

C H A P T E R
TWO

Self-Advocacy

After a stroke, there is rarely any “going back.” While the road to recovery almost always takes more time and effort than anticipated, there are things you can do to make the journey easier to travel. This chapter is designed as a road map for your stroke recovery journey.

Foremost, it is essential to recognize that while you have suffered a stroke, you are not a victim – you are a survivor. Taking a positive approach to your recovery is the single most important step you can take. You may hear from different people including family or members of your own healthcare team to not get your hopes up, or to only expect a certain amount of progress. While a significant portion of recovery is done within the first 6 months to a year after a stroke, research shows that progress can be made years after a stroke. Remember – recovery is a lifelong journey. Stay positive. Stay the course.

What is Advocacy vs. Self-Advocacy?

The definition of advocacy is “active support,” especially the act of pleading or arguing for something. In this case it is for yourself – your well-being. To be a self-advocate is to be a supporter, believer, encourager, and activist of and for yourself. It is standing up for your needs in a clear, specific and firm way. It is not being afraid to ask for help when you need it.

Why is Self-Advocacy Important?

Suffering a stroke is often an overwhelming experience that takes from you a sense of control – over your physical and mental health and well-being. Practicing self-advocacy allows you to empower yourself – to personally take responsibility in making the most of your recovery from stroke. You have a say in what you want and need, and can directly impact your own quality of life.

Self-Advocacy Steps

Prevent another stroke

Take the steps necessary as prescribed by your doctor to prevent another stroke. This includes things such as monitoring your blood pressure, finding out your cholesterol numbers and working to control them, quitting smoking, etc. (see next chapter).

Educate yourself

One of the most important things you can do is educate yourself. Gather information to help you understand what has happened to you, and what to do next. Learn about stroke, your disabilities, and what treatment options you have. Find out what resources are available to you. You can find this information by:

- Reading books, pamphlets and fact sheets
- Watching informational videos, CD-ROMs or DVDs
- Browsing the Web or having a friend or family member do it for you
- Attending a workshop, seminar or talk
- Talking to a social worker, case manager or community resource specialist
- Contacting National Stroke Association at 1 - (800) STROKES

Ask questions

Seek out and listen to those individuals who are familiar with or specialize in the area of stroke and rehabilitation. This not only includes members of your healthcare team or other stroke experts in the community, but other stroke survivors as well. If you are uncertain or not satisfied with what they are telling you, seek a second opinion.

Determining Wants and Needs

There are many considerations which should go into planning for your care after hospitalization. Your needs and the resources available to meet these needs are key. Many families have found it helpful to think about several alternative plans. This way it is possible to respond effectively to whatever situation confronts you. Your social worker and therapists are the best sources of accurate, reliable information on options that fit your values and resources. It is important to try to address the following questions in an open manner. Be sure to take a realistic inventory of your strengths and weaknesses.

Physical

- Can you transfer from a wheelchair to a bed independently?
- Can you move independently whether walking or in a wheelchair?
- Can you control bowel and bladder functions during the day and at night?
- Can you carry out basic independent activities of daily living (dressing, personal hygiene, etc.)?
- What communication limitations are there? Can you call for help?
- To what degree are visual and perceptual problems present?
- Do you have special care needs such as a catheter, diabetes, etc.?

Emotional

- Do you or others think that you behave appropriately?
- Have you experienced emotional difficulties in the past or present, such as severe depression? If so, what kind of special care is needed?
- Do you thrive on social activity or is there a strong need for privacy?
- How do you feel about not living at home?

Anticipated Improvement

- What is your potential for improvement in each of these areas?
- What follow-up services, such as outpatient or homebound occupational therapy, physical therapy, speech therapy, psychotherapy, etc. are required to achieve the goals?

Financial

- What are your financial resources, including whether or not insurance will cover needed services?
- Are you eligible for assistance through government entitlement programs, such as Medicare, Medicaid, Social Security Disability, etc.?

Caregiver Needs and Limitations

- What other responsibilities and time commitments does the potential caregiver have? (Include family, work, community, and recreational commitments.)
- Is the caregiver emotionally and physically healthy?
- What are the family financial resources?
- What is the physical layout of the place of residence (home)?
- How does the family feel about caring for you?
- What were relationships like before the stroke?
- How has the stroke affected those relationships?
- How does the potential caregiver feel about the changes in you?
- Is time spent together rewarding for all involved?
- Is guilt or external pressure involved in their decision to help care for you?

These are tough questions that you and potential caregivers must ask and answer for the sake of everyone involved. As difficult as they may be, if these questions are answered either before discharge from the hospital, or prior to a specific type of care being needed, everyone will face the new situation having made a conscious choice. Remember, whatever decisions you make should be based on your own individual situation, not on what some other family did or what you think is expected of you.

Goal Setting

Developing Goals

Developing goals or a plan of action can help you make decisions and choices. In the months following a stroke, the rate of recovery predictably slows. Don't become discouraged. Most hospital rehabilitation programs take place in a highly structured environment where you

follow a daily schedule of therapies designed to meet rehabilitation goals. There is a great deal of opportunity to be around supportive and understanding people. Isolation and inactivity are rarely a problem.

Upon returning home, you can feel overwhelmed by all the spare time. In everyday life, all of us rely on our work, family and community activities, as well as on our hobbies and interests to give us a sense of purpose and self worth. After your stroke, you may find that physical changes require you to develop new interests and involvements so that you can continue to feel good about life under changed conditions.

Developing these new interests, strengths and abilities will be made easier by setting long-range as well as short-term goals. A good way to achieve these goals is by planned daily activities.

Setting goals can help you deal with the times of discouragement that come during the recovery period. A crucial part of setting goals is examining what you can reasonably accomplish. You must take into consideration what you would like to do given your current abilities and disabilities. Goals need to be *realistic*. Goals also need to be *flexible*. It is also helpful to set time guidelines for completion of your goals. There are four main areas to think about:

- Physical rehabilitation
- Recreational/social
- Family/community
- Personal

In each area, there will be certain activities necessary to reach the goal. Breaking each step into smaller parts can help both yourself and your family see that real progress is taking place. Some of your goals could fall into several categories. Place your goals in the category that seems most sensible to you.

Achieving Goals

All goals should be “measurable,” meaning you must be able to tell when you have accomplished the goal or how close you have come by measuring tangible results. “Doing a better job at my leg exercises” is not specific enough to be measurable. “Walking around the block with my cane” is measurable, because you can clearly tell when you have accomplished a trip around the block.

Setting Long-Term Goals

To begin goal setting, write down your long-range goals in each of the areas described earlier – physical rehabilitation, recreational/social, family/community and personal. Don’t rush the process. Take your time during quiet moments to think carefully; allow goal planning to be a personal process that helps you learn more about yourself.

Setting Short-Term Goals

Short-term goals are measurable goals that are necessary in order to accomplish the long-term goals, but may or may not be activities in and of themselves. For example, if your long-term goal is “joining a stroke club,” your short-term goal might be “locate available stroke clubs in my area.” If your long-term goal is “taking a weekend trip,” your short-term goal might be “ride in the car for an hour.”

Problem Solving

When you encounter unusual periods of stress in your life, problem-solving methods which worked in the past can begin to break down. Sometimes stress makes even small problems seem overwhelming. It is impossible to anticipate all the problems that might be encountered by you or your family upon leaving the hospital or rehab program. However, there are techniques which, when applied to any problem, can contribute to finding a solution. One thing to keep in mind is that problems need to be solved one at a time.

- Acknowledge the problem.
- Identify the problem/make the problem clear.
- Observe yourself carefully and write down how you behaved, reacted, responded or thought when confronted with the problem.
- Identify possible causes.
- Decide what you want to accomplish.
- Brainstorm solutions.
- Review your solution list.
- List specific things that you will do that will contribute to carrying out your chosen solution.

Evaluating Evidence to Make Informed Decisions

If you are like many stroke survivors, conventional medical approaches may have only taken your recovery so far. Perhaps you still have speech, movement, and/or cognitive problems that impact your quality of life and ability to perform valued activities. Today more and more survivors are turning to alternative medicine treatments.

An “**alternative medicine**” treatment is one that is not traditionally embraced by Western medicine. For example, acupuncture is one “alternative medicine” approach that is used in many diagnoses, including stroke; another is hyperbaric oxygen therapy. However, whereas acupuncture has many research studies supporting its effectiveness, hyperbaric oxygen therapy does not. So how do you determine which, of many available approaches, might have merit?

You and your family need to be able to sift through the multitude of rehabilitation choices and make an informed decision on what is best for you. In addition, it is very important that you be sure that your healthcare providers are aware of good care options that may be available. There are several things that you can do to make yourself a more informed consumer, and to ensure that the therapies that you are receiving have a body of evidence supporting them:

- Look at the “evidence.” A body of “evidence” consists of research studies that have been performed on a particular device or therapy; if several studies with a large group of people have been performed on a particular therapy, and they support the effectiveness of the particular therapy, we say that the therapy is effective and it has evidence to support it.
- Ask your healthcare providers to share the evidence supporting the techniques that they are providing to you. Don’t just assume that what they are doing works. Indeed, even if you are showing changes, it may be due to the therapy, but it may also be due to other factors. Ask for articles, as well as reasons why they think it is the best fit for you.
- Use Medline. Medline (www.pubmed.gov) is a computerized index of most “good” articles that have been published in a certain area. For example, if you were interested in speech therapy after stroke, you could go to Medline, type in “speech therapy stroke.” The latest studies on speech therapies would then come up. Furthermore, if a company is selling a particular product or therapy, making certain claims, or if a therapist tells you the specific name of the technique or device he/she is using, look it up on Medline. Medline is run by the National Library of Medicine and is, thus, supported by your tax dollars. It is also what researchers use when looking up the effectiveness of certain techniques.
- There should be MULTIPLE studies performed on a technique. Be skeptical of therapies where only one study, or no studies, have been performed. The more positive studies that there are, the more people on whom the technique has been successfully tried, and the more generalizable it may be to your circumstances.
- Be skeptical of any product claimed to be effective against a wide range of unrelated diseases – particularly diseases that are serious. Often, stroke survivors and families approach their doctor about new therapies that are being advertised. While some of these therapies are legitimate, some of the claims are grandiose, and often the company will claim that the technique is a “cure all” (called “snake oil” or an “elixir” in the early 1900s). Be very skeptical of products with such claims. Even if the symptoms sometimes look similar, every disease has its own cause(s) and progression(s). Do not assume that just because something may be effective in one group that it applies to your circumstances.
- If you are reading an ad from a company and there are claims that it works, ask where the data were published and, if not published, ask why. There are many alternative therapies that are heavily advertised but do not actually have scientific evidence to justify their use. Be wary of “infomercials” as well. Many of the people shown are paid to talk about the product.

- Be skeptical of a device or technique that only has subjective claims. Videos or testimonials can be great ways to sell a product, or illustrate how something was successful for one particular person. But there may be alternative explanations for one person's (or even a group of persons') successes. Some stroke symptoms also pass with time, or improve on their own. The only way to truly discern if something is going to work reliably from patient to patient, and to rule out the effect of something else, is to systematically test it with a group of patients, as is done in research. Demand these types of studies from companies marketing products and techniques.
- Be sure to tell your doctor about any herbal or over the counter medications or alternative therapies you are taking/are involved with. These actions could negatively impact other areas of your treatment regimen (i.e. other medications or therapies).