

STROKE CAREGIVERS HANDBOOK

by

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STROKE CAREGIVERS HANDBOOK

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STROKE CAREGIVERS HANDBOOK

Introduction

This book is dedicated to the many caregivers to stroke survivors – more than 500 of them – who have contributed, during the past 5 years, to an Internet support group known as the Stroke Caregivers Support Group. This group formed on July 5, 1996, started with less than a dozen caregivers, who banded together to support and nourish one another through this challenging and often hurtful world of stroke. Since the inception of this group, hundreds more stroke caregivers have found us. Some have left and some have stayed, but nearly everyone who has joined us has found other people who understand, care, and help cope by sharing experiences and giving a shoulder to cry on.

We are caregivers to parents, spouses and friends. Our ages range from the 20s to the 80s. We are men and women, faced with a situation almost no one else can understand without walking in our shoes.

After five years, our group decided to share our knowledge and experiences with others who cannot join us online. Hence, the creation of this book. It is currently a work in progress, as material be continually added to it, in order to provide useful, practical advice to caregivers dealing with stroke. Whether new to this plight or an “old-timer” – we hope our tips and ideas will help anyone facing this situation.

The Stroke Caregivers Support Group can be found on the Internet by going to <http://www.strokesafe.org>.

Disclaimer: We are not medical professionals, but only seek to share our experiences and layperson opinions. Always confirm specific suggestions with your doctor(s) or other appropriate professional(s).

Editor's note: For the purposes of this manual, the terms “survivor”, “victim”, “strokee” and “patient” are interchangeable.

The information in this manual is provided by many caregivers, and authored by Joyce Dreslin, who cares for her husband who had a stroke in 1999. The manual was edited and formatted for web presentation by Rex Stocklin, a 44-year old survivor of a 1995 stroke.

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STROKE CAREGIVERS HANDBOOK

Chapter 1

Stroke: An Equal Opportunity Attack

Chapter Summary

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Who? Where? When? Why?

Many questions ... few answers in common

Stroke ... cerebrovascular accident ... brain attack!

You can be anywhere, doing anything and Stroke can attack. Stroke doesn't discriminate. It has NO regard for who or where you are or what you are doing. In a matter of 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 BIG 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 Two Kinds of Strokes

While, typically, no two strokes nor their resulting effects will appear to be the same, there are really 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") or (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 than a trickle to deliver the required amount of oxygen to function properly. These strokes can also be called thrombotic (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 a vessel 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 is 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 hemiplegia) 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 vital autonomic human survival functions, so there may be paralysis on both sides 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?

It's alphabet soup time 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 em-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. So 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 recovery from stroke can be effected.

Although there are just two basic types of stroke, there are many causes for 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 than one-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 tests 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 be forever 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. And 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'll 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 strokee 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 joy 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 a new strokee and their family. We're complex too! And 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 the heap called "average."

Stroke Caregiver: An Unwelcome Job Opportunity

It's not a job you apply for. Chances are, if 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 their job prior to having to do it yourself. And it's not a decision 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 manual!



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Chapter 2

Acute Care

Chapter Summary

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Emergency Room – A Matter of Life or Death

Checklist

- Within 3 hours of onset of stroke, get CT & MRI scans and evaluation for possible treatment with tPA (clot buster drug) – if this treatment is appropriate and given, this can save a life, or save the strokee 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 than 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 than 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 can't move 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 their guilt and sense of duty by just dropping off one 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, take in dry cleaning, etc. PLEASE!"

Keep a notebook. Better, keep two notebooks. Label them appropriately. Caregiving 101 will be the toughest course you'll ever study. Invest in a three-hole punch if you don't have one, a couple of very fat three-ring binders, and some index 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 & 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's 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 put EVERY scrap of paper and every record into that 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 pay \$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 environs cheery with 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's in the form of hugs and complimentary notes to those in charge, telling them who was 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 thin liquids come back up or, worse, aspirate into the lungs. Foods may need to be puréed 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 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 therapist.

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 and when 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. Have the hospital put this in the file and ask them to make it part of the PERMANENT medical file. Even if you have these forms at home or in your safety deposit box, do this anyway and save time. If things go bad, you will not have time for attorneys to review forms. Be prepared!

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 have to call.

And 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 rely on the patient's memory or ability to tell you who was there. Sign in yourself and sign some guilt away later on when you count up how often you were there for your strokee!

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 Watson, 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 strokee has a communication problem to begin with. Mastering the call button may take you the equivalent of a Master’s degree in teaching skills. And then the staff shift changes, and you have to start all over again.

First, make sure the button is located 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 of 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 strokee 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 issues0

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 (severe 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 strokee 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: Bedpan, Water, Thank you, Sorry, I love you, Help. 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 at 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 than 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. Play music like golden oldies or something that will personally stimulate them, like a holiday carol or "I Left My Heart in San Francisco." If you're one of the rare breed 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, be 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 Function

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 onward. Grief is a very personal experience that takes time and work. And there is no socially acceptable way to grieve for a person who hasn't died. Though 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 for that matter; you might be in grief 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 strokee, 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 to be right.



STROKE CAREGIVERS HANDBOOK

Chapter 3

Moving On to Rehabilitation

Chapter Summary

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Selecting a Rehabilitation Facility

Checklist

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

- Reputation
- Recommendation
- Personal Visitation
- Geographic Location
- CARF accreditation

After the stroke 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 event this is not initially offered. Often just a personal meeting with the survivor’s primary care physician, neurologist and/or psychiatrist 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 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). And some doctors have been known to steer patients to the facility in which they have some sort of financial interest. So 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 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.

So 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 go to 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 start 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 but ABC. 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 and foremost, a facility must meet the medical needs of the patient.
- What 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 percentage 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 strokee is someone who's, 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 geographic 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 gonna drive there no how no 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 the quality of care. And – 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 lay 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 strokee's chances of greater physical and mental recovery. But, 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 on Accreditation of Rehabilitation Facilities) that will do the homework and answer that question for you. It's like the Good Housekeeping Seal of Approval for Rehab Facilities. Except CARF seals of approval 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, because 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 of 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 strokee, and they move in. One thing to keep 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 what 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.

- 1 p.m. Individual PT scheduled.
- 1:05 Inquired as to whereabouts of therapist. No explanation can be given.
- 1:10 Supervisor makes calls. "Therapist is on the way."
- 1:22 Therapist appears, looks around for equipment.
- 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.
- 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. And, often, a patient will express a great dislike for a therapist that drives them hard, and challenges them. But, the matchup 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 than 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 these 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 you 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 there who knows who and what the patient was before the stroke.

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

One thing to keep 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 overnight even if the therapy is timely, and the therapist works every minute of their 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. And if you think it’s 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 a 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 so 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 aware 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 right then and there, 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 strokee 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, listen to music. Talk about

what you are seeing, doing, 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 care hospitalization, decorate the patient's room. Put up pictures of friends and family. This helps the strokee remember who they are and gives the staff another dimension of the fallen soul lying there: this was an active person with a family, loved ones. Looking through photos with the patient is mentally stimulating, but go easy. The brain at this stage needs to heal, it can quickly overload and result in exhaustion. Ask if there is anything from home they'd like in the room, any magazine from the newsstand, if they are 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 strokee 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 whatever needs may arise. Go get a noninstitutional type meal! (A greasy hamburger with French fries and a 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 Christmastime probably isn't a good idea.

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. But no 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 inpatient 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.

In the next chapters, we hope to provide you with advice that will help you and your loved one go on, despite lives (yours *and* the strokee's) that are probably forever changed.



STROKE CAREGIVERS HANDBOOK

Chapter 4

Home Sweet Home

Chapter Summary

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Now What?

Remember our mantra of the early chapters: No two strokes are alike? That meant that we couldn't put a pattern down and trace exact methods guaranteed to work towards recovery or figure out just when everything was going to occur. We used terms like "expected to," "probably," "may," and "in all likelihood." But when it comes to leaving rehab or hospital care and coming home, the following statement has no such flexibility. We even use the forbidden term "never." You can bet the farm on this one: **Life after stroke will never be the same as life before.** It's guaranteed.

It doesn't matter if the patient is returning to the same home they lived in before and in the same relationship (spouse, parent, etc.). This family member will not have the same role in the home as before. The statement also holds if the patient is moving into a new location and situation thanks to the generosity of a caregiver (son or daughter taking in a previously independent parent, for example). In some instances, those who were cared for will now become caregivers. Family breadwinners who used to call the shots lose all control. The family rock might now be just a mere pebble. What seems to be the same old body may now contain a totally different person or you may have the same person in a different body. It may take time to figure out just what you've got because the survivor may be unable to communicate that he's still in there. How frustrating is that? Mucho – for everyone concerned.

It also doesn't matter how much recovery has or hasn't taken place or how much recovery can be expected to take place through therapy or with time. At this time, however, we can repeat it with absolute and irrevocable certainty. Even if the patient has a seemingly full recovery, **life will not be the same after the stroke as before.** (Note: the term "full recovery" is qualified because those of us who have experienced stroke agree that there is seldom truly full recovery from stroke. Recovery is a lifetime endeavor. Improvement can and often does continue in many survivors – the recovery landscape is ever in flux.)



So What's Different?

Just because a stroke survivor is no longer hospitalized doesn't mean they're well or as well as they often think they are. As we said at the conclusion of the last chapter, chances are an insurance company, not a doctor or a family member, has made the decision to send the patient home. This decision is often based on criteria from insurance company statistics and seldom on evaluation of individual cases.

A good rehab facility will have someone on staff whose job it is to make sure the environment the patient is being discharged into is physically able to handle the patient's needs. This should involve a home visit or an extensive questionnaire. How many steps must be negotiated? What is the proximity of bed to bathroom? In a multi-story home, can the bedroom be set up on the ground floor? What sort of adaptive equipment will be necessary to insure safe bathing and use of toilet facilities? A trial run of one night at home before permanent discharge might quickly bring potential problem areas to the forefront. Rearrangement of furniture, installation of ramps, etc. could then be made before they come home for good. And while you're at it, make sure the "experts" haven't missed anything, because you know your home and your loved one the best.

Obviously a person with physical limitations will require more attention than before.

That's common sense and preparation can be anticipated. One is never quite sure how permanent the disabilities are or what can be improved through therapy, so naturally the first focus is usually on the physical effects of the stroke. However, when a patient has cognitive limitations and emotional issues, caregiving becomes much more challenging – such issues are much more "invisible" and difficult to address than are absolute physical limitations. Dealing with such things as depression, emotional lability (bouts of crying or laughing, often at inappropriate times), impulsiveness and change of personality may require professional help. Nothing in your previous life can prepare you for this, so your training is going to be of the on-the-job sort. Eventually you'll learn to hit those unexpected curve balls because you've been thrown so many and have been knocked down by a few.

Caregivers have limitations too. If you have been overseeing hospital care and handling day-to-day decisions, be aware that you're in a weakened state. You have been clobbered by shock, wrung out by life threatening situations, and operating on pure adrenaline without regard to eating properly, getting enough sleep and exercise. You've walked arm-in-arm with Stress each day, and you've survived, so you think you and Stress have come to terms with one another. Well, hello! It's time to meet a new and different form of that destructive character named Stress. This one may not hit you in the head to knock you over. It's more like nibbling away at your feet, bit by bit, until you collapse. While it's happening, you may not recognize that your entire physical, mental and emotional well-being is being eroded. It's important to constantly work at replenishing these resources and to realize that they will not necessarily all come back at the same time or with the same amount of recovery:

- Physical –** Re-establish regular eating habits, get back on good, healthy foods, including real fruits and vegetables, drink plenty of water and leave those fast food “fixes” and vending machine snacks behind. You’ll be spending more time at home now, so try your best to kick the convenience food habit you’ve no doubt had to take up just to survive hours and days at the hospital. Plus, if your loved one is eating normal food, you’ll be providing a better diet for them as well!
- Relax your standards.** Rest is more important than dusting, exercise should take precedent over vacuuming, which is not classified as a good exercise. You’ll have many new responsibilities taking up your time – so learn quickly to forgive yourself, and not be embarrassed over, a few dust bunnies under the bed ...or even in more obvious places.
- Mental –** Try the power of positive thinking and make the running commentary in your head a positive string of thoughts. It could be within your ability to make your life better or to make yourself miserable. Try not to get uptight about the “what ifs” and “if onlys.” **Get help if you can’t do it alone!**
Join a support group and/or enlist the help of a trusted friend or professional counselor. Also, many caregivers (under a doctor’s supervision of course) are better able to cope with the help of antidepressants or anti-anxiety medications. You should not feel shy or embarrassed to seek help and support in any form. It is likely to save your sanity.
- Spiritual –** Caregivers and their stroke survivors may have some unresolved issues with God as a result of all they have been through. It’s important to get spiritual guidance to get you through these issues.

Safety is the First Issue at Home

Upon discharge there may be all kinds of recommendations given to you by the hospital on how to set up your home to be strokee-friendly. The bathroom is of paramount importance because of the small space in which to maneuver surrounded by lots of hard surfaces. It’s the scene of an accident waiting to happen.

One suggestion will probably be to install grab bars to make toileting and showering easier and safer. That will take a little doing, to find the bars (Home Depot, e.g.) and then find someone to install them (attaching them to tile isn’t an any-fool-can-do-it kind of chore). So, you might think that since this need is only temporary – soon the patient will be strong enough, mobile enough, have good enough balance so they won’t need them – that this might be something you can work around and instead, you’ll just be there to help each time instead. Bad idea! Better idea: **assume every need is a forever one** and make every effort to set up the best possible equipment to facilitate those needs. You’ll probably have to be there to help anyway, but you need all the help you can get too. It’s better to have equipment you’re not using after a few months than to go those months without. Proper tools make unpleasant jobs easier. Have you

ever had to vacuum with a \$29 cleaner? If you can afford the Cadillac line of equipment, don't go for Volkswagen. Think of this journey as a long cross-country one with the Rocky Mountains to climb over and the Mojave Desert to cross over — the ride may be smoother if the vehicle is of good quality.

Other bathroom needs: shower chair or bath bench, hand-held shower spray, raised toilet seat extension, non-slip bath mat, long handled body washers, portable bidet, one-handed tooth-paste dispenser, scrub brush to attach to sink for one-handed hand washing. (A good source for such products is <<http://www.sammonspreston.com>> or 1-800-323-5547.)

A Decree Came Down from on High that Said You Must . . .

Hospitals have a way of sending you off into the real world armed only with a sheaf of papers, thinking that life is something you can handle with a 50-page manual. If you do everything as they say, life will be good. Take medication at 8, do exercises at 8:15, get dressed at 9 – **this** manual, however, is giving you permission to deviate from the prescribed program. The patient won't die if you need to modify the program they've set up for you. What works for you is going to work. It's OK, say, to help those with only the use of one hand to put on socks if that means you're going to free up a half hour for more enjoyable activities. It's also OK to take as long as is necessary so that they learn the skill of sock donning. No one else's rules have to be YOUR rules.

Having said that, you can make your rules, caution must be issued that it's important to set up some sort of a routine. You've got to organize and prioritize because you'll have more to do than you have time in which to do it, and before you know it, you'll be overwhelmed. Those who were highly structured before stroke may have difficulty easing into a more go-with-the-flow lifestyle, while those who had no organization in their life will have another sort of difficulty. Finding the right formula is going to take time.

The patient may come home from the hospital with a new set of habits. It's really hard to unlearn what has become a habit. One who has never eaten a breakfast before in their life will be awaiting the morning meal upon a tray. Addiction may be a problem – can't live without the constant presence of a TV, for instance. 8 p.m. may trigger a desire for a bowl of ice cream. Medications are something delivered at the appointed hour with a glass of ice water and for which the patient has had to take no responsibility. Assess the situations and habits and decide early on which ones have to go and which are worthy of keeping. Ring Bell, Get Service might be one of those at the top of the "gotta go" list. Gradually begin to reinstate responsibility back into the patient's life, but be sure they are cognitively and physically able to handle it.

Accept Reality

No one knows what the future will hold. Caregivers need to realize early on that if they're waiting for their stroke survivor to "get well," they may be waiting until the 12th of Never. Stroke is not an illness or disease where you can take some pills, do some exercises and in X number of weeks, the patient will be fine. Always look for progress even if it is in minute ways. **Recovery**

should not be measured in terms of regaining what one had before the stroke, but the progress one attains and the adjustments one makes in being able to make do with what one has left. If you are realistic (not necessarily negative), you may be pleasantly surprised instead of profoundly disappointed. Unfortunately, the patient also has to “buy into” the recovery process. No caregiver can do that for them. A good therapist might be able to convince the stroke survivor what has to be done for optimum results. However, if the survivor isn’t willing or because the stroke has damaged that part of the brain which gives them the ability to perceive and understand that it’s all worth trying, the challenges will be greater and the results will be lesser.

“*Sometimes it is the artist’s task to find out how much music you can still make with what you have left.*” Violinist Itzhak Perlman upon finishing a concert after breaking a string.

Be Prepared For . . .

The toughest job of your life. Don’t say no one ever warned you. We just did.

That you’ll be scared to death. Strokees have been known to sleep an inordinate amount, sometimes doing so in the middle of a conversation, and they can make the strangest sounds while they’re sleeping, holding their breath, snorting, wheezing while various limbs sometimes convulse. Since you probably haven’t been exposed to this aspect of stroke while they were hospitalized, it can be pretty frightening to the new caregiver. Add this to fears of falling and failing — that you’ll fall down on the job and the one you’re caring for will literally fall – and the fear that you’ll never ever have a life again, and you can work yourself into a pretty good-sized frazzle. Chances are you’ve already been told that once a person has one stroke, the odds increase that there’ll be another, so finally getting your patient home can be one worry after another.

The possibility of seizures. This seems to rank consistently amongst the top ten of things nobody tells caregivers. Every caregiver’s worst fear is the possibility of another stroke until a seizure takes place, because a convulsive seizure can look a whole lot scarier than what happened when the stroke occurred. Because a stroke survivor has suffered a brain injury, there is always the possibility that a seizure may follow – sometimes months or years after the stroke. Sometimes it’s an isolated incident or the beginning of a series of incidents. Medication is available to prevent seizures, but since there are multiple side effects associated with this class of drugs, finding the best one for your strokee may be a trial and error process. While being aware that seizures may happen is not a comforting thought, should one occur, you’re ahead of the game to be able to recognize it as a seizure and not death knocking on your door. Also, as scary as seizures seem to be, *most* seizures don’t result in permanent damage, in the same way that strokes do – and, in fact, only a small percentage of stroke survivors have seizures at all. You just never know who’s going to fall into that small percent, so it’s something you want to know about in advance. Don’t hesitate to have a frank discussion with the strokee’s doctor – ask how to recognize a seizure and exactly what to do. In the long run, it will give you peace-of-mind.

Incontinence. Such a messy subject, and another topic for the everyone-is-different head-

ing. It seems that nearly every caregiver is going to experience this problem to some degree. We touched on it in an earlier chapter as the possibility occurred that it could be a communication problem: the patient can't get the idea across that they have to go to the bathroom. Stroke survivors can also experience a lack of muscle control so while they know they have to go, and they can communicate that thought, they just can't hold it until they can get to the proper facilities. Sometimes the problem is temporary, often the patient can be retrained in toiletry skills, but in some cases, adult diapers are going to be forever a clothing accessory. (Order by the case from: Allegro Medical Supply at <<http://www.allegromedical.com>> or 800-861-3211.)

Accidents (urinary and bowel) have a way of happening even to those most seemingly in control. When the mind gets diverted, when amongst crowds or in situations where the patient becomes nervous or uneasy, you never know when the floodgates are going to open. It helps to check out the location & handicapped-accessibility of bathroom facilities whenever in a new environment. One caregiver learned this lesson well when she found her husband improvising by urinating into the potted plants at the mall. Be prepared and bring extra clothing on outings. If necessary, revert to diapers for safety when heading out into the real world. In many ways, it's like preschool all over again! But there are also prescription drugs that can be given to help forewarn and control, and if all else fails, here's a recipe for getting **IT** (and we mean the dreaded "#2") out of your carpets:

- A bunch of thick terry towels that you can ruin (though you can use again in the "recipe" after washing)
- A glass container with a tight screw-on lid (an old mayo jar works great) – do *not* use plastic anything
- One tablespoon of Tide
- One tablespoon of white vinegar
- One cup of super hot tap water (but not boiling water)

First, clean up as much of "it" as you are able, with paper towels or other disposable helpers. Fill the glass container with the very, very hot water, add the Tide and vinegar, and shake vigorously. *Generously* apply to the stained area on the carpet with a sponge or rag, so that the area is wet and saturated with the mixture. Fold the towels and lay them flat over the area, at least six layers thick. Find some *incredibly* heavy object with a flat bottom – a five gallon water bottle works well, or piles of very heavy books. Put the object(s) on top of the towels. Let sit overnight. The stain magically soaks up into the towels. Depending on the depth of the stain, it can take more than one application ...but it really works pretty well!!!

Stroke effects may last forever, but therapy generally won't. It's another Caregiver Law of Certainty that eventually you'll butt heads with your insurance provider. They seem to have these little timetables (that they don't share) about how much therapy is enough. Just when you think you're seeing improvement, those improvements are deemed not "significant functional improvement," and you're outta there. It's supposed to be related to whether progress is still

being made, but in reality, it's probably calculated in months or days according to some law of averages (that they also don't share). Somehow, somewhere they found two stroke survivors who were similar and set rules accordingly – or so it seems. You can appeal these limits based on continual improvements or possible risks to patient safety. If, in a doctor's opinion, the patient is close to being able to do "X" (walk, talk, etc.) often the insurance company will extend therapy beyond their preconceived limits.

Also the doctor can reorder therapy at a later time if abilities that were regained are lost again or if suddenly there's a marked improvement. These things happen. For a long time everything appears to be the same, and suddenly improvement can start up again at some totally random time. Changes, improvements and setbacks are going to be a routine part of life from now on. Be nice to the doctor, you need him in your corner. The fight with insurance providers is worthy of pay-per-view coverage, but unless you have the benefit of a support group or a supportive doctor, therapist, or human resources director to give you the war maneuvers, you'll be fighting the battle alone and in the dark.

The disappearance of friends and even family. This is one of the very hardest things to accept. Caregiving can become a very lonely endeavor. Because stroke recovery is such a long, slow process, it will quickly surpass the attention span of some of those you thought were near and dear to you. When stroke first happens, the outpouring of support can be heartwarming. But after awhile, the crisis stage is over, the victim is going to live, the gang moves on, and since you're not able to hang with them, they leave you behind even though you still need them. Often people are uncomfortable seeing and accepting the disabled person the strokee has become. Perhaps it serves as too visual a reminder of one's own vulnerability. There, but for the grace of God, go I. Others assume you must be far too busy to want company or social activities. The solution to this problem is to grieve a little for your losses, and then move on. Be proactive and reach out, and try very hard not to dwell on what are really the shortcomings of others who will never understand your new life. If those you reach out to shy away, look for new friends, new groups, new leisure activities within the realm of the disability. For each of us there's a need to have outside contact with people outside the world of stroke. Avoid isolation. There can be a life after stroke and it can be good – different, but good. Unfortunately it may not come knocking at your door. You've got to seek it out and create it for yourself, your loved one, and your sanity.

Depression – Patient's and Caregiver's. Depression often sets in when survivor and caregiver start to realize that disability is a reality. Don't fight it. A horrific thing has happened and torn your life apart. Don't pretend that it didn't. You have a right to be angry. It's common for spouses to feel first resentment towards their mates for having had a stroke and turned their life upside down and then guilt for those feelings. It's natural and normal for the patient to get angry at the caregiver and overly possessive of your time, energy and attention. You wouldn't be human if you weren't sad at this time.

Be honest with yourself and be honest with others. Pretending that everything is hunky dory and going swimmingly isn't going to cut it. It takes too much energy to put up a good front and it just makes the road back to good mental health that much longer. Crying will release many pent-up emotions, and even men shouldn't be afraid or embarrassed to indulge. You've got to experi-

ence all these emotions if you're going to move beyond them. And eventually you've got to allow yourself to be happy again. There can be laughter and smiles despite the situation you've been thrown into. But it may take professional help to accomplish this. Don't hesitate or be afraid to seek a qualified therapist or counselor. A good place to start is with your primary care doctor. If your insurance and finances will not allow for such counseling, seek out local or on-line support groups for caregivers. In fact, do that part anyway – even if you are able to participate in counseling. Misery *does* love company, in fact, and exchanging war stories with others can change your life – and others'.

Doctors, OTs and PTs who don't know it all. First they tell you all strokes are different and then they try to lump you all into the same category to predict what happens when. If you have more than one doctor, primary care and specialists, and an assortment of therapists working with the survivor, chances are the day will come when they'll contradict one another and dispense conflicting advice. It gets dangerous when they also dispense conflicting drugs. Make friends with your local pharmacist to stay on top of such errors – and even consider purchasing your own drug reference book. The Physician's Desk Reference is the most respected, but there are others that weigh and cost less, and don't hesitate to check things out each time a new drug is prescribed. You never know when your favorite pharmacist might be out on vacation.

Things will get better and easier. Even if the patient doesn't. Doing things for the first time is always the hardest, and the hardest task becomes routine with practice. You will survive! Try to look at the all the big tasks as composites of little sub-tasks. Pick the result you need and focus on each little sub-task that leads to that result. When you conquer the little tasks, they can be put together to accomplish the big one.

Most of All, Prepare for the Care of YOU!

You're the most important in the world to the person you're caring for. If the foundation cracks, so goes the building. Take time to mend the little crumbles before they turn into major problems. Try to continue with your outside interests, do whatever it takes to buy a break now & then. It's not selfish to care for you. Caregiving requires inner strength, and no one can be strong all the time, especially if sleep-deprived, overworked, under-appreciated, frustrated & lonely.

For Love, not Money

You got this job as caregiver because you love the person who has been affected. This love will make you very observant, sensitive to the patient's wants & needs, and carry you through the darkest hours. Even though you didn't train for this job, you've been tested mightily and have obtained an encyclopedic knowledge, so you can become an outstanding caregiver. You can't go wrong if what you do is done with love for someone you love. Believe in yourself and know that it's within your power to do whatever needs to be done. We know you can. We've all done it.

"We are each of us angels with only one wing; and we can only fly by embracing one another." —Luciano de Crescenzo



STROKE CAREGIVERS HANDBOOK

Chapter 5

Nursing Homes - Never Say Never (Again)

Chapter Summary

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Stroke Changes the Playing Field

As part of your dutiful goodness, you may have promised yourself or your loved one that you would **never** consider a nursing home. Sometime in a pre-stroke conversation, you or your loved one may have even said, “I’d rather be dead than in a nursing home.” If so, this difficult decision may become the most difficult one you will ever have to make, because there may come a time when a nursing or assisted living facility just has to be considered.

There Are No Rules . . .

Unfortunately, there are no definitive rules as to when that time will arrive. It’s not like you can say when this, this, and this occurs, it’s time. Like all strokes, all caregivers are different. We come in various sizes and strengths - physically, mentally, emotionally. A stroke situation that one caregiver can handle without missing a beat might be too much for another who could be juggling a variety of other family, work or other personal stress factors. It comes down to knowing your limitations and then how far you can push yourself beyond that point. After all, back in an idyllic world before stroke, one might have felt that just dealing with anything to do with stroke was beyond our limitations. And then we found out just how tough we were - or weren’t.

. . . But Here’s a Rule

If pressed to provide a general rule, the classic textbook response is probably: **consider institutional care when the patient requires too much skilled care to live on his own and is too needy (emotionally or physically) to live with family**. A sub clause under that rule might be that the needs of the patient should not jeopardize the health and well-being of the caregiver and/or the caregiver’s family. Special and unusual circumstances will be touched on later in this chapter.

As you enter into this decision, feelings of doubt, personal guilt or failure are very normal. We’d all like to be Super Caregiver and have limitless reserves. These feelings may also be intensified by the patient’s fears of being in such a facility. While it is very difficult to move past these emotions, obsessing on them will ultimately stand in the way of you making the best decisions, with the clearest head, in reaching a balance of cost and good care. Hopefully, the information you read here will give you a sense of some control and direction - and also confidence that this is sometimes the best decision to make for everyone involved.

Two Considerations: Temporary or Permanent Placement

Temporary Placement - the easier decision

When a stroke survivor is ready to leave resident rehab (as determined by the doctor or the insurance company), a skilled nursing facility - what most people think of as a “nursing home” - may be suggested as an alternative to going “home.” The suggestion may have all to do with insurance coverage and nothing to do with the abilities or desires of the family. It may also be

that the patient's progress, or lack thereof, would be better suited to the care that can be provided by such a facility. It may mean that the patient needs more medical recovery before he or she is able to better respond to or participate in rehabilitation therapy. There is hope and indication that more improvement will take place, and placement in a nursing facility is a temporary measure.

As with most decisions involving temporary situations, this isn't that difficult a choice to make. You've gone through this decision-making process dozens of times in your life - "I can live any place for X amount of time," "I can make it through this root canal because in X time it will be over." Because X has a finite value, there's an end more or less in sight. It's do-able! Choosing the facility (coming up shortly) isn't easy, but the decision to do so isn't that bad. It may a decision you'll have to live with for only a short period of time.

Permanent Placement - hard-core decisions

When the patient has more medical needs than it is possible for the caregiver to provide, long-term institutional care must be considered. A facility that provides nursing care 24 hours a day, with a medical doctor on call, may be the safest place for someone who needs continuous medical care and assistance with the most basic activities of daily life.

Making this decision against the wishes of the patient who is able to verbalize his objection and against your own previous convictions and promises to yourself is, in a word, *tough*. If you haven't heard a nursing home horror story, you've been living without any social contacts and probably on some other planet for the past twenty years. As medical science finds ways to prolong life, but not necessarily the quality of that life, a recent statistic stated that a stay in a nursing home will be in the future of 45% of all of us. Ah, and you may have heard the even grimmer news that most people don't live very long once in such a facility - one to three years, maximum. However, to give more comforting perspective to these statistics, it's important to keep in mind that most individuals who go to nursing homes are already quite elderly and/or terminally ill before this decision is made. Unless your loved one has other threatening illnesses, they may be living in a nursing facility for some time - making your search process even more critical, especially in terms of the patient's long-term safety and comfort.

Special and Unusual Circumstances

A stroke survivor who still needs assistance, but who does not have family available or willing to help out, might be better suited to being in an Assisted Living Facility, also known as intermediate care facilities. These provide general custodial care and health monitoring, but generally do not have skilled nursing staff available.

Assisted Living Facilities typically are not covered by medical insurance, whereas, under some circumstances, skilled nursing facilities can be. But, if one is digging into the savings account (sans insurance) to pay for post-stroke care, an Assisted Living situation can be less expensive than a nursing home. But, as noted, the patient must be able to care for him- or herself with some degree of independence, and requirements for "how much" independence will vary from facility to facility.

Although a bit outside of the norm, Assisted Living can be an answer for survivors who may feel a need for separation from their family situation. This could be for a variety of reasons, including a sense of being a burden at home, or a personal need for less isolation and more personal freedom. While not completely able to live on their own, the patient has more independence in this type of facility, with some degree of care and health monitoring by those who are not so close to the situation as to be smothering. While family knows who and what the patient was before the stroke, and may be constantly striving to regain that status, an independent caregiver can more readily see that even in a diminished state, the patient is able to do much more on his or her own. Eventually considerably more independence may emerge.

Finding and Choosing a Facility

The first thing you must do is to resign yourself to work on the premise that **the perfect nursing home does not exist**. Having that thought clear and foremost in your brain as you start out on this impossible mission will make your job much easier. The next thing you have to deal with is that to make the best possible decision for patient and family, you should devote a considerable amount of time to research. You're not going to find every feature you would like in one facility, so you will have to prioritize and assign weights to the features you'd prefer. **Separate your list into Musts, Would be Nice, Can Live Without, Not at all Necessary**. And as the patient's condition changes, for the better or for worse, your priorities may change, and these features may jump to other columns. Reevaluation from time to time should be made to determine if what was a Must is now a Can Live Without.

Just as we discussed in Chapter Two, Choosing a Rehab Facility, one of the highest priority considerations is that **a facility must need the medical and safety needs of the patient**. If we're following The Rule put forth above for considering a nursing home - when the patient is too sick to live on his own and too needy for someone to assume his care - medical needs have to be up there at the top of any list. An on-site hairdresser, barber and nail salon might be a plus, but it can't be even put on the same page as doctors and nurses when making your lists. Important medical issues could include the following:

1. In case of emergencies, a physician available at all times, on staff or on call;
2. An arrangement with a good nearby hospital for quick transfer of patients;
3. At least one registered nurse or licensed practical nurse on duty day and night;
4. A staff trained and certified in CPR or advanced life support.
5. Physical, occupational and speech therapy - both group and individual - available by certified therapists.

Having devised your Wish Lists, the second order of priority should be to visit the available facilities. Someone must make in-person inspections. If the decision-maker cannot possibly do this, this very important task must be assigned to some trusted advisor. This is too big a deal to

rely on reports, virtual tours, brochures, or even too much on recommendations from others. You've got to be able to check out things like the smells in the halls and the general appearance of the patients. Are they smiling? The smile quotient is a good one to include in your decision-making criteria.

During the selection process for a Rehabilitation Facility, we suggested that location was not as important as excellence in medical care and technological advances. When it comes to nursing homes, however, being close to family and friends - a visitation network - is one very important thing to take into consideration. It would be better for the patient to be in a lesser facility that is near friends and family than to be in a first-class facility so geographically remote that no one comes to visit. And while we're discussing visiting, some issues that might go on your lists are:

1. Flexible visiting hours
2. Policy regarding leaving the facility for short day trips or overnight
3. A phone in the patient's room - at what cost?
4. Private visiting rooms
5. Can visitors bring food in for the residents?

Shopping around

This is one time-consuming process. Just as Christmas shopping for a blue oxford cloth shirt of a particular brand with button-downed collar of 100% cotton in size 16 with 35-inch sleeves for under X dollars is more difficult than looking for a dress shirt of any kind, any color, at any price. And you know what happens when you're in a time crunch on December 24 - you spend too much for not exactly what you wanted, and the recipient gets stuck unhappily with burnt orange with too-short sleeves. Choosing nursing homes obviously comes with far greater stakes and more anxiety than fighting post-holiday crowds at the department store return desk, so start your shopping early - just as soon as it becomes evident that you might be needing a skilled nursing facility. If the patient is going from a hospital to this facility, chances are insurance isn't going to permit an extended check-out time while you search for the perfect bed. Get moving!

Upon visitation of facilities, meet with the home's administrator and/or admissions director and bring a notebook with you with all your lists and research. (Besides being a good idea for your own organization, this will send a strong signal to prospective facilities that you mean business, and that you expect professionalism in return.)

Your homework should have included going to the website <http://www.medicare.gov> to get comparisons of nursing homes in your area. Under "Nursing Home Compare," you can obtain all the general information as well as a list of any citations against them. Print out the pertinent information and serve notice to the facility's administrator that you are an informed shopper.

Another website - <http://www.eldercare.gov> - will lead you to additional local resources for information about nursing facilities in your area.

Ask to see each facility's "Survey or Review Book" that must be visible and available to everyone. This will tell you what they have done to correct any citations. Ask for copies of their latest inspection reports. Maybe even be brave and ask if they have ever been sued!

From your initial visit, you should get a feel for the home's philosophy. Do they promote independence and encourage individuality? Is there a written statement of patients' rights and is it displayed where it can be seen? Are the residents and families encouraged to participate regularly in planning conferences and care? Is there a resident council where residents can voice concerns? Who receives and is responsible for resolving complaints? Is there an activities director? What is the policy on advanced directives?

Your power of observation should be fine-tuned to pick up on two of the most important criteria in selecting a facility: **(1) cleanliness and safety and (2) the other residents.** To meet licensing and accreditation demands, the facility should have wheelchair ramps, *solidly-built* handrails on both sides of the hallways, grab bars and easily-reached emergency alert alarms in toilet and bathing facilities and other safety features. Check to be sure the exit doors are clearly marked but secure enough so that residents don't leave when they're not supposed to. Your nose and eyes should determine the cleanliness. Check out windows and floors. Are halls free of clutter and every room is well lighted? Ask for a tour of the home, including the kitchen and laundry rooms. As for the residents, check out that smile quotient.

If possible, talk to them, but more importantly (and probably more reliably) talk to their visitors. Family members and caregivers will have the real scoop. Are they speaking freely or seem to be guarded in their responses? Are the residents dressed and groomed? Are they encouraged to move around or are they restrained in chairs? If the weather is nice, are they outside? Do the patients' rooms feel "homey" - are they allowed to have personal effects (pictures, small pieces of furniture, books) that will allow them to feel comfortable? Are there a variety of recreational, cultural and intellectual activities available for patients?

One important thing to note is the average age of the residents and how it compares to your patient and also why they're there. Putting a 50-year-old stroke victim in a home where most of the residents are 80-year-old Alzheimer's patients will not be a good match. Ask about other stroke patients and any special considerations made for them.

Especially if you are very limited in budget, try to see beyond choosing a home based on "new" versus "old." Some smaller, older nursing facilities may have excellent local reputations and be run with great pride and care, whereas a new facility may be run by a large corporation that cares only about its profit margin, cutting corners everywhere they can. "Old" does not necessarily equate to "dirty" or "incompetent." In choosing a hospital, a state-of-the-art modern facility is an important consideration when you are going to have a heart bypass. A long-term nursing facility, however, should be viewed for its qualities as a safe and humane home-away-from-home, with very different criteria at work.

The Staff

You may find the cleanest, safest nursing home in the world, but if the staff is impersonal, is not well trained, or there is too little of them, that is the worst stink of all. Your nose won't pick up on it, but your heart should. How they answer your questions will be your first clue. Are they open, friendly, happy to converse, or do they act like it's a chore and/or become evasive? By all means ask about the staff/patient ratio, the employee turnover rate and the average time employed by the facility. Ask if staff often has to work overtime to maintain minimum staffing levels, and beware of facilities that practices "forced" overtime. All facilities seem to be under-staffed or minimally staffed, but a severely overworked nurse is not what you want watching over your loved one. Watch staff in action as they interact with residents. Are call bells answered promptly? Are residents treated with dignity? Is privacy respected? Big focus point: Check out how the patients with no family members present are treated.

Eventually, food will likely become a major factor for the stroke patient - especially for long-term care. Even if the patient is getting nutrition through a tube when they arrive, this could easily change. Be sure and stick around for a meal service and ask if there's a dietitian, can special diets be requested, is help in eating available for those who need it, and can family members join residents for meals. Do patients go to a dining room or are they fed in their rooms and are there options? Chances are the food won't be four-star gourmet, but is it healthy and what you would consider edible? If you have the time, ask to sample a lunch in the patient dining room - or (if the facility won't serve you lunch) perhaps just have a cup of coffee in the dining area during mealtime. This is a perfect time to chat casually with patients and also observe how they are attended to during mealtime.

Shopped Out, It's Time to Purchase and Pay

Though we haven't mentioned price, we presume that you have been shopping within your and/or your insurance provider's budget. Make sure you know all costs up front, including what costs must be paid out of pocket, like laundry, medications, special equipment. If you working under Medicaid or Medicare parameters, you may come up with a more limiting set of options. A bed might not be available where you decide you want your loved one to go. Put your name on all desirable waiting lists - you never know what will come up and when.

Important note: if you're in a time crunch and have to make a decision in a hurry, it is probably a good idea to not sign any contracts for longer than month-to-month or even day-to-day. Sometimes you just don't know how things will turn out for your patient in what seemingly was a great facility until they've experienced it. And if you want out, you'll want out as easily and quickly as possible. Also, be extremely wary of something called "life care" contracts. These often involve paying large, non-refundable fees, and even sometimes transferring assets to the nursing home, in exchange for its promise to care for the resident for life. If a facility goes out of business, such a contract is worthless, and this is a big risk to take.

Before you sign any contracts, and if you are dealing with Medicaid, Medicare or insurance coverage of any kind, make sure that you have all approvals from the insurance company in

writing. Be sure that the approvals match the specific care level at the facility you are considering. “Misunderstandings” of coverage can cost some pretty big bucks, when it comes to nursing homes. Don’t leave yourself vulnerable.

In fact, have absolutely *everything* in writing. Every question, every comment, every complaint needs to be sent to the administrator with copies to every pertinent staff member. Keep copies of everything. Serve notice (in writing) as to who is to be contacted for which part of the patient’s care. Ask to be notified when any medications are changed, added or discontinued, when any incidents occur, when doctors see the patient and to receive copies of their reports when they do.

Get to know the staff personally - as many of them as possible, especially the nurses and the aides. Do not respect visiting hours. Show up at odd hours so that the staff doesn’t know exactly when you’ll appear. Carry a clipboard or your big notebook and keep notes while keeping staff on their toes wondering what’s going into the notebook. Remember from your home tour where the offices are and how you can find the head honcho when needed.

Get to know other patients’ family members and agree as a group to watch out for others and communicate anything you feel is not right.

Other Resources

Find out the contact information for the Patient Ombudsman for your region. That is a position required by the government under the Disabilities Act. Every state must have them, and they can be very helpful to you in finding and ensuring care.

Look in your phone book or on the internet for any sort of Brain Injury Services or agencies or organizations with similar names. Contact your local Council on Aging. Look for any Department of Rehabilitative Services. All this research takes time but you may be rewarded with some delicious fruits for your labor.

It is a very difficult decision to turn the care of someone you love over to someone you don’t know, and it may take a long time to adjust to the decision you’ve had to make. The patient may adjust lots faster than his or her caregiver. It may be all a matter of attitude and acceptance. The perfect situation doesn’t exist, but the world of stroke is in itself a whole lot less than perfect. It just isn’t a perfect world we live in.