Always keep an up-to-date list of all medications, dosages, and prescription filling histories handy. It will be needed every time you see a doctor, therapist, or have to have the stroke victim hospitalized. It might help to create this list on a computer, so it is easy to update and print. Likewise, a scanner can be used to scan and print out copies of medical bills to send to the insurance company. Saves making copies, and keeping a backup on a floppy disk gives one extra place to look for receipts that are "lost".

And, if all this organization is simply too much for you at this very stressful time – see if someone can help with this task, else, find yourself a big box, and deal with it when your head is clearer. Store the box in an easy-to-find place. There will come a time when you will be glad you took five minutes to do this.

Do NOT pay any bills before the insurance company goes through their entire approval process – which may be months in the making. If the insurance company disallows any payment, it is YOUR RIGHT TO APPEAL that judgment. One major insurance provider admitted that 98% of all judgments are reversed when appealed. Once you pat $1 of a bill, you are claiming full responsibility for that bill, and once you pay a doctor or hospital yourself, you will spend years trying to get that money back from the insurance company, if at all.

Hospitalization – Be Vigilant

Checklist

- ✓ Ask questions – make sure they're answered clearly to your satisfaction.
- ✓ Arrange for a swallow assessment.
- ✓ Physical therapies begin now – be proactive.
- ✓ Health Care Proxy, Powers of Attorney, Do Not Resuscitate (DNR) Orders should be negotiated, as appropriate.
- ✓ Maintain a positive attitude, but be realistic.

✓ Don’t allow negative comments in front of the patient. They may not be able to speak, but can hear. They may also understand.

✓ Make hospital environments cheery with the appropriate comforts of home.

This is no time to be shy and demure. There are times in life when it’s smart to pretend to know what you don’t. Not now. In the schematic of a stroke time line, you’re the equivalent of a two-year-old – so act like one. Ask *“Why?” “How come?”* and *“What for?”* a hundred times a day. Throw a tantrum if things don’t go the way you think they should. Be a tattletale and go to authority figures if those beneath them misbehave. (Also, give thank you in the form of hugs and complimentary notes to those in charge, telling them who were especially good.) If you can’t transform yourself into an aggressive, in-your-face, don’t –give-me-any-guff type of personality, call in a *“big brother”* to help fight your battles. But don’t be a whiner. Nobody likes a whiner at any age. You are fighting for the life of someone you love, and you deserve respect from everyone.

Stroke may be hard for you to swallow emotionally, but, physically speaking, swallowing may be the survivor’s first problem. Muscles on one side may not be working properly, and the opposite of what you think is true: the thinner the consistency, the harder it is to go down. Water and think liquids come back up or, worse, aspirate into the lungs. Foods may need to be pureed until a swallow test can be done. It’s sort of like a moving X-ray where therapists watch as dyed liquids are ingested to see where they go – successfully down the esophagus, or unsuccessfully elsewhere. Only after they pass the test should a stroke victim be allowed real food. If they flunk, don’t despair! That doesn’t mean they’ll never eat again. The swallow muscles can often be therapeutically rehabilitated just as the bigger ones can.

Physical, occupational, and speech therapies should begin in the hospital, as soon as the patient is medically stable enough to tolerate them. To reduce their descriptions to the lowest possible terms, physical therapy takes care of the legs, occupational therapy takes care of the hands and arms and personal care skills, and speech takes care of verbal communications.

Occupational therapy may be the hardest concept to figure out because at this stage it has nothing to do with one's occupation. It doesn't matter if the patient is a doctor, lawyer, or Indian chief. After a stroke, their main job is to learn how to dress, brush teeth, and learn life's basic skills, coping with the disabilities the stroke has handed them. That's the job of the occupational therapists.

It's important that all nonworking parts be put through the motions they would do if they were working normally. These are called Range of Motion (ROM) exercises. Impress the therapists by asking them to teach you how to administer these. They can also give you instructional sheets to keep in your notebook. This will be your first hands-on job since you're the one with two working hands. Jump in and keep the patient's limbs loose! Besides being valuable physically, it will send a strong message of love and commitment that will be missed by no one.

If the brain recovers enough to tell those limbs to move again, they must be ready to respond. *"I forgot"* is seldom a good excuse in any situation, so move on in and don't allow muscles to forget their moves. **Riddle***: What is life's greatest luxury that you will have more of while the stroke victim is in the hospital, but you won't realize it until the patient is home and then you'll have none of it.*

Answer: *Time!*

Take advantage of that little lifesaver on the hospital nightstand called the telephone and get your lives in order before time runs out. Here's who should be called to hear your call for HELP:

The hospital social worker:

Do you have a Durable Power of Attorney in your loved one's will? You will need both a regular (financial) Durable Power of Attorney AND a Medical

Power of Attorney. Get the social worker to access the hospital's Notary Public (this should be free) and have these two forms signed. Do not leave an ending date for the term of the contract. This may legally be left open.

The employer of the stroke survivor:

Speak to the immediate supervisor and to the Human Resources person-in-charge. Get names and phone numbers. Discuss Long-Term Disability, Sick Leave, and Social Security Disability with them. (The social worker above may be helpful in this regard as well.) Find out how much they can do for you, and let them do it. Remember the answer to the question, *"Can I do something for you?"* is always a resounding *"Yes!"*

Social Security office:

Look in the phone book for the local phone number, or you can find Social Security online at *http://www.ssa.gov*. Find out what benefits are available and how to go about applying for them. This process takes months. The paperwork is monumental, but once the application is approved, the benefits pay back to the date of the beginning of the disability. Get it going while you're sitting bedside.

Insurance company:

Get the name and DIRECT phone number of a caseworker you can call regularly. They may become your best friend. They may cringe every time they hear your name, but recognition is better than starting anew every time you will have to call.

In addition, while you're sitting in the hospital room, look around and see how it can be made more cheery. On a bulletin board, display get-well cards, post photos of family members, your home, favorite pets, a beloved truck, children's or grandchildren's art work. Bring in a little radio set on their favorite station; a Walkman with tapes of music they like is a good idea (make sure it's durable – they land on the floor a lot). A calendar with birthdays and holidays noted is nice, and celebrating all is even nicer. Make a sign-in sheet for visitors so you know who came and when. You can't reply on the patient's memory or ability to tell you who was there. Sign in yourself and sign some guilt away later when you count up how often you were there for your survivor!

That dreadful call button may cause more problems and frustration than all the stroke disabilities put together. '*Push the button, get help'* may seem elementary, my dear Waton, but to a stroke survivor it can be as complex as calculus. It doesn't help that those on the helping end of the button frequently forget that the survivor has a communication problem to begin with. Mastering the call button may take you the equivalent of a Master's degree in teaching skills. Then the staff shift changes, and you have to start all over again.

First, make sure the button is locked on the working side of the patient so they can reach it. It's on a cord; tie it to the bed rail. Twist ties work well for this purpose. Put up a sign reminding aides that one side (of the patient) is not working, and call buttons, water pitcher, etc., must remain on working side. In many areas of the country, hospital workers are often in Hispanic origin and speak limited English – if you have a friend who speaks Spanish, ask them to help you make signs in Spanish as well, if this is appropriate. Another sign saying *"Unable to Speak"* will be helpful because big signs will be read before charts. Sometimes it seems charts are never read.

Make sure there's a note at the desk receiving the call (from the call button) that your survivor may not be able to respond to just a verbal *"May I help you?"* Practice, practice, practice with the patient to see that they know how to use it, when to use it and what the

response will be. If the button is located on the same device with the TV controls, put apologies on that list of practice items. Approximately 150 times a day they will push the help button when they're trying to change the channel!

Common Early Problems – How to Deal with Them

Checklist

✓ Aphasia
✓ Subluxation
✓ Skin breakdown
✓ Loss of bladder and bowel function
✓ Depression/emotional issues

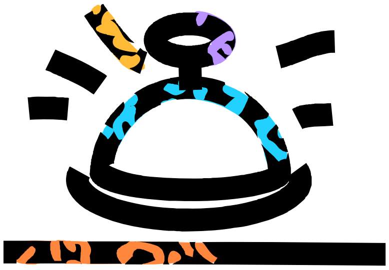
Aphasia: Difficulty Communicating

Aphasia is the medical term used to indicate a communication impairment that results in an inability to express oneself by speaking, writing or gesturing (expressive aphasia) and/or an inability to understand written or spoken language (receptive aphasia). This typically happens to those who suffer a stroke that affects their body's right side. The range of severity varies from patient to patient. Each person with aphasia has a unique set of speech and language problems. It may mean complete loss of speech (sever aphasia) to just an occasional difficulty finding the right word or using an incorrect word (mild expressive aphasia). Receptive aphasia problems may range from an occasional misunderstanding of a word to a complete inability to understand all words.

Most individuals with aphasia are competent mentally and have not lost intelligence or common sense, which makes aphasia a very frustrating disorder. They know what they want to say; they just have trouble putting their thoughts into speech or writing.

The good news is that aphasia doesn't get worse unless there's another stroke or brain injury. Almost all people improve. How much and when it will happen falls into the *"each survivor is different"* category. The primary goal is to learn to cope with the problem and communicate effectively despite the aphasia. To reach this goal, a speech therapist is an absolute must.

Some helpful hints for dealing with aphasia:



1. A call bell (like those at hotel desks), bicycle horn or other noisemaker can be used by the survivor to signal that something requires attention.

2. A laser pointer can be useful.

3. A pictorial dictionary, basic letter boards and picture boards help the patient express their needs. These can be made with a computer using large type and clip art. Elementary school flash cards can be used in a variety of ways.

4. Index cards can communicate most commonly needed items and expressions:

   <u>Bedpan</u>, <u>Water</u>, <u>Thank you</u>, <u>Sorry, I love you</u>, <u>Help.</u>
   Laminate them to last longer. Labels on all objects in the room that they may want to use: telephone, lamp, TV, glass, book. Name

everything you touch as you use it. Aphasiacs frequently lose the names of objects or numbers. They may call everything a "*key*" or person's name and although they know dinner is a six, they may call it "*ten o'clock.*"

5. Speak slowly and clearly (not loudly, they can still hear), one person at a time. Being aphasic in a roomful of people is like having that many televisions all set to different channels at the same time. It's impossible, confusing and upsetting to follow any one plot.

6. Assume the patient can understand and don't say anything negative, or what you wouldn't want them to hear, in front of them.

7. Encourage the patient to talk even if the words aren't correct or are just repeating what you say. Not talking for fear of embarrassment is worse then trying and not doing it well. Try not to answer for the individual, as practice is necessary for improvement.

8. Often a stroke survivor who cannot speak can sing. If you're one of the rare breeds who can sing the national anthem, go for it!

9. Keep the TV on ESPECIALLY when there's no one around. If you have the TV option for captions of words being spoken, use it – it's a good stimulus for the brain.

10. The American Heart Association has some good booklets, such as Caring for a Person with Aphasia: 1-800-242-8721; *www.strokeassociation.org/*. Other good resources are The National Aphasia Association 1-800-922-4622; *www.stroke.org* and the National Institute of Neurological Disorders and Stroke: 1-800-352-9424; *www.ninds.nih.gov.000*.

Subluxation: Dislocated Shoulder

Support the shoulder of the affected side, don't let it be left hanging, the arm's "dead" weight will cause it to pull out. Hospital therapists should be providing for this – if they are not, by sure to inquire as to why not. Have an occupational or physical therapist explain and demonstrate the proper resting of the affected arm on a pillow to aid in subluxation prevention.

Skin Breakdown

Protect skin from breaking down by moving the patient often, keeping the skin clean, aerated and dry, and having any red spots or sores treated as soon as they appear. The use of a bedpan frequently may cause skin irritation. Adult diapers may be a better idea.

Loss of Bladder/Bowel Functions

Often after a stroke, survivors find it difficult to pass urine or are unable to control when the urine is passed, and the same is often true of bowel movements. While this could be caused by damage to the part of the brain that governs control, it may not be a problem of incontinence, but a problem of communication. The patient may be unable to communicate the need to empty their bladder. It is important that the caregiver be sensitive to this situation and work with the nurses in charge to reestablish a normal pattern.

Depression / Emotional Issues

Stroke, like death, represents a catastrophic personal loss. The only way to heal, to be able to cope, is through a grieving process of several stages. There is (in no particular order) shock, anger, relief, depression, denial, mourning, acceptance, and a moving on. Grief is a very personal experience that takes time and work. In addition, there is no socially acceptable way to grieve for a person who hasn't died. Through the patient should be encouraged to grieve their loss, it is a natural catharsis and therapeutic towards their getting on with life. Stroke can be more devastating than death because there is a living reminder of the person who used to be. Depression is the most common normal reaction, and anger and frustration

fall right into the line. For stroke survivors, the depression issue is often increased because stroke can greatly alter brain chemistry – and literally depletes the survivor's brain of the natural chemicals that control depression. The only way to get beyond feelings of anger, guilt, and sadness is to experience and express them, and to seek medical advice about possible antidepressants for the patient (and for yourself and many of these principles might apply to you too). Gradually, with compromise, understanding and patience, and with the help of family, friends, doctors, counselors and even antidepressant drugs, coping will take place.

Conclusion of Acute Care

It's important for the caregiver to know that by virtue of the fact that you love the stroke victim, you have everything you need to make the right decisions that must be made during emergency room, intensive care, and acute care in the hospital. Despite the shock, sorrow, and terror you are feeling, the caregiver must ask many questions, challenge medical advice, research alternative options, get more opinions and act on your own common sense. It certainly doesn't make it easier that you're physically exhausted and emotionally zapped. Be aware of the possibility that the doctors, nurses and therapists do not know it all. Insurance limitations and professional ego, and often NOT the best care possible for the stroke patient, may be the guiding factor in their decisions. Only the caregiver's common sense, commitment to the survivor, personal observation, courage and research will give you the insight to know whether or not the care that is given is indeed best for your loved one. Trust yourself, and don't be embarrassed or afraid to fight for what you believe is to be right.

CHAPTER 3

Moving On to Rehabilitation

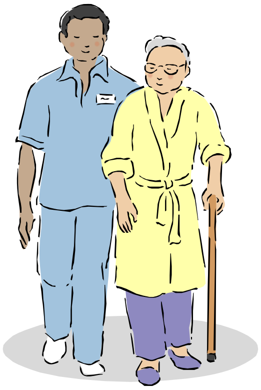
Selecting a Rehabilitation Facility

Checklist

Select the best possible rehab facility for your loved one based on:

- ✓ Reputation
- ✓ Recommendation
- ✓ Personal Visitations
- ✓ Geographic Location
- ✓ CARF accreditation

After the stoke victim has been in the hospital long enough so that their insurance can declare them a survivor – and a medically stable one at that – it will be time to move on to rehabilitation.



How does one decide where to go to get the best possible rehab? If given a choice between inpatient rehab, outpatient rehab or even *"in home"* rehab, most caregivers who have been there, done that, will advise you to not even attempt outpatient rehab until the patient has been through at least some inpatient. The period after hospital discharge is stressful enough without having to deal with the additional stress of transporting a patient who isn't very mobile and may be very weak to rehab several times a week. More than likely, this is a decision that is driven by one's insurance coverage. However, inpatient rehab is worth fighting for with the insurance company, in the even this is not initially offered. Often just a personal meeting with the survivor's primary care physician, neurologist and/or physiatrist is all it takes to enlist their help in making this recommendation become reality. If insurance continues to refuse an inpatient program, the next step to fight for is in-home rehab, when therapists come to your home, making early therapy much easier on caregiver and patient. This is a temporary solution until the patient gains sufficient recovery and strength to more easily get to outpatient rehab.

A professional photographer once advised that to obtain the best possible photos, you just have to buy the most expensive camera. The pricier the lens, the higher the quality the resulting photos. We're here to tell you that insurance providers and doctors don't shop that way for rehabs. Insurance will go for the facility with the lowest price (you get the picture) or the facility that will cut them the best deal (sometimes the one most desperate for business). In addition, some doctors have been known to steer patients to the facility in which they have some sort of financial interest. Therefore, it's important to do your own research to get the kind of results that will please you, and then fight insurance to pay for it. If insurance coverage is through one's employer, one effective measure for bringing the pressure against a stubborn insurance company is to contact the human resource director or union representative at work. Insurance providers tend to listen more carefully when the one who is purchasing large quantities of their product starts talking. Therefore, in the end, the rehabilitation facility you select may not be picture perfect, but you should have no doubts that it's the best available place for your loved one to start down the road to recovery.

The first determining factor of the selection process is where you live. In some areas, or if you are part of a strictly "*in-house*" HMO, there may not be any choice, In that case, you to go ABC rehab, no decision necessary. However, if upon planning the hospital exit, you're given a paper to sign saying you weren't coerced into selecting ABC, a big light bulb should illuminate over your head. It's one of life's "*Aha!*" moments. Alternatives must be out there!

As with all else related to stroke and all catastrophic illness, keep asking questions. It's hard to have any sort of medical experience without running into several others whose brother-in-law had the same thing. So, staring talking up a storm until you've started a tornado of information whirling about you. A good place to start is with medical personnel. Ask any doctor or nurse, specialty doesn't matter: If you had a stroke, where would you want to be sent for rehab? A pattern will emerge, and it may be negative: "*Anyplace by ABC. I wouldn't send my dog there.*"

While chances are you'd buy a doghouse without too much research, would you send your kid to a school you never visited? Buy a house from a brochure? Personal visits to rehab facilities are an absolute necessity. In addition to the basic personal observations – like, is it clean? – other questions should be asked:

- ✓ Is there a doctor on site? If not, how often does one visit? What happens in the event of a medical emergency? First, a facility must meet the medical needs of the patient.
- ✓ What a percentage of patients have had a stroke or other traumatic brain injury? Are needed therapies – PT, OT, speech – available? Is therapy individual or group? Is it administered by certified licensed professionals? How many hours are devoted to therapy? What do the patients do for the rest of the day?
- ✓ How long is the average stay for a stroke survivor? What percentages go home from rehab versus go to a nursing home?
- ✓ Do they have cable television, and does it include ESPN if the patient is male? Or Lifetime if female? If it's important to your patient, ASK! You may think we jest, but even patients suffering from aphasia and other speech problems, enjoy the familiarity of certain entertainment they enjoyed before the stroke. And, it may also be an indicator to the overall humanity and comfort level a facility seeks for its patients. A country club you probably don't care about – but it is also not your goal to place your loved one in a place where they are treated like a package of rice on the shelf.
- ✓ Observe the average age of the patients. If the survivor is someone, whose say, not even 50 , a rehab facility filled with 80-year olds isn't going to be the most inspiring environment.

There's a lot to be said in favor of geographical convenience. If visitors are important to the patient, don't send them far from their visitation network. Driving into a big city may not faze some folks, but to many others, especially older people, you might as well have placed the patient in the middle of Broadway and Times Square. Nobody's going to drive there no how any way. However, if we're

talking the Mayo Clinic versus Podunktown Rehab, go to the superior facility and the heck with visitors.

Still, for some, the insurance company will erect brick walls everywhere you turn. Once you have fought the good fight to no avail, certainly you must take *"something"* if it is offered, over nothing. And, while money talks, most of us do not have it (often heavily in the throes of the financial stress that follows in the wake of major illness) and ultimately have to accept what insurance will pay for. *Do not despair!* Unless a rehab facility is completely incompetent (unlikely, given board certification requirements), basic care and therapy will be provided. But you will probably have to work a little harder, and not be able to rest quite as easy. If the facility is not of your choosing, it does mean you may want to be there more frequently, or solicit the good favor of a dear friend or relative who can share the load of monitoring he quality of care. In addition – who knows? – little gems … a marvelously talented or compassionate therapist, e.g., can be discovered in the most unlikely of places. And, finally, there is one more thing to keep in mind if you feel insurance is not providing what you had hoped. This isn't a reason to lie down and give up hope. Stroke recovery is only *part* therapy. Sure! – getting excellent therapy, with the most progressive techniques available, is what you want if you can get it – and, yes, you should bother to fight for it. It will, certainly, improve the survivor's chances of greater physical and mental recovery. However, if this isn't in the cards, a great deal of stroke recovery happens anyway, as some pathways in the brain begin to rebuild themselves in a slow, natural process. Remember our mantra: *no two strokes are alike?*

Until there are medical advances that actually enable the brain to build new pathways around the destroyed tissue, therapy is not the be-all-end-all. The best therapy in the world generally cannot help most stroke survivors recover completely… and the most mediocre (or even no) therapy won't prevent some stroke survivors from recovering a great deal. You simply do not know until time passes (sometimes months, sometimes years), and recovery potential becomes more clearly evident.

What Makes a Good Rehab Facility?

There's an organization named CARF (Commission of Accreditation of Rehabilitation Facilities) that will do the homework and answer the question for you. It's like the Good Housekeeping Seal of Approval for Rehab Facilities. Except CARF seals approvals aren't so prevalent. CARF doesn't give out its seals capriciously. It's very difficult for a rehab facility to get CARF accreditation. And if they succeed, you can bet your gait belt that they'll display the framed citation in a prominent place and stamp "*CARF Accredited"* all over their literature and stationery. Make sure the accreditation is for the current year and not left over from 1986, be-cause it's even harder for a facility to get reaccredited. Also, make sure the accreditation is for *Adult Rehabilitation* as it may be for some other program like *Reentry into the Job Market.* A hospital that offers both in- and outpatient rehab may get an accreditation seal for one and not the other. The framed citation will list the programs included in the accreditation.

A facility that does not have CARF accreditation may or may not be a bad one, but one that does have it is certain to be a good one. Reach CARF at *http://www.carf.org* or 520-325-1044.

Life at the Rehab Facility

Checklist

- ✓ Continually reevaluate your decision on selecting this facility.
- ✓ Get to know therapy and therapists.
- ✓ Establish yourself as the advocate in charge and liaison between patient and staff.
- ✓ Realize recovery isn't fast; celebrate the small steps.
- ✓ Be a constant source of positive encouragement.
- ✓ Make surroundings pleasant, but getting out of there often is more pleasant.

You've selected the facility you feel is a good match to your survivor, and they move in. One thing to keep in mind in the back of your mind is that **this is not an irreversible decision.** If things don't work out the way you thought they would, remember that the door that you walked in through also has the capability to let you back out.

At the beginning, it's very important for the caregiver to be there to make sure the patient settles in well and has some understanding of the routine. Meet every person that has a role in your loved one's care. Introduce yourself to each therapist and sit in on the sessions. Have the therapists explain exactly why they're doing and why, and then ask how you can help and what activities you can do during *"off-therapy"* time, weekends, or during visitation. It's important to establish your position as someone who wants the best possible care for your patient and one who is willing to help get it.

Depending on your loved one's condition, it may be difficult for them to verbally communicate needs and pain to the therapist. For the first few sessions it may be up to you to devise a communication method between therapist and patient to signify what hurts and the degree of pain or displeasure. This may be a hand, finger, nod or an eyebrow signal. The method of communication doesn't matter as long as there is a dialogue that is understood. You know the patient best; in your role as advocate, it's to everyone's advantage to make sure the therapists get to know them, their physical discomforts and emotional needs as well.

Evaluating the Competency of Therapists

Carry that symbol of authority, THE CLIPBOARD, and take notes.

o **1:00** Individual PT scheduled.
o **1:05** Inquired as to whereabouts of therapist.
No explanation can be given.
o **1:10** Supervisor makes calls. *"Therapist is on the way."*

o **1:22** Therapist appears, looks around for equipment.
o **1:30** Area is finally ready for therapy. Patient asked to do 12 leg lifts. Can patient count to 12? Can patient do leg lifts? Does patient even know what a leg lift is? Therapist leaves before finding answers.
o **1:40** Therapist returns, wakes up patient, asks if 12 leg lifts have been done. "*Yes*" is the reply. "*No*" should have been the reply.

If these are the sort of notes you're taking, and the therapist is acting in that manner while you're obviously taking notes on a clipboard, imagine what happens when you're not there. That's why you're there. As soon as you realize what you are documenting is a negative trend, do something about it. Determine if the problem is with one therapist or aide and request a change from the supervisor.

Sometimes there is a personality conflict between patient and therapist. While you may not be qualified to judge a therapist's technical expertise, you certainly can tell if they're condescending, impatient, belittling, apathetic, cruel, negligent, heavy-handed, harsh, or just plain gives up on the patient. You should be aware that many therapists are necessarily "*tough*" because they must be, to motivate an otherwise unmotivated patient – and do try observe enough to sort this out first. Moreover, often, a patient will express a great dislike for a therapist that drives them hard, and challenges them. However, the match up between patient and therapist has to be a productive one. This isn't a marriage – it's more important than that! A life is at stake! Some patients do better with male therapists rather then female (men patients who have an abundance of women running their lives especially may need a male presence). Always have good documentation to back up your request for a change in personnel. If your documentation shows that the whole place is operating at substandard efficiency, run to the nearest phone and demand an audience with the Executive Director of the facility. Remind them and yourself again, how the door to the facility works both in and out. If there's no other alternative facility to threaten with, threaten to go to the one with the big bucks: the insurance provider. Insist on a breakdown of billings for all services rendered. Make sure you have a log to back up disputes: show that the one-hour billed was, in fact, 20 minutes. It can turn into an unpleasant job, but you'll need to dig your heels in and fight for what you know to be right.

Your loved one deserves an opportunity to regain as much as their developmental functions as they can. Good therapy will help maintain and retrain a stroke victim's body, spirit, and mind, including muscle tone, flexibility, coordination, motor skills, cognition and speech. A good rehabilitation facility should be committed to make this happen. You may have to remind its administration of those basic rights and that you intend to do whatever is necessary to obtain them. Your "*right*" to do so is granted by virtue of the fact that your love the person who can't fight for himself. A good rehab facility has a staff that will listen to the caregiver and ask your opinions. You are the only one where who knows who and what the patient was before the stroke.

In the Best of Times, in the Best of Rehabs …

One thing to kind in mind is that even if you found the finest rehab facility with the very best therapists in the world, progress in stroke recovery is usually measured in very small increments. This is not a fast process. Walking, talking, moving the affected arm do not come over-night even if the therapy is timely, and the therapist works every minute of the allotted time. Individual results often vary. **Reread Chapter 1.** Two strokes are seldom the same. Unfortunately, there is no published timetable available to determine the degree of recovery and when it's going to come. Recovery doesn't end at three weeks, or three years. It continues for a lifetime. In addition, if you think it slow now, guess what? It's going to get slower with time, so rehab is the time to utilize the staff and the doctors and to "*make hay while the sun shines.*" Use this time wisely and to the best advantage of the patient. Make sure everyone around your loved one thinks and acts in a positive manner.

There isn't a place for negativity in this scenario. Try *very* hard not to make comparisons to others in therapy. Make others (friends, relatives) aware as well – that every brain recovers at a different rate and to a different degree, no matter how motivated the patient, how much therapy is provided or by whom. Don't ever allow the word NEVER to be uttered. If your patient is receiving pain or muscle-relaxing medication, make sure that it's given at a time when it will most benefit therapy. It certainly is easier to do physical tasks when one is pain-free, so be sure that those medications aren't just dispensed at an x o'clock without regard for when the therapy will take place. No, the doctors and nurses don't always think of that.

Because progress is slow, it's very important to continually encourage the patient to work hard and not give up. Celebrate the improvements, no matter how dinky. Get a BIG calendar like the ones used as desk blotters. Circle the date of the stroke and write in all milestones when they are achieved: first solid food, first step, etc. Make the patient ware of the date – numbers and names of days and months are often lost – it helps them in their awareness and time frames. It's also helpful when they're discouraged: *"Look two weeks ago you couldn't even do ___________. Now you're an expert."* When something big happens (first step, first glimmer of movement, ANY recognizable accomplishment), have a party! Have balloons and approved *"party food and drink"* on hand for such an occasion. Impatience is a BIG part of stroke so it's important to not have to wait for a celebration. Just show the patient how very proud you are of them now, and don't forget to write it down on the calendar, surrounded by stars! Take pictures or videos – because it is nearly guaranteed that the patient will be unlikely to see their own progress. They just remember how they were before the stroke, and is constantly aware that they're not that way any more. Try hard to keep the survivor aware of their presence in the real world. Watch the news and discuss it, if language isn't a barrier. Watch comedies. Listen to radio and listen to music. Talk about what you are seeing, doing, and hearing. Talk about family and friends, about all things you would normally have talked to them about in the same voice you used to use. Yes, they have suffered a stroke, but they need to know that the outside world is still there and waiting for their return.

Just as you did during acute hospitalization, decorate the patient's room. Put up pictures of friends and family. This helps the survivor remember who they are and gives the staff another dimension of the fallen soul laying there: this was an active person with a family, loved one. Looking though photos with the patient is mentally stimulating, but goes easy. The brain at this stage needs to heal; it can quickly overload and result in exhaustion. Ask if there were anything from home they'd like in the room, any magazine from the newsstand, if they were able to read.

If possible take the patient for walks/rides throughout the facility. Explore every nook and cranny, inside and out. Take advantage of outings they may have – make sure your patient gets signed up, even if you have to sign on too as a chaperone for the group. Try to get the survivor out of their room as much as possible. The room is for sleeping and resting, not a place to hide or escape from the world. As soon as it is allowed, take the patient out on a pass away from the facility. This may require some testing by the staff to be sure that you can transfer the patient and attend to what ever needs may arise. Go get a non-institutional type meal! (A greasy hamburger with French fries and malt will cure a lot of what ails you, and contrary to medical opinion, it will not cause instant death.) Just be careful not to overload the senses. After being in a controlled environment, Saturday afternoon at a mall at Christmas-time probably isn't a good idea.

Before the survivor is discharged from the hospital or reap, take advantage of any Patient Services staff that can assist you with the transition to home. They can help you define and order any home equipment needed. They can direct you services for home nursing care, home rehab services, and home health aides. If the survivor has been under the care of a physical/occupational or speech therapist, request a meeting with his therapists and learn how to safely handle transfers (bed to wheelchair, commode to standing, etc.), exercises you can do with him once he is home. The physical therapist is the best person to ask questions about assistive devices, implements that can be added to the wheelchair (back cushion, seating, brake handles, flip up table, etc.) This may be not be in all cases, but if the hospital Patient Services orders equipment, such as a wheelchair, if may need to be upgraded or features added that are adapted to the survivor. Seating is a whole issue in and of generally, home therapy visits are limited to a number of visits or to a limited time period. After that, outpatient rehab will need to be arranged.

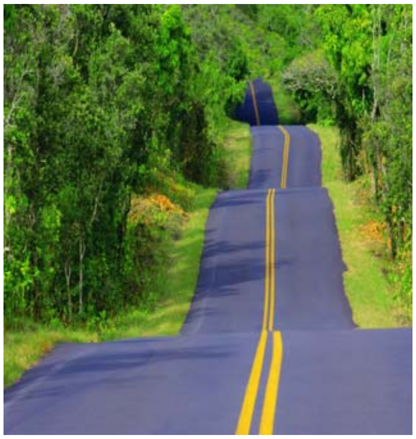
If at all possible, plan to be present during the initial rehab evaluations by the therapists. Periodically observe rehab sessions to see how the survivor is doing, get a progress report from the therapists, and learn any new exercises to do at home.

Can We Go Home Now?

Your idea, and the insurance company's idea, of when the time is right for *Home Sweet Home* are not likely to coincide. Twenty years ago, a patient might have convalesced in a rehab facility many months until they could go home and live independently. However, do more. Some inpatient rehab stays are as short as a few weeks. The main criterion for leaving the rehab facility may be as basic as being able to transfer to and from a wheelchair with assistance. It may also be that the patient is not recovering sufficiently (in the "*Great Eyes*" of the insurance case worker) to continue to benefit from a continual program of impatient rehab.

So no matter how you cut it, the burden is placed squarely on your shoulders as the caregiver. (And, this is the instant when you will begin to treasure that time when your loved one was out of medical danger, but temporarily under care and feeding of someone else.)

You'll generally face one of two scenarios at this point.



Sadly, neither heralds the end of this long road. The most positive one: the patient has recovered enough to go home (often with lots of daily assistance), and can continue with outpatient therapy, sometimes at the same inpatient facility. In the second scenario: recovery has been limited, and the patient pretty much requires full-time care. Typically, therapy is no longer covered by insurance, and it becomes a decision whether the patient can be cared for at home or requires continued stay in a nursing facility.

CHAPTER 4

Preparing the Home Environment

Safety

The homecoming of your loved one following a stroke is a time of relief and anticipation. It is also a time of adjustment to the physical home environment as well as the change in daily routine. Before a stroke survivor returns home for the first time, he (the term "he" is used to refer to both genders for simplicity's sake) has most likely spent some time in a hospital or rehab environment where the equipment, floor plans, entry and passageways were designed for people with varying levels of disability. The home environment, on the on the other hand, may need some adjustments to make it accessible, safe and relatively trouble-free for the survivor. Keep in mind that it may take some time to assess the individual needs of your loved one. It may take more than one solution before you find the one that works.

Adaptations to the home environment should be made prior to the homecoming as much as possible (see Hospital/Rehab Support for related information). Granted, some changes can be made only after the survivor has been home. Then his individual needs, what works and what doesn't can be observed over time.

Safety Assessment (installing safety features i.e. garb bars, bedside grab bars, handrails)

Before the survivor comes home, carefully look at your home from his point of view. Think about whether he uses a wheelchair or will walk with assisted devices, or will spend more time in bed. If he is using a wheelchair, ensure each room will be free of scatter rugs, electric cords, and anything that can create a potential safety issue. Passage areas should be kept clear of clutter, small furniture, lamps, etc. that can also get in the way or cause accidents.

Consider whether doors are easy to push/pull open.

Safety Bars and Other Safety Features

Most homes are not equipped with safety rails and grab bars. You will need to figure out what type of safety features are needed for the survivor, and where they need to he placed for optimum facility and safety. If the survivor is able to walk about, with or without assistance, grab bars can be installed in strategic areas.

Grab bars are very useful for pulling oneself out of bed or sitting up from a couch. If a regular bed is being used, a product called Bedcane (a looped, padded grab bar anchored to a wide piece of wood) can be placed between the mattress and box-spring, and further secured by a nylon strap to the bed frame.

The same manufacturer produces Sofacane, which has a metal base that fits under the sofa legs and a looped padded grab bar to hold when rising from the couch, or other heavy armchair. Similarly, there are grab handles that can be attached to the inside of the car to facilitate getting out of the car.

Grab bars can be installed at any point where they are needed to pull oneself up. Always make sure any grab bar installed into a wall or door jamb is secure enough to support the survivor's dead body weight. Drawer pulls and cabinets are not strong enough to use as grab bars.

Bathroom Safety Features

Bathrooms are potentially hazardous places because of slippery hard surfaces. Grab bars that have textured surfaces and meet ADA guidelines can be installed in the bath or shower area. Installation into existing tile must be done carefully, since the bars must be attached to studs behind the existing wall. To secure grab bars, clamp them onto the sides of a bathtub. Also, support bars designed to use around the toilet may be installed. There are inexpensive versions of these safety systems, so be very careful they are designed to support the appropriate weight. Make sure they are installed by someone who can mount them into support studs behind the wall.

The bathroom can pose its own challenges, as well as its own hazards due to slippery or hard surface areas. A handheld shower will enable the survivor to bathe himself if he has use of one hand and arm. Slip-proof mats both inside and outside the tub are helpful.

A tub bench that extends beyond the width of the tub or shower is very useful. The tub usually has a back, arm rail on one side, strong suction cups to anchor the bench to the tub, and holes in the seat for water drainage. While climbing over the edge of the tub is not possible for many people, the tub bench allows the survivor to sit outside the tub, lift his legs into the tub and slide over so that he is now seated in the tub area.

Toileting Equipment

If the survivor is able to get to the bathroom to use the toilet, consider installing safety rails or bars to assist in sitting and getting up. Toilet seats are available to raise the seat height by about 4-5 inches. There is one type made of durable hard plastic with a lip that hooks onto the regular toilet bowl. Make sure that the raised toilet seat does not slip or slide around. A rolled bathmat may work if wedged between the raised seat and toilet tank. The soft cushiony raised seats "give" too much and do not provide adequate support

Assisting with Safe Transfers (wheelchair, bed, and vehicle)

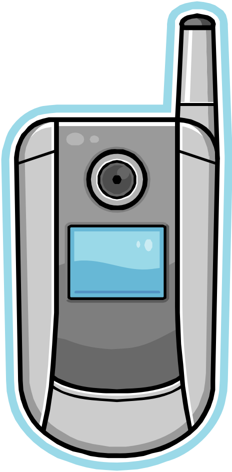
Transfers to and from the wheelchair and toilet need to be practiced. The main concerned is preventing the survivor from falling and the caregiver from putting her back out. If the survivor is right side affected from the stroke, always transfer him to his left (strong) side. When getting him out of bed, park the wheelchair so that he can reach across with his left hand and pull himself from the bed to the chair with minimal assistance from the caregiver. Obviously, the opposite instructions apply to somebody whose left side has been affected by stroke.

Always have the brakes on before transferring, so the chair doesn't roll away with the patient ending up on the floor. Using a (gait three?) also makes it easier. Grabbing a patient by the arm (especially on the affected side could injure or cause dislocation of the arm). Be the stand-by to help guide the patient onto the chair if he should lose control and tries to overshoot it. A wheelchair with a removable arm helps with transfer. It can be taken off or moved back out of the way. The same types of transfers apply to getting on and off the toilet (grab bars are essential), and in and out of the shower.

Car transfers involve pushing the wheelchair as close to the front seat as possible, and having the patient reach up and grab the door frame (with window door?), and pull himself up using the door frame. Again, the wheelchair is locked into position until the patient stands; then unlock the wheelchair and move it out of the way while holding onto (gait?). Then gently guide the patient's butt onto the seat of the car. Help to lift the affected leg into the vehicle, then have the patient lean forward holding onto the dash of the car. Raise his butt to push onto the seat so he's sitting all the way back on the seat. Make sure the seat belt is hooked and wheelchair loaded before driving off (it's easy to forget the wheelchair if it has to be unloaded to get big items in the van).

Universal Precautions at Home (gloves, sanitary hand cleaners, etc.)

Several websites online carry discount medical supplies that are needed at home. Shop around using Google for discount medical supplies. Many of them offer free shipping with a minimum dollar amount on the order. Order the gloves, bed pads, sanitizing hand cleaners, tongue depressors (for speech therapy), and glycerin swabs for mouth cleaning, etc. all online. USE THE GLOVES AND THE HAND CLEANERS and make sure anyone working with the patient does the same. Change the gloves after each use - (i.e., if cleaning a patient's mouth, DO NOT USE THE SAME GLOVES to work with the feeding tube area). They are essential in preventing the spread of bacteria causing infections.



Emergency call alert or phone system

A related issue is setting up some sort of emergency call alert on a phone system. There are various companies that offer an emergency alert service in which the person can press a single button on a device that is worn around the wrist or neck and will signal a dispatcher who can respond.

A cell phone that is programmed with emergency contact numbers is also a good idea, although not as easy to use. If the survivor will be left alones for any time, or in the hands of a home health care provider, make sure your contact numbers as well as any emergency contacts in the neighborhood are posted clearly as well as given to the care provider. Your cell phone number or the phone number of that emergency contact can be taped to the back of the handset for easy reference.

If continuous monitoring is a concern, a baby monitor is useful to hear calls for help in the middle of the night, or if you are in other areas of the house and out of hearing range.

Care and Convenience

Wheeling Wheelchairs

Many homes have a threshold in the doorway between rooms that is higher than the floor. The threshold pieces that to goes across the doorway can be removed or the bump made less of an obstacle. A heavy rubber mat can cover the threshold and taped down, or a graduated piece of wood can be fashioned by a carpenter to make it easier to cross, especially in a manual wheelchair. In cabinets, doorways between rooms, the door may need to be removed to widen the entry way for a wheelchair.

Keep in mind the turning radius required by a wheelchair in any given area.

Extra furniture or lamps may need to be removed to widen the wheelchair opening. If turning areas are tight and the wheelchair will bump into cabinets, door moldings and the like, corners can be protected with bump guards either purchased or home made.

Accessibility to Household Utilities (lamps, light switches, phone)

If there are any areas outside the front door where the stroke survivor will be walking with or without an assistive device (walker, quad cane, etc.) safety rails or grab bars will be essential to their safety, especially if there are any steps involved.

Safety railings installed outside of the house should meet ADA specifications and should be installed by a professional. Metal hand railings, like ones commonly seen in fire stairwells are durable and secure. These railings are usually 1-1/4 to 1-1/2 inches in diameter. Metal bars will be affected by outdoor temperatures and the person will need a heavy glove or mitten, so that they can comfortably handle a railing that is too hot, cold or wet to grasp safely.

If your house has a step up to get into the house, vertical bars can be installed on either side of the front entrance. If there are steps, and he is able to use them, safety rails should be installed alongside the steps.

If the survivor is wheelchair bound, and there are steps, then a ramp will need to be installed. Depending on the number of steps to be installed and layout of the pathways involved, a portable ramp may work for a single step, or a system of ramps may be required. The ADA guideline for a ramp is no more than a 12 degree grade, allowing one foot of ramp length for every inch of rise. In other words if the height of your steps is 24 inches to ground level, you will need 24 feet of ramp length to maintain a 12 degree grade. Ramps can be built with switchbacks if there is not enough room for a single straight ramp. There are also other specifications to consider, such as the width of the ramp, height of railings, and ramp edges.

Another option is a wheelchair lift, if your entrance and surrounding area will support this structure.

Special Note: It is possible to take someone up or down steps if he is seated with a seat belt fastened to the wheelchair. The combined weight of the survivor and wheelchair must be considered. This should be attempted only by someone wearing nonskid shoes who has experience, upper body strength, a strong lower back, and good balance. This is accomplished by tipping the wheelchair back onto the rear wheels to a 45 degree angle. The caregiver needs to face out and very slowly roll the chair down or up one step at a time. A second person can act as spotter in the front. The above method of transport up/down steps should be done with great care.

If there is a single step, such as a street curb that must be passed, the following procedure requires slightly less strength. Position the person in the manual wheelchair towards the curb. Step on the back extension of the wheelchair just enough to place the smaller front wheels on top of the curb (onto the sidewalk). Lift the handles of the chair to lift the rear wheels onto the top of the curb, while pushing the chair forward.

Toilet (T)issues

If the real bathroom is not accessible, a portable commode may be placed near the bed for easy access. There are hanging toilet paper holders that can be attached on one of the arms with Velcro. A weighted standing paper towel holder is also useful for storing rolls of toilet paper. Personal hygiene wipes in a plastic box are also helpful.

After emptying the pot and cleaning, leave an inch or two of clean water with a small amount of bleach or disinfectant in the commode pot. Keep a box of disposable protective gloves nearby. The portable commode can also be used for quick baths, with or without the pot, by placing plastic and/or towels around the base, and using either no-rinse body shampoo or a small basin of hot soapy water.

Portable urinal bottles can be kept at bedside for night-time use. Invest in spill- proof urinal bottles; they cost more (around $40) but they will save a lot of cleanup for you and frustration on the part of the user. A spray bottle of bleach and water solution will help keep them clean and odor-free. It is also a good idea to have a urinal bottle handy when traveling in the car, or visiting anywhere that a bathroom is not readily accessible.

If possible, clear the bedside area of rugs. They may be prone to accidental spills and urine odor is difficult to get rid of, even with the use of enzyme cleaners. A vinyl mattress protector will safeguard against accidents.

Keep a box of disposable gloves handy for clean ups, especially when handling fecal matter. Used gloves should be removed by turning them inside out as you slip off the gloves. Then dispose them immediately into a lined trash can.

Clothing and linens soiled with body waste should be washed separately in hot water and detergent. Additional enzyme cleaner can be added. If the clothing is heavily soiled, it may need to be put through the wash cycle twice.

Bathing

Cotton towels get heavy when wet. Switch to hand towels for drying or more lightweight bath towels. Bathing sponges on a stick are useful for scrubbing feet, the back and other hard to reach places.

If the survivor is unable to use the bath, then there are alternative ways for bathing and toileting. A sponge bath, using rinse-free body shampoo is one option.

If he cannot be moved from the bed, roll him over, place a plastic sheet and towels on the bed and roll him back. There are absorbent pads with waterproof backings that can be used in the bed, available at discount medical supply companies. You can then use a basin of warm water to give a modified wet bath as well as a wet shampoo.

If more thorough bathing is needed, the following set- up has worked. If it is not possible for the survivor to get to the bathroom, but has access to the kitchen, (which is generally larger than a bathroom), cover the kitchen floor in front of the sink with large towels. Use an inflatable swimming pool, 3-4 ft. in diameter. Place the tub bench in the pool with the extension sticking out. Transfer the survivor onto the bench, placing his feet inside the pool and sliding over so he sits within the area of the pool. Have a few small basins handy and slowly pour hot water over him or use a shower attachment to the faucet.

This is a bit of work, since the water collected in the pool will need to be bailed into the sink, and the surrounding area will get quite wet. However, it makes a real shower/bath experience possible when bathroom access is limited.

Be sure the person is completely towel dried before transferring out of any bathing situation. Use a canvas safety belt across the chest if you need to provide some support in the transfer. Check the placement of his feet before transferring and make sure the surface beneath his feet is not loose or slippery.

Special Clothing Needs

If the stroke survivor has been left with paralysis or weakness on one side, garments may need to be replaced with ones that take these limitations into consideration. Even if there is no hemi paresis, buttons, zippers, hooks and other fasteners should be examined for ease of use.

Pants—Elastic waistbands or a partial elastic waist are preferable. Special clothing online catalogs feature fake fly fronts for appearance, pants with Velcro closures, and other features that make dressing easier for the survivor. Zippers should slide easily and have large enough tabs or tab attachments that make it easier to grasp.

Shirts- Traditional men's shirts generally have small buttons and buttons on the cuff that may be hard to deal with. If possible, switch to washable knit shirts as they may be easier to work with.

Underwear–It should be comfortable, not tight or binding.

Socks-The stretchy non-binding socks for diabetics are easy to put on, by either the survivor or the caregiver. If there is paralysis in leg/foot, these are less constrictive around the ankle. There are assistive devices which are useful for putting on socks with one hand. There are different types. Some take more work to put the sock on the device, so you may need to try more than one.

As an aside: if you are putting on the socks for the survivor, always check the feet carefully, particularly if one foot has no sensation. Check for toenails that dig into another toe, calluses, tender spots, etc.

Shoes- If the survivor is not able to walk, then comfortable slip-on shoes with Velcro closures are practical. If the person is able to walk, invest in walking shoes that have adequate padding, support, and adequate toe box height and fit properly. If going to the shoe store to try on shoes is difficult, order shoes online and order several to be tried on. One company, Zappos.com, does not charge shipping for delivery or returns. Footsmart is another online catalogue company that specializes in comfortable, special-needs shoes and accessories

Jackets, Coats — Winter outer gear tends to be bulky and heavy with awkward buttons or zippers. Add sew-on Velcro tabs to provide another option for buttoning up. If the survivor is in a wheelchair, coats that hang below the waist can get "caught up" in the act of sitting down.

Gloves—It can be difficult to pull a glove on a hand that has lost feeling or is slightly spastic. Mittens are easier and come in various weights. Sometimes even getting the thumb into the mitten is difficult, and thimbles mittens can be ordered from special needs clothing companies.

Raingear—A waterproof hooded poncho designed for wheelchair use is especially helpful if you have to go out in the rain. Ones designed for wheelchair users have a shorter back, so that it doesn't get caught while sitting down. For ambulatory survivors, a similar waterproof hooded poncho is useful. In fact it is a useful thing to have for the caregiver, who generally will not be able to hold an umbrella while assisting the survivor in the rain.

Special Dining Ware (non slip plates, easy grip flatware)

There are a number of specially-designed flatware, dishes, bowls, and drinking cups. For survivors who experience difficulty in grasping and lifting food, (sometimes with one hand) there are useful aids for eating and drinking. For example, there are dishes and bowls with suction bottoms to hold them in place. Flatware comes with large rubber grips, or with handles that can change the angle of the fork or spoon to better suit the survivor.

There are rocker knives that will cut food using a rocking motion with one hand. Glasses and cups tip over easily, so there are weighted drinking glasses available. With compromised ability to use eating utensils, there are bound to be more food spills. Aprons are available from disability product companies. Sometimes it may be less objectionable for the survivor to wear a chef's kitchen apron that loops around the neck and has a bib front and full lap aprons.

Medication Organization – How to set up medications

Most stroke survivors take medications daily. If you are a caregiver, chances are you will be responsible for managing your survivor's medication. I have found the following procedure to be most effective.

First, make a list of each medication, the dosage (i.e. 25 mg), and the prescribed amount and number of doses to be given each day. Separate the medications into categories. Pain, blood pressure, heart, (ask your physician's nurse to help you if you aren't sure what the medication is used for).

Purchase medication trays available at your pharmacy. Sometimes two trays are helpful because of the number of medications needed each day. The good thing about these trays is that you can set your medications up once each week. If any changes are necessary to the medications throughout the week you will be able to easily make them.

When setting up the medications for the week take your list and use it as a guide to your medications. Set all your medications on one side of the tray and go right down your list. After you have filled one medication's weekly dosage move it to the other tray.

You can use one tray for meals. By doing this, if you are out for lunch and/or dinner you can just lift the meal box out of the tray, slip it in a bag and off you go. You may be able to use just one tray, and if you can that is great. If not, use the second tray for the "in between" times and bedtime. Also, if at all possible, give all meds at breakfast, lunch, dinner and bedtime.

In the hospital there are three nurses to manage the medications. As a sole caregiver, if the medications are given at the same time every day, it should be good enough. For example a medication prescribed for two p.m. can be given everyday at lunch.

If you list all medications along with the dosage and number of dosages to be given each day, you can take the list with you to your doctor's appointments rather than all the medications. The nurse will love you because she won't have to write each medication down every time you visit.

1. On-line prescription refills – Is this service available through your pharmacy? Check the web – very convenient!

2. If the survivor receives medication through Veterans Affairs, you can refill those prescriptions on-line through his/her web-site (see #3 in the next section).

Organizing Tools

1. On-line Calendars:
   http://stroke.live.lotshelpinghands.com (sponsored by NSA).

2. Cell Phones:
   If you use a cell phone, look for the datebook or calendar option. When you are making appointments, put the appointment in your cell phone and set a reminder for the day before your next appointment. You may soon scratch using an online calendar!!!

3. Veteran's Health Pages Resource "My Health"
   http;//www.myhealthyvet.va.gov/mhv-portal- web/

Caregiver as 'Advocate'

Talking to Doctors

1. Appointment times are generally set for 15 minutes. To get the most out of your appointment, make a friend of the nurse. She can relay questions to the doctor for you.

2. Don't apologize for your questions or concerns. Remember, you are with your survivor 24/7 and can really help the doctor track progress or issues.

3. Always take a list of all medications, including the dose and time it is administered.

4. Take a list of questions – don't rely on your memory.

5, Take notes so you will have a written reminder of any instructions that are given.

6. Don't forget that your pharmacist is an excellent source for information regarding possible side effects or medication interaction problems. If you have a concern – ASK – there really is no question that is "stupid".

Legal Issues

If the caregiver will assume responsibility for the stroke survivor's medical care, then it is a good idea to have Durable Medical Power of Attorney drawn up by a lawyer or legal aid clinic. Without this document, the caregiver may not have access to prescription information, including inquiries about refills, dosage, or have access to medical records and diagnostic reports, or inquire into his medical care on his behalf. If the survivor qualifies for Social Security Disability, the Social Security Administration does not honor a Durable Medical Power of Attorney to give you authorization to manage his disability benefits. You must go to an SSA office and submit an application to be the survivor's representative.

CHAPTER 5

Caregiver

A Caregiver Emergency Care Plan

As caregiver we don't have time to even think that we might need assistance for ourselves. First, even the thoughts of the need for assistance due to an emergency can be very stressful. One more stressor is not something a caregiver needs. You do need, as a caregiver, some kind of plan for <u>your</u> medical emergency.

The following is a sample plan.

1. List of all stroke survivors' family telephone numbers.
2. List of all caregiver's family telephone numbers.
3. List all physicians' names, addresses and phone.
4 List all agency telephone numbers that may be need.
5. Separate lists of all survivor's and caregiver medications.
6. Detail all important information including sleep habits, invisible (vision, cognitive) challenges, equipment used on a routine basis

as well as any specific food needs or conditions – i.e., diabetes, thickened food, feeding challenges or needs.

7. Put all important papers – power of attorney, wills, mortgage papers,any information that may be needed in a “worse case” scenario – in one place and note where they are.

APPENDIX

HELPFUL ONLINE LINKS

ABLEDATA provides objective information about assistive technology products and rehabilitation equipment available from domestic and international sources.
http://www.abledata.com/

Products for Independent Living
http://service.maddak.com/productsearch.asp

Wheelchair Ramp Information
www.northeastrehab.com/Articles/ramps.htm

Power Wheelchair Information (this is a link from Abledata.com)
www.abledata.com/abledata.docs/PowerChair-Safety.htm

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