

## **Caregiving after Stroke**

When a stroke occurs, the life of your loved one as well as the life of the caregivers have changed dramatically. One thing to remember, is no one can understand what you are going through, unless they have been through caregiving themselves.

Caregivers may be spouses, partners, children, brothers, sisters, and friends. They may provide care for only a few months, or for several years. Although being a caregiver may be a rewarding experience, it also can be frustrating and stressful.

As a caregiver, you will experience a vast array of emotions and needs after your loved one has had a stroke. A few of these emotions may be:

- A sense of isolation
- A fear that the you cannot provide the adequate care
- Guilt
- Frustration
- Sadness
- A fear of abandonment by family and friends

These are all normal feelings.

A caregiver of a stroke survivor will need extreme patience, and understanding that their loved one has had a traumatic brain injury and recovery will be long. A “Never Give Up” as well as “You Can Do It” attitude must be front and center at all times. Remember, the survivor is the one that is fighting to regain themselves.

There are many problems that may happen after a stroke. Most are common and will improve with time and rehabilitation. Common physical conditions after a stroke include:

- Weakness, paralysis, and problems with balance or coordination.
- Pain, numbness, or burning and tingling sensations.
- Fatigue, which may continue after you return home.
- Inattention to one side of the body, also known as neglect; in extreme cases, you may not be aware of your arm or leg.
- Urinary or bowel incontinence.
- Speech problems or difficulty understanding speech, reading, or writing.
- Difficulty swallowing.
- Memory problems, poor attention span, or difficulty solving problems.
- Visual problems.
- Depression, anxiety, or mood swings with emotional outbursts.
- Difficulty recognizing limitations caused by the stroke.



Your job as a caregiver starts immediately in the hospital, and will transition from inpatient rehabilitation, to the home where the most support will be needed. Some survivors may have loss of speech, and will need an advocate. There can be a lot to learn, so take advantage of every opportunity to

learn about stroke and your loved one's condition and prognosis. Talk with the health care team about what the stroke recovery and rehabilitation process looks like, and ask them for any bit of information they have.

Attend as many rehabilitation sessions as possible so that you can support your loved one during their recovery. You can get instruction from the rehabilitation specialists to see what you can do on off hours in the hospital as well as in the home.

Encourage your loved one to practice all aspects of their rehabilitation as much as possible. Repetition is key, practice, practice, practice!

Remember, do not always jump in to help. We may want to make the survivor feel safe, but it is imperative that the survivor work as hard as they can to recover. Be supportive, and allow survivors to do things for themselves. This will help them to be more confident and independent, and doing more for themselves will help the caregiver in the end.

### **Going home after Rehabilitation**

Recovery does not end, when leaving rehabilitation. **RECOVERY NEVER ENDS.** A small gain in recovery continues all the time. When a survivor is home, encouragement and support will be needed for the survivor. A new life is beginning and things will be challenging for both survivor and caregiver. A social worker at the rehabilitation center will be able to guide you as to what your steps will be when going home.

Many questions will be unanswered as recovery differs from person to person. There are survivors that may be able to walk out of rehab almost fully recovered, while others will be faced with many deficits and will need 24 hour assistance.



Keep in mind, the stroke survivor may need the following:

- Personal care such as bathing and dressing (depending on what type of stroke experienced)
- Coordination of their health care needs including medications and doctor and rehab appointments to help the survivor maintain and increase his or her ability to function. Study up on the medications prescribed and be aware of their side effects.
- Meal preparation. The survivor may need a special menu, and foods once adored may now be shunned. Take cues from your loved one and make you allow them some choices.
- Personal finances, such as paying bills will need to be addressed. You may want to think about an accountant
- As a caregiver, you will need to educate yourself as to your rights of caregiver. You have rights to access your loved-one's medical and rehabilitation records. You are entitled to copies of the medical records, including written notes and brain imaging films.

### **Safety in the Home**

Safety is key when caring for a survivor. Your loved one will want to do daily tasks on their own, however, they may not have the capability to simple tasks as they once did.

Inquire about being provided an occupational therapist to asses and determine if you need to do anything to make the home safer.

- You may need to move the bedroom to another floor to avoid stairs, remove rugs to prevent falls, or install grab bars and seats in the bathroom and shower.
- If your survivor is in a wheelchair, make sure that they cannot tip the chair over.

- In some cases a hospital bed will be necessary in the home. If not, then make sure railings are fitted on the bed so the survivor does not roll out.
- Remove any glass items such as vases and/or candles so they do not fall and break.
- A baby monitor is a great way to keep an eye on a survivor when you are not in the room with them.

### **Prepare for Emotional Changes**

Get ready for behavior or mood changes. The losses from stroke, whether temporary or permanent, can be devastating to the survivor. There are a lot changes in behavior or mood swings could happen to your loves ones.

Stroke survivors are at risk for depression and can significantly affect their recovery and rehabilitation. Isolation is a common and can be devastating for a survivor. Make sure that your loved one socialized with friends, family or even support groups to maintain normalcy. If you start to see signs of depression, consult with a physician immediately to develop an action plan.

### **Be aware of the risk factors for a second stroke**

Survivors who have had one stroke are at high risk of having another one if the treatment recommendations are not followed. Make sure your loved one eats a healthy diet, exercises, takes medications as prescribed, and has regular visits with their physician to help prevent a second stroke.



## **Taking Care of Your Life**

There are several key things to remember as a caregiver, primarily to take care of yourself and your needs. Remember that caregiving is a choice that people can fall into unexpectedly. Do not let your loved one's recovery and rehabilitation always be the only focus.

You deserve good health and quality time to yourself. These two things may be the best gifts you can give to your loved one.

Caregiving is not a one-person job. Look for, ask for, and demand help if necessary.

Ask your family members and friends to help with respite care.

Accept help and suggest things for people to do. Likewise, be aware of what you can and cannot do. Set realistic goals and priorities.

Educate yourself. Learn about new medical treatments and ideas.

Be aware of depression. Some signs of depression include:

- A loss of energy
- A change in appetite
- Feelings of hopelessness or worthlessness
- A loss of enjoyment about things that were once pleasurable
- If you feel depressed, do not delay in getting help. It is possible to get a referral for a psychiatrist or to get antidepressant medicine.

