

Be An Informed Advocate

As mentioned earlier I belong to the Stroke Caregivers Support Group and had written them for advice. I then sent the following information to be included in the *Stroke Caregivers Handbook* which is on the Internet at <http://www.strokenetwork.org/>.

1. Advocate. You are probably going to have to act as your parent's/loved one's advocate in many ways; however, do not take on what they can do. When they have already lost so much, it is a very fine line to do what they cannot do and not assume their right(s) to handle what they can. Sometimes it is a judgment call on what they can or can not realistically handle. Err on their side until it is proven they cannot handle it. Be careful not to demean your parent's intellect or capabilities, remember they managed to raise you. Self-esteem is so important and age should be respected, not negated at this time of their life. If a doctor, nurse, staff member, is asking you questions your parent is capable of answering (especially if your parent is present)...politely say "ask mother/father." Be certain to let your parent know you don't resent having to do for them, remind them they took care of you, and if the situation was reversed would not they now be taking care of you.

2. Leaving the hospital. If the patient has a catheter or is hooked-up to other equipment that they won't be using at home or a nursing home, ask about having it removed two or three days prior to moving to ensure the body is going to accept the change without major problems. Talk to the doctor/nurses in detail about what to expect and what future treatment needs will be. Understand and know limitations and care requirements prior to leaving the hospital. Do not accept such comments as "all that will be given to the health care facility/home care agency". You need to know the care requirements to ensure that proper care is given after the move.

3. Skilled Care Facility. All are not equal. Spend as much time as possible "shopping" for the best that you can afford. Talk to patients and family members, if possible, away from administrators/employees. Visit at times other than 7:00 A.M. to 3:00 P.M., when most facilities are fully staffed. Normally there is a shift cut-back from 3:00 P.M. to 11:00 P.M. and another cut-back from 11:00 P.M. to 7:00 A.M.. If visiting at lunch/dinner time, patients should be out of their rooms, if not, wonder why and ask questions. On weekends, you may discover that staff coverage is very "slim." Ask about the facilities therapy programs (speech, physical, occupational).

After selecting a care facility you must be responsible for ENSURING the staff knows the patient's limitations and requirements. Make it a point to visit as often as possible, and most important, do drop in at unexpected times and occasionally call to ask how the patient is doing when you cannot visit. Though we believe the staff should automatically check every two hours if our loved one is incontinent and bedridden, the truth is that facilities are understaffed and even the best have emergencies erupt and sometimes forget to check. This is especially a problem with a patient that cannot use the call button. Yelling and losing one's temper is usually not the best course of action, but firm, concise speech when expressing concerns can help get your point across.

When visiting, try to do things for them...brush/wash their hair/wash their face and hands. If you have time, and see the staff are overwhelmed, straighten up the room, and if feasible, change the sheets. This is their home and when you can help, your parent will feel your love and continued support and care. The staff will see that you are trying to help when they are busy and may show their appreciation by trying to do more for your loved one when you cannot be there. REMEMBER, the staff does not have much, if any, time to "VISIT" with your parent. To keep the time from dragging try to make out a schedule with family and friends to visit when your parent is not in therapy/watching their favorite TV programs/etc. Mental stimulation is vital and depending on your parent's capabilities, supply them with books (audio if they cannot read), puzzles, schedule rotation of visitors...anything to keep their minds active and have less time to think about their changed situation.

CNA, etc. in these facilities are hardworking and not highly paid. Be appreciative and respectful of those caring for your loved one when you are not present.

4. Therapy, of whatever type, is essential. It helps maintain, and sometimes retrain, residents' bodies and minds...e.g., muscle tone/flexibility, coordination/motor skills, speech, etc. Therapy can be difficult for all involved, resident/family/therapist. As the resident's advocate, you need to make the effort and take the time to introduce yourself to the therapist and sit in on the first few therapy sessions. Let the therapist(s) know that you, as a care giver, want the best possible care for your loved one and ask for a list of things you can do to assist the therapist and the resident. After therapy commences, periodically stop by to offer encouragement, check on progress, and learn how you can help keep-up therapy on weekends and other times you are visiting.

Depending on your loved one's condition, it may be difficult or impossible for them to verbally communicate needs and pain to the therapist. The first few therapy 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. This may be a hand/finger/eyebrow signal...it doesn't matter as long as the resident can communicate to the therapist.

Most residents are automatically given medication on a set schedule. Talk to the nurse/doctor in charge of the resident's care and ask about scheduling pain medication an hour or two prior to therapy. My mother was getting her pain medication at 10:00 A.M. with her other "normal" medication and as she had therapy prior to 10:00 A.M. she had difficulty doing some of her physical therapy. After talking to the nursing staff she began receiving pain meds at the 7:15 A.M. morning rounds; because she had less pain during therapy she was able to tolerate more. Since this incident, there is a new policy to give residents having morning therapy their pain medication on early morning rounds.

5. Medical Treatment/Information. Don't be afraid to ask questions and have information explained that a lay person can understand. DO NOT LET MEDICAL PERSONNEL, INCLUDING DOCTORS...talk "over your/your loved one's head." It is vital that you know what the treatment is/what the treatment is for/what results should be forthcoming. Do not be afraid to ask for a second opinion. Do not rely on

nurses/doctors/medical records keeping all the information required or being readily available. Start taking notes immediately and keep your information in a notebook or expando file where you can review/pull anything you need to refer to or consult with doctors who may have forgotten information (they do have more than one patient). This is critical in nursing homes due to frequent changing of health care personnel, i.e., new doctors/therapists.

6. Medical Bills. Keep copies of EVERYTHING. Before mailing off insurance forms for reimbursement, make copies, note date mailed and any other pertinent information. Keep copies of payment checks. Do not be afraid to ask about questionable charges. If you know your loved one didn't have a test or an aspirin, speak up. If the insurance company denies payment, don't just accept it, fight back. If necessary get the doctor to write a letter on why the treatment, ambulance trip, etc., was necessary.

If keeping track of insurance/bill payments, following up, is impossible, there are companies/services who do this...for a fee. However, your loved one is still responsible so you need to ensure the service is a good one and follow-up occasionally to ensure the work is being done.

7. It used to be that when we were thinking about life insurance requirements, we only thought of our spouse and/or children. You need to consider if loved ones you are responsible for, in addition to your spouse and/or children, would be provided for should anything happen to you. You may think they are adequately provided for; however, are you considering all the time and care that you individually provide? When you start factoring in the cost of having to pay someone to fulfill the many duties, that you may not even realize you are presently responsible for, you may come to the conclusion that maybe you should purchase more life insurance with your parent/loved one as the primary beneficiary.

8. Living Wills/Powers of Attorney/Supplemental Insurance. Ideally, all of us should think ahead of what would happen if we are incapacitated and prepare living wills and powers of attorney appointing someone to make decisions for us should we be struck with a health situation. Unfortunately, most of us don't. If your loved one has not prepared for this situation, as soon as they are able, try to get this done. You may need to involve the doctor and an attorney to ensure that all requirements of competency are met.

9. Stimulants. Listen to the doctor but also access the damage yourself. If they love music and/or books, bring in a radio/cassette player and play the music/books they love. If they enjoy reading the paper/Bible/certain magazines, read to them. Talk to them normally and have visitors speak normally. If they are unconscious DO NOT ASSUME they cannot hear you/understand you. If you need to discuss something that might upset them, leave the room. Cheer up the room, place cards where they can be seen, bring in one or two of their favorite things from home. A guest register with a few personal notes might be something they would enjoy when they wake up to see who has been to visit them (this can be a simple spiral notebook), who brought flowers/gifts

and sent cards. If they are awake but their speech has been affected...if they can write, get them a pen and tablet or etch-a-tablet, if they can not write...supply a few key words on index cards they can point to (if their vision has been affected, the words need to be written as large as possible)

10. Guilt/Anger/Depression. When a person we love is incapacitated, most of us at some point find ourselves feeling angry that it happened. And when we feel overwhelmed with the worry, stress, exhaustion, and extra time that it takes to help take care of them, there will be moments when we become angry and/or resentful which increases the guilt, and this frequently leads to depression.

There are also going to be moments when the one who is incapacitated is going to feel angry, saying "Why me? I've always taken good care of myself and done what the doctor advised," what have I done to deserve this? etc." Resentment and frustration that they can no longer do "normal" things or express themselves the way they used to. Worry about money, using up all their life savings and worrying about their spouse and their children having to take care of them. Additionally, they may be dealing with losses of their home and, if elderly, loss of family members and friends, which means the loss of sharing memories with those who shared in the making of those memories. Many times these "frustrations/losses" are vented on those closest to them...their children/spouses.

From the beginning, the person incapacitated and family members need to be made aware that the anger, resentment and resulting guilt feelings (and possible depression) are normal and just part of the process. In many ways it is like a death in the family and there is a similar "grief" process as everyone attempts to deal with the new "life situation." A friend recommended a book, Dancing with Anger which helped considerably with her own anger and her mother's.

11. Help. As Americans we frequently feel we should be able to "pull ourselves up by our bootstraps." This may not be as true as it was for our parents' generation...but on the whole I believe we still hesitate to admit that we aren't coping. Information on availability of programs, books, national hotlines, etc., to assist in finding the best treatments, coping, and where to get assistance for problems encountered needing to be readily accessible.

12. Grand mal seizures can happen with stroke patients. Six months after my mother's stroke, with no warning, Mother had her first grand mal seizure. At that time, we learned this was not uncommon. Mother's medical staff were surprised that we had not been told that this could happen. Due to doctors' heavy patient load, paper work, etc., it is very possible for your family's doctor to overlook providing you with pertinent information. This is why it is essential for you to ask questions, questions, and more questions. It is also important that you read literature that is readily available regarding your loved one's condition so you can ask pertinent, necessary questions. Because of Mother's grand mal seizures, it was necessary that any time she uses the bedside commode that someone be with her should she experience a seizure. This is given as

an example of why it is so vital that we have the knowledge of parent's medical condition, treatment, and prognosis.

Never forget -- **YOU ARE YOUR LOVED ONE'S ADVOCATE.**