



**A Guidebook  
for Caregivers  
of Veterans  
with Stroke**

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# **Giving Hope**

## **A Guidebook for Caregivers of Veterans With Stroke**

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## ABOUT THIS GUIDEBOOK

A stroke happens very fast. After a stroke, it can be hard for the survivors *and* their caregivers to learn how to manage their lives. Plus, taking care of yourself while you care for a stroke survivor is very important. A healthy caregiver can give better care. Also, stroke survivors with healthy caregivers do better after their stroke. This guidebook will help you, your family and the stroke survivor you care for during a stroke recovery.

The goal of this book is to give back to the veterans and caregivers who were a part of our study. The information in Chapter 1 of this guidebook was obtained from the *National Stroke Association*; the *American Stroke Association*; and the *Partnership for Clear Health Communication*. Chapters 2 & 3 of this book are based on findings from a research study which described how stroke survivors and their caregivers manage daily life after a stroke. Caregivers and stroke survivors just like you talked about their daily lives after a stroke. The knowledge, feelings, hopes and fears of these veterans and their caregivers have shaped this book. We hope to share their wisdom with you, to support you, and to give you helpful hints. These will help you understand how to give care to veterans after a stroke while taking care of yourself. The message of this book is this: things change after a stroke and it helps to know what to expect. Feel free to share this book with the person you care for and other friends and family who can help you and the stroke survivor in your life. The gift of love and support you give to a stroke survivor is important to a healthy recovery. Thank you for all you do to support our veterans.



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**“The best thing about the future is that it only comes one day at a time.”**

## CHAPTER 1

### THE BASICS ABOUT STROKE

Stroke survivors and their caregivers have many questions after a stroke. Although doctors and nurses talk with patients and caregivers about stroke, people often still have some questions when they leave the hospital. This chapter provides answers to questions often asked by stroke survivors and their caregivers. The information in this chapter was obtained from the *National Stroke Association*; the *American Stroke Association*; and the *Partnership for Clear Health Communication*.

Questions answered in this chapter are:

1. What is a stroke?
2. What are risks for having a stroke?
3. How do you prevent future strokes?

#### 1. What is a Stroke?

A stroke happens when the brain does not have good blood flow. This is caused when a blood vessel is blocked by a clot or has become too narrow for the blood to pass through it. A stroke can also happen when a blood vessel ruptures in the brain and the brain cells lack blood flow because a blood vessel in the brain ruptures causing the nerve cells



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to die. Once the nerve cells die, the part of the body the nerve cells control cannot work. This causes the person to lose control of that part of his or her body.

It was once believed that when brain cells are damaged, they cannot recover. New research suggests the brain can sometimes recover. There is now hope that the effects of the stroke may not be permanent.

The signs of a stroke can last for minutes or come and go in seconds. Stroke is always an emergency. The signs of a stroke are listed below.

✓ **Signs of a Stroke**

- Numbness or weakness of the face, arm or leg on one side of the body
- Sudden confusion
- Sudden problems talking or slurred speech
- Sudden trouble seeing
- Sudden trouble walking or feeling dizzy
- Sudden, severe headache for no reason
- Sudden problems with simple things, like eating or using a phone

**If you or a loved one is having one  
or more signs of stroke seek help or  
call 9-1-1 or go to the emergency room!**

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### ✓What is a TIA -Transient Ischemic Attacks?

A TIA is like a mini-stroke. Symptoms may be brief and not as severe as a regular stroke. These brief symptoms are the warning signs of a stroke. TIA is caused by a blood clot blocking an artery for only a moment. If you have had any of these signs in the past and ignored them, talk with your physician about this. Warning signs should not be ignored. **Call 9-1-1 or go to the emergency room.**

### 2. What are the Risks of Having a Stroke?

Many strokes can be prevented. It is important to know if you or the person you care for are at risk for a stroke. If you are at risk, consult your doctor right away and talk with him/her about these risk factors.

The risk factors for stroke are listed below:

- Smoking
- Lack of exercise of any type
- Eating an unhealthy diet
- Chronic stress
- Having health conditions like:
  - Heart disease
  - Previous TIA attacks or stroke
  - High blood pressure
  - High blood sugar level (diabetes)
  - High cholesterol



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If a family member has had a stroke in the past, you may be at greater risk of stroke. However we do not know for sure if heredity plays a roll in stroke. These health conditions can increase your risk for stroke. Next we talk about managing these health issues to prevent strokes.

### **3. How do You Prevent Future Strokes?**

There are many ways to prevent future strokes as seen in the list below:

- ✓ Being aware of heart disease
- ✓ Managing high blood pressure
- ✓ Controlling blood sugar level and diabetes
- ✓ Managing high blood cholesterol
- ✓ Avoiding smoking and drinking alcohol
- ✓ Exercise and weight management
- ✓ Eating a healthy diet
- ✓ Getting regular check-ups
- ✓ Talking with your healthcare provider
- ✓ Taking medicine as prescribed

These topics related to preventing future strokes are discussed in the next sections.

#### **✓ Being aware of heart disease**

Having heart disease increases your risk for having a stroke.

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Having frequent check-ups with a doctor and getting early treatment can help prevent heart problems. For example, some people don't feel an irregular heartbeat, which can be detected by the doctor and treated to prevent a stroke. If you have questions about heart disease, talk with a doctor or nurse - you may save a life.

✓ **Managing high blood pressure**

High blood pressure can be related to having a stroke. Managing your blood pressure is key in preventing a stroke. Blood pressure levels are listed below. Do you have high blood pressure?

**Stop to Monitor Your Blood Pressure Level!**



**140/90 or higher - High risk for a stroke**  
121-139/81-89 - Needs to be closely monitored  
120/80 or lower - Low risk for stroke

You can check your blood pressure at home on a daily basis. The VA may provide an electric or battery operated blood pressure machine. You can also purchase one at a local store or a pharmacy. It is helpful to keep a list or daily blood pressure records to show your doctor at each visit. If you are concerned about high blood pressure for yourself or the person you care for, talk to a doctor or nurse. If you or the veteran you

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care for are taking blood pressure medicine, do not make any changes to your medicine routine, always talk with a doctor first.

✓ **Controlling blood sugar level and diabetes**

Diabetes is a major risk factor for stroke. In Puerto Rico, diabetes is more common than anywhere else in the United States. At least 12% of Puerto Ricans have diabetes, and 60% are overweight. Both increase the risk of stroke. Managing diabetes is an important part of staying healthy and preventing a stroke. If the stroke survivor you care for has diabetes, the VA may provide a blood sugar machine (Glucometer) to test blood sugar levels. They can teach you how to use it and may prescribe medicine to control blood sugar. People with diabetes often know how to manage their medicine on a daily basis with the help of a blood sugar machine (Glucometer). It is a good idea to keep track of daily blood sugar levels. Keep a list of daily blood sugar levels and share the list with your doctor at each visit.

✓ **Managing high blood cholesterol**

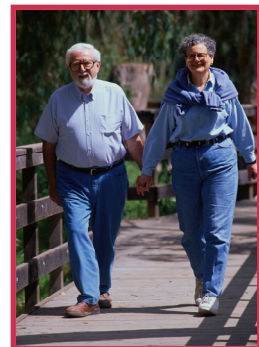
High blood cholesterol is another risk related to stroke. Cholesterol forms a plaque that builds up inside the walls of blood vessels. Cholesterol levels above 200 can cause the plaque to stick to the

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walls of your blood vessels and block blood flow. Getting your blood cholesterol level checked every year and getting care if needed can prevent a stroke or heart attack.

✓ **Avoiding smoking and drinking alcohol**

If you stop smoking you reduce the risk of having a stroke. Drinking more than 2 alcoholic drinks a day may increase the risk of a stroke. Alcohol often interacts with medicines and can lead to health problems. Stopping drinking or smoking can be very hard. It is sometimes helpful to get support from a healthcare provider. Check to see if smoking cessation classes are offered at your VA medical center. Talk with a doctor or nurse if you think the stroke survivor you care for is at risk.



✓ **Exercise and weight management**

Not getting enough exercise can put you at risk for a stroke. Walking 30 minutes a day is suggested to remain healthy. Veterans are invited to get involved with *MOVE!*, a national *Veteran's Affairs* program to help veterans increase exercise, lose weight, and keep it off. Being overweight, having high blood pressure and diabetes can be prevented with exercise and weight control. Diet and exercise plans can

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be helpful in preventing future strokes. To get involved with this program visit: [www.move.med.va.gov](http://www.move.med.va.gov) or ask VA healthcare providers about *MOVE!* You can also ask the rehabilitation therapist for exercises that your loved one can do at home. You can both do these exercises together. You can give him support and take care of your health too.



✓ **Eating a healthy diet**

A healthy diet gives the body the nutrients needed to maintain health. Generally, avoiding fatty, fried, high calorie and sugary foods is a good idea. Also, salt intake should be limited if you have high blood pressure. Talk to a health care provider about a proper diet and ask about foods that should be avoided. Learn to read labels on foods to know sugar or carbohydrate content. A nutritionist may be helpful in planning a proper diet to help with weight loss and lower the risks of another stroke. Stroke survivors are often on strict diets after their stroke to help reduce the risk of another stroke. Caregivers can help by buying and cooking foods that are on the stroke survivor's new diet.

✓ **Getting regular check-ups**

Regular health check-ups and routine health screenings can

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prevent many health problems. People who get preventive care are less likely to have poorer health. Talk with VA healthcare providers about getting screenings and preventive care needed to promote good health.

Some routine check-ups are listed below:

- Yearly general health check-up
- Eye/hearing exam
- Colon exam
- Prostate exam

### ✓ **Talking with your healthcare provider**

Talking with healthcare providers is not always easy. Here are some tips that can help you get what you need from your providers.

- Take notes while talking to doctors/nurses
- Bring a list of medicines being taken and bring it with you to each doctor's visit
- Bring a list of questions or things you want to talk about - including the 3 questions listed below provided by the *Partnership for Clear Health Communication*:

1. What is my main problem?
2. What do I need to do?
3. Why is it important for me to do this?

Ask the doctor to answer these questions and write down the answers.





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Knowing the answers to these questions can help you know the needs of the stroke survivor you care for.

✓ **Managing medication**

It is helpful to know the names of the medicines the stroke survivor is taking, the prescribed amount, and the reasons why each is being taken. It will also help to know how long the stroke survivor will take the medicine, what the possible side effects are and how to recognize them. This can help you notice the signs of a side effect early and know what to do. If you know these facts, you will be better able to manage an emergency. If you still have any doubt, it is helpful to talk to a pharmacist. The list below are questions you can ask the doctor or pharmacist about the medicine:

1. What is the name of the medicine?
2. What is the medicine supposed to do?
3. How and when does it need to be taken?
4. How long does the medicine need to be taken?
5. Do any type of foods, drinks, other medicines or activities need to be avoided while taking this medicine?
6. What are the possible side effects?
7. If a side effect happens, what do I do and who do I call?

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8. Could missing a dose of medicine cause another stroke?
  9. How will I know that the medicine is working?
  10. What are the risks of not taking the medicine?

When a person is taking more than one medicine, it is often hard to remember when to take it or even if it was taken. Caregivers are often the key person helping stroke survivors remember to take their medicine. Setting up a simple way to remember to take prescribed medicine is important. Keeping details on a calendar can be helpful:

- ✓ Name of each medicine
- ✓ Amount taken
- ✓ How often the medicine is taken
- ✓ What time the medicine is taken



Other helpful options include: setting an alarm clock as a reminder for the time when a medicine is needed or using a labeled pill box. Pill boxes may be offered through the VA or they can be bought at a pharmacy.

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### **In Review...**

As a caregiver it is helpful to know what a stroke is and how to prevent future strokes. Knowing the signs of stroke can help you recognize when you or a loved one is having a stroke. You can prevent future strokes for yourself and the stroke survivor you care for by eating and living healthy. Taking walks together may be helpful for both of you. The next chapter focuses on what is involved with being a stroke caregiver after the stroke survivor returns home from the hospital.

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## CHAPTER 2

### CARING FOR A STROKE SURVIVOR

About 6 out of 10 caregivers of stroke patients are a spouse and 4 out of 10 are friends, daughters and/or sons.

Nearly 9 out of 10 caregivers live with the patient.

This chapter is about caring for a stroke survivor. We recognize the key role you play in helping your loved one manage at home. This chapter discusses what it means to be a caregiver for a stroke survivor. This way you can be more prepared to face the changes and know more about how to take care of yourself as a caregiver.

Most of the time the caregiver is the stroke survivor's spouse. Often women in the family take an active role in caregiving (daughters, sisters, and nieces.) Sometimes men also help out (sons, grandsons, and friends.) It is helpful when stroke survivors have more than one caregiver so all of the tasks of giving care do not fall on just one person.

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## Caregiver Tasks

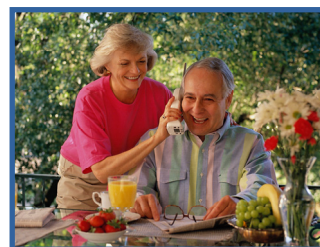
Caregivers help the survivor in chores like:

- Providing personal care (for example, dressing, bathing, eating)
- Going for a ride and going to see the doctor
- Managing his medicine
- Doing errands, like buying groceries
- Doing household tasks (for example, cooking, laundry, washing dishes)
- Keeping up the home and yard
- Taking care of finances

In our study, driving, helping with daily self-care and home tasks were needed by some survivors throughout recovery. For others, these needs will lessen by the end of the first year. Recovery time and help needed varies from one survivor to another.

**“...She watches over me and she brings me water...when I'm out working or doing something she'll be out there working with me and then she'll tell me to sit down and take a break...So I need her...”**

**Quote by a stroke survivor**



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**“I have the wheelchair over there for emergencies only. I try to walk when I can. I’m always hoping that some day with the exercises, some day I will walk.”**



### **Assistive Devices & Services**

Providing stroke survivors with assistive devices such as walkers and canes can help them have more freedom and make the caregiver’s job easier. Survivors will often need assistive devices, such as walkers or canes to help them feel more safe moving around and keeping their balance. Some stroke survivors may not want to use a walker or cane in public places. Caregivers, family and friends can help the stroke survivor accept these devices into their life. It may help to talk openly about this. You can point out the benefit of being able to go out to eat, visit friends or go to church. Wheelchairs and powered scooters can also be very helpful, making tasks like going shopping easier. If stroke survivors use these tools they can do more without the help of a caregiver.

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Here are some examples of assistive devices that may be helpful:

- Wheelchair
- Walker
- Quad cane
- Shirt Buttoner
- Tub bench
- Shower grab bar
- Urinal
- Bath brush
- Reacher
- Rocker knife
- High-sided dishes
- Shoe buttons
- Elevated toilet seat
- Sock aid

Some agencies that can help include:

- Home health aids
- Senior day care
- Visiting nurse
- Counseling services
- Emergency services
- Hospital visits



The VA may be able to give you these assistive devices and can help arrange for agency supportive services. If you think these devices or services may be helpful, a social worker or nurse at the VA will be able to guide you.

### **What Can You Do as a Caregiver to Help a Survivor After a Stroke?**

- Wheelchairs and walkers can be helpful for survivors who cannot walk on their own after their stroke. Physical therapy may help the survivor regain ability to do things like eat and walk on his own. The caregiver can learn from physical therapists how to help the survivor use their assistive device and thus feel comfortable helping the survivor.
- One out of two survivors feel fatigue after having a stroke. Finding ways to cope with fatigue can be helpful during recovery. Find ways to help him conserve energy; avoid letting him spend too much time in bed; he can build up stamina through exercises and learn ways to move around more easily. Developing an exercise plan may help decrease his fatigue. A rehabilitation therapist can help.
- Even if the stroke has changed the survivor's physical abilities, being able to talk to other people and have a social life can help him have a meaningful life. It is often helpful to together create an active weekly routine.
- When stroke survivors return home, creating a daily routine is helpful. Also, arranging the house to promote safety is important. This includes night lights, removing throw rugs and moving furniture to make walking easier.



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## Safety at Home

A few simple changes are often needed to make the home safe for a stroke survivor. You can prepare the home for the stroke survivor before they return home by checking your home for safety. For example, furniture may need to be moved to make way for walkers and wheelchairs. Moving extra furniture, electric cords and loose rugs out of the way to make a clear path for walking may help. If you need equipment to move in and out of showers or adjust lighting to avoid glares, arrange for these changes early. Non-slip flooring strips installed in a tub or shower with grab bars can help prevent falls. Elevated toilet seats can make toileting much easier for the veteran and relieve the caregiver of lifting. Night lights in bathrooms and hallways are simple safety devices to consider. An occupational therapist or physical therapist may be available to make a

**“If I didn’t have her I’d be in a nursing home. She does everything.”**  
Quote by a stroke survivor





Caregivers normally spend about 50 hours giving care each week.

home visit to help you spot hazards and fix them. Ask if the VA can arrange for some help or seek the help of a family member to point out things that can be done to make the home safer.

### **Time Giving Care**

The time spent caring for a stroke survivor differs depending on the need of the stroke survivor. Survivors with more issues need more help. Some survivors need only a little help some of the time, while others need a caregiver's help almost all the time. Often, a stroke survivor's care needs lessen with time. If the person you care for needs a lot of help, try to ask others to help out. Ask other family members and friends to help with some specific things so you can have a break.

### **The Caregiver's Health**

As a caregiver, it is key for you to recognize that your health can suffer due to the fatigue and

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stress caused by daily caregiving tasks. The best option is to find someone to help out or give you a break. Having a hobby or time for yourself can help you manage your health while being a caregiver. Also, taking time to eat good meals and exercise can keep you healthy while taking care of someone else. Getting exercise can be as simple as walking around the block, pulling weeds, or gardening.

### **Getting Help & Respite Care**

Often when giving care to stroke survivors, caregivers need help. Getting help from others lessens the physical and emotional stress of being a caregiver is important in planning how you will continue caregiving over a long period of time. If you neglect yourself, you cannot give proper care to others. It is important to ask for help and support from friends and family as you need it. It is common for people to offer help when the stroke first

**2 out of 10  
caregivers  
receive  
outside help  
with their  
caregiving  
activities.**



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Nearly 6 out of 10 stroke caregivers report staying nearby to watch over the person they care for.

happens and the company of others can be an important source of support to the stroke survivor. However, after a couple of weeks people return to their lives and the caregiver is left to care for the survivor on her/his own. Be sure to talk about ways others can help you and make a plan for helpers during the recovery period and not just in the beginning. Often caregivers have a hard time accepting help from others. It is okay to let others help so when people offer to help – let them!

Local support groups can also help you cope with the stress you may feel as a caregiver. The VA may have a support group or know of one in your area so talk with the nurses, care coordinators, social workers, or doctors so they can help you get the support you need.

Ask about respite services that can give short-term caregiving relief, so you get the break you need.

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**Respite services provide caregivers with a break from giving care; for example, in-home assistance, short nursing home stays, or adult day care programs.**

Respite care allows the caregiver to get out of the house and take a break while someone else provides short term care to the stroke survivor. This time alone can allow you to catch up on personal tasks or take a much-needed break. Respite care can also be planned so that you can travel, or visit your children, or attend family events like weddings and family reunions. It is important that you find ways to get involved outside the home and enjoy life. These breaks and time away can be very refreshing for caregivers and can help prevent depression and feeling overly stressed.



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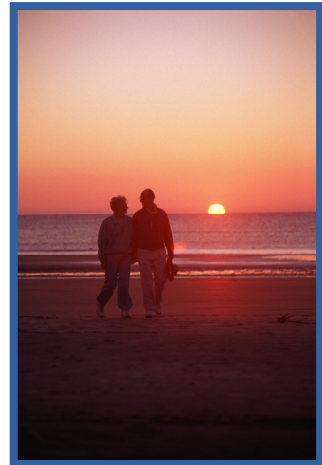
## **Managing Role Changes**

When the veteran has assumed the role of managing finances and other family duties that he/she can no longer do, the caregiver often takes on these responsibilities. These new responsibilities may be very stressful. Finding a relative or trusted friend to assist with financial management can be helpful. Another strategy is to develop a new organizational system for keeping track of bills and payments.

## **Feeling Lonely & Depressed**

Caregivers may feel lonely when giving daily care to a stroke survivor. Being a caregiver often limits your own activities and reduces your chance to be with others. Feeling sad and lonely for a long time can result in depression or illness. Be aware of the signs of depression so you can get help before these feelings become overwhelming. The list below are signs of depression.

- ❑ Feeling sad during most of the day for two weeks or longer



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2 out of 10 caregivers feel depressed and 4 out of 10 stroke survivors feel depressed during stroke recovery.

- Lack of interest in things you normally like to do
- Spending much time alone
- Feelings of being worthless
- Recurring ideas of death or suicide
- Feeling hopeless or useless
- Change in eating habits
- Change in sleeping patterns
- Crying often or feeling emotional
- Feeling tired often (fatigue)
- Poor hygiene

If you notice any of these signs for longer than two weeks, consult with your doctor for advice.

The survey on the next page can help you see if you are having signs of depression. These 10 questions ask you about how you have felt during the past week. For each item, determine your answer, then place the number value in the column on the right side. You will get your score by adding the 10 numbers you put in the right column. Find out what your score means on the following page.

## Are you Depressed?

Choose the best answer for how you have felt during the past week:	Rarely or none of the time (<1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	All of the time (5-7 days)	YOUR SCORE
1. I was bothered by things that usually don't bother me.....	0	1	2	3	_____
2. I had trouble keeping my mind on what I was doing.....	0	1	2	3	_____
3. I felt depressed.....	0	1	2	3	_____
4. I felt that everything I did was an effort.....	0	1	2	3	_____
5. I felt hopeful about the future.....	3	2	1	0	_____
6. I felt fearful.....	0	1	2	3	_____
7. My sleep was restless.....	0	1	2	3	_____
8. I was happy.....	3	2	1	0	_____
9. I felt lonely.....	0	1	2	3	_____
10. I could not get going.....	0	1	2	3	_____
<b>YOUR TOTAL SCORE</b>					_____

*Reference: Radloff, LS. (1977). The CES-D scale: A self-report depression scale for research in the general population. Applied Psychological Measurement, 1;385-401.*





### **What Is Your Score?**

A score of 10 or more indicates symptoms of depression. If you have score of 10 or more, talk to your doctor about getting the help you need. Remember, you need support too.



### *The Caregiver Bill of Rights*

- ☞ Take care of yourself. Taking care of yourself will make you a better caregiver.*
- ☞ Give and receive respect and love; forgive and accept your loved ones.*
- ☞ Get help from others. Know your limits. Know when to get others to help you and the person you care for.*
- ☞ Express your feelings. Be true to yourself.*
- ☞ Maintain your life, do things that do not include the person you care for. You have the right to do some things for yourself.*
- ☞ Protect your right to make a life for yourself, to sustain you when your loved one no longer needs help.*
- ☞ Do not be controlled by guilt, anger or depression from the person you care for.*
- ☞ Take pride in what you do and what it takes to meet the needs of the person you care for.*

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## Caregiver Stress

Often when caring for a stroke survivor, caregivers feel a high level of stress. They sometimes feel weighed down, tired or hopeless. In our study, caregivers who had higher levels of stress also reported poorer health. Being aware of how you are coping and feeling is key to staying healthy and being able to give the best care for your loved one. Caregivers should seek support from others to relieve their sense of stress and maintain their health.

**For example, if you have problems that seem too hard to solve, ask others to help you think of new ways to solve your problems.**

The questions on the next two pages will help you assess your stress as a caregiver. Answer the questions to find out if you are feeling a high level of stress.

The more caregiver stress, the more likely the caregiver will feel depressed.

## Do you feel stressed?

ZARIT SCALE - A	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
	(0)	(1)	(2)	(3)	(4)
1) DO YOU FEEL that because of the time you spend with the stroke survivor that you don't have enough time for yourself?					
2) DO YOU FEEL stressed between caring for the stroke survivor and trying to meet other responsibilities (work/family)?					
3) DO YOU FEEL strained when you are around the stroke survivor?					
4) DO YOU FEEL uncertain about what to do about the stroke survivor?					
<b>Total Scale A Score:</b>					

*Bedard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J.A., O'Donnell, M., The Zarit Burden Interview: A New Short Version and Screening Version. The Gerontologist, 2001. 41: p. 652-657.*

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### **What is Your Scores?**

On the first scale Zarit Scale, a score of 8 or higher reflects a high level of stress. If your score indicates you have a high level of stress, be aware of the stress you are feeling and talk to a friend or family member about how you feel. Let your healthcare provider know you have a high level of stress and get the help you need to get through this time. You need support and you deserve support.





## **What Are Your Thoughts?**

**What is being a caregiver like for me?**

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**What help do I need to provide better care for the stroke survivor and myself?**

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**What things do I need to talk with the healthcare provider about, for example support services.**

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**What can I do to relieve myself of some of my caregiver tasks?**

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**What can I change to help the stroke survivor become more independent?**

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**What are some fun things I can fit into my life?**

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### **What Can You Do to Help Yourself as a Caregiver?**

- Ask questions; this will help you know what to expect and help you manage better at home.
- Talking about how you feel and the help you need from family, friends or other caregivers may be helpful.
- Find out if there is a caregiver support group near you. Becoming a part of a caregiver support group may help you express your feelings about what you are going through. Other caregivers may help you find ways to improve your life as a caregiver.
- Take time to care for yourself and do things you enjoy, like getting out of the house or having a hobby.
- Regular exercise may help reduce feelings of depression and stress.
- Assess your needs. Are there devices you can use to help you or the stroke survivor you care for? Getting needed assistive devices can make life easier for you and the stroke survivor you care for.



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### **In Review...**

The point is that knowing what to expect as a caregiver can help you anticipate the needs of the stroke survivor. Knowing what to expect as a caregiver can also help you manage your role as a caregiver. You are not alone - it is important for you to take care of yourself and get the help you need when caring for a stroke survivor. The next chapter focuses on what to expect for the stroke survivor after returning home from the hospital.

## CHAPTER 3

### WHAT TO EXPECT FOR THE STROKE SURVIVOR

Understanding why the stroke happened may help the survivor accept the stroke and move on with recovery.

#### Why did the Stroke Happen?

In our study, we found that veterans often wanted to talk about what caused their stroke and if there was anything they could have done to prevent the stroke. In this section, we describe our study findings related to how veterans talk about why the stroke happened and how it affects their life. Knowing why the stroke happened can help the survivor accept his stroke and move on with recovery. Stroke survivors in our study talked about three main ways they understood their stroke event:

1. Health behaviors
2. Getting older
3. Spiritual beliefs

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## 1. Health behaviors

Some veterans stated they believed their health behaviors over the years led to their stroke. They often blamed their stroke on poor health habits such as drinking, smoking, lack of exercise, and bad eating habits - such as soda and pizza. Stroke survivors also believe that other health problems like diabetes and high blood pressure caused their stroke. Caregivers can help veterans change some of these health habits. To help the person you care for prevent future strokes you could give the stroke survivor these tips offered by the *National Stroke Association*:

- ✓ Don't smoke
- ✓ Improve eating habits
- ✓ Exercise regularly
- ✓ Take medicine as directed



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"Well I'm getting older and I just don't have strength and energy that I used to have."

Quote by a Stroke Survivor



- ✓ Get your blood pressure checked
- ✓ Maintain healthy weight
- ✓ Decrease stress level
- ✓ Seek support from others
- ✓ Have regular check-ups

## 2. Getting older

Many stroke survivors talk about their stroke taking place as a normal part of getting older and even younger survivors believe it is a sign of aging. They believe getting older and being ill go hand-in-hand and see this as a normal life course. The belief that having an illness, such as stroke as a part of getting older seems to help the survivor face the stroke and accept the changes it brings. Some people in our study felt changes brought on by the stroke were not a major upset in their life. More tips about how to live healthy and prevent future strokes can be found in **Chapter 1**.

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### 3. Spiritual beliefs

Many veterans in our study believed God played a key role in their stroke. Some veterans talked about their stroke as part of God's plan for their lives. This belief often helped veterans accept changes caused by the stroke. Several men reported turning to their spiritual beliefs as they coped with their stroke. For example, some veterans in our study reported praying, knowing that others are praying for them, reading the bible, and going to a house of worship as helpful after their stroke.

Spiritual beliefs can help the survivor accept the stroke and changes that were caused by the stroke. Talking with a survivor about why he believes he had a stroke may help him cope with changes after he goes home. Caregivers can listen and help them make the link between healthy behaviors and preventing future strokes.



**“I live by God’s will...I don’t know what’s going to happen to me. If I’m going to be better, if I’m going to get worse or not, I don’t know, let it be what God wants because He is the one who knows.”**

**Quote by a Stroke Survivor**

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**“The inner spiritual self can be beautiful and whole even when the material, physical body is broken or diseased.”**

**Quote by a stroke survivor**

**A common feeling that stroke survivors have expressed is the sense of not being the same person after their stroke.**

Making this link can inspire survivors to improve their health behaviors.

### **Changes After Having a Stroke**

Often people do not know what to expect after having a stroke. They may not feel like themselves and are unsure of what they can or can not do when they get home. This section talks about common changes stroke survivors go through when they return home. This information can help caregivers and family members provide support to stroke survivors deal with these changes and help them cope after discharge home.

Many things affect how a stroke survivor feels and how he lives his life after having a stroke. While not all stroke survivors go through major life changes, many do. Over time many survivors are able to adjust and get back to ‘normal.’ Our research found that although each person’s recovery time is different, the pattern

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of recovery is gradual. There is rarely a quick return to normal function. Therefore, it is helpful for caregivers and family members to find ways to help stroke survivors recognize small gains and encourage them to enjoy life each day. Improvement can continue for a year or longer after a stroke. Sadly, sometimes improvement does not occur. This can be a challenge for veterans and caregivers.

After discharge home, stroke survivors often do not know what they can and cannot do safely at home. They often struggle with trying to figure out how to get along and the best ways to do things. In the first 6 months after discharge, survivors and caregivers go through a learning process. Caregivers can support the stroke survivor to do as much as he can on his own. It is good for the stroke survivor to have as much freedom as they can. By 6 months after discharge, survivors have often learned what they can and cannot do safely and have learned

After a stroke, at least 8 out of 10 stroke survivors who had changes in the way they felt about themselves were also depressed.



**“I see myself as different because of the way I walk and the way I act. I can’t go anywhere like a normal person.”**

**Quote by a stroke survivor**

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ways to manage. It is helpful to set up a daily routine after discharge home. Caregivers can help stroke survivors create a daily routine by doing the same things each day around the same time.

**For example, waking, bathing, eating, walking, or getting out of the house can be scheduled to help the survivor create a daily routine. This can help get things back to normal.**

Being informed about the changes stroke survivors face in recovery can help you know what the stroke survivor is going through – thus, helping you help him. Some of the changes survivors face during recovery are:

1. Changes in his body
2. Changes in how the stroke survivor feels about himself
3. Coping with feelings
4. Changes in communication
5. Feeling isolated from others
6. Getting out of the home



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## 1. Changes in the body

After returning home from the hospital, stroke survivors often lose physical strength and cannot do the things they were once able to do. During the first month of recovery, many people in our study reported they did not feel in control of their body due to these changes in their bodies. Some survivors stated they felt disconnected from their bodies as a result of numbness in their arms and legs and other physical changes after having a stroke. These physical changes can be upsetting for survivors and their caregivers. For example, feeling tired (*fatigue*) is a common problem reported by stroke survivors. Survivors with functional changes often cannot do their normal daily activities. Sometimes stroke survivors find it hard to walk after a stroke. Being able to walk was a major concern for veterans in our study. Many veterans from our study talked about



**“I can do the same things, it's just motivating myself to do them. I know they got to be done but I just don't get motivated to do it.”**

**Quote by a stroke survivor**

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Because some people experience changes in their physical functions, they may feel life is chaotic—that they are living in “limbo.”

needing help with walking and moving around after a stroke. Many stroke survivors in our study said help from others with walking was very important in helping them recover from their stroke.

When stroke survivors first go home, they often go through a learning process to find out what they can do as they recover from the stroke. In our study, survivors and their caregivers learned about the survivor’s abilities and limits through trial and error. Many people in our study reported finding ways to manage with their physical changes caused by their stroke.

**For example, some veterans in our study reported doing things slower and taking breaks to conserve energy. Caregivers and family members need to be patient and give the survivor time to do the things he can.**

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Sometimes being a caregiver is a balancing act. Caregivers have to provide help but too much help may not be good for the stroke survivor. A caregiver or other family members may want to protect the survivor and do too much for them. This protection can limit a survivor's progress in recovery. It is important that family members and caregivers let the survivor do what he can on his own, as much as possible. Supporting the veteran in doing what he is capable of is an important part of the balancing act. It is also helpful when caregivers and family provide support so the survivor can be active, get around as much as possible and be social with others.

**For example, many stroke survivors have a fear of falling after their stroke. This fear can cause stroke survivors to avoid going out in public.**

**"I am more eager to live than before."**

**Quote by a stroke survivor**



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“Yeah, fallin' is the worst. It's hard to describe 'cause it's like a sack of rocks, this side of my body.”



“Last night the youngest grandchild had a concert...I was sitting there, I kept sliding to the left, because the left side is gone [due to stroke]...she pulls her chair right up side of me, leans up there so I can lean against her, instead of falling out of the chair.”

For support, caregivers can help with balance and offer the stroke survivor help, like a shoulder to lean on or an arm to hold when walking. A physical therapist may also help the veteran learn how to maintain balance and walk better. Walkers, quad-canes, and wheelchairs can also be helpful for helping the survivor get around after a stroke.

By six months after getting home from the hospital, stroke survivors who are unable to walk on their own are often more willing to use a wheelchair, walker, or other assistive device to help them get around. These tools can be very important in helping a stroke survivor enjoy life after having a stroke and can relieve the caregiver of the strain involved in helping with walking and moving. Talk with a VA healthcare provider to learn how to use these tools safely.

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### **What Can You Do as a Caregiver to Help a Survivor After a Stroke?**

- Knowing what is important to a stroke survivor can help guide caregivers. For example, if spending time with others is important to the survivor, recovery should focus on their ability to talk to others. Writing or typing skills may also help survivors interact with others after a stroke. If hobbies, such as fishing are important, focus on the skill needed to continue the hobby. You can adapt the hobby to meet the survivor's needs. For example, if he likes to play cards, but can't use his hands get him a card holder so he does not have to hold his cards when playing.
- It is important that family and friends educate themselves about stroke recovery. You can get information from the health care team, books, videos and education classes.
- A simple way to manage the time after discharge home is to have a daily routine. Routines create a sense of time for the survivor and help the caregiver build a schedule around tasks such as bed time, meals, personal care and taking medicine.

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"It's just self-degrading. I really hate the way I feel, feel about myself."

Quote by a stroke survivor

2 out of 3 of stroke survivors experience changes in how they feel about themselves after a stroke.

## 2. Changes in how a stroke survivor feels about himself

A caregiver may be the key person who helps stroke survivors feel good about themselves after a stroke. In our study, we found that veterans often have to come to terms with how they felt about themselves. We found some men do not feel the same after a stroke. Many things affect how a person feels about himself after a stroke. How a stroke survivor views these changes is not shaped by his feelings alone. Stroke survivors are often affected by the way their family and friends view them after their stroke. It is healthy for the survivor to feel accepted by others.

A survivor's feelings about himself can be influenced by his family and friends. If others see him in positive ways, he will likely see himself more positively. If others view him in negative ways and focus mainly on what he

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cannot do, his negative feelings may increase and he may avoid others. He may not want to join in activities or social events. Four ways you can help are:

- Help him find ways to be a part of social events
- Help him find ways to feel useful in the home
- Help him find ways to give to others
- Help him find new ways to express intimate feelings

Some stroke survivors cannot fill their usual role in the family as they did before their stroke. In our study, survivors who continue to help with household chores - no matter how small - feel better about themselves after their stroke. We also found stroke survivors in our study took pride in doing chores around the house. Several survivors felt progress in their recovery was from keeping up with chores, like watering the lawn, gardening, cooking, or



**“I’m teaching my son how to cook...him or my wife, cause neither one can cook, she can’t cook but she’ll try, so I go in there and I guide her.”**

**Quote by a stroke survivor**



“I don't want to be a burden to anybody else... now I can't seem to get out and do what I want to do...I just want stay by myself...I've gotta feeling, like I'm useless and you know, I can't do anything anymore, it's depressing.”

Quote by a stroke survivor

watching over children in the family. Some survivors used their daily household routine as important markers of their improvement. As survivors are able to do more around the house, they could see progress in their recovery and feel better about themselves. All of these little things can make big differences in how a stroke survivor feels about himself after a stroke.

**For example, a stroke survivor can contribute to the household by taking care of family pets. Taking care of a pet can help the survivor feel useful and encourage exercise, such as walking the family dog.**

Many men are guided by traditional ideas of what a man should do. During our interviews with stroke survivors, they often talked about what it means to be a man and their concerns about how their limits affect what they can do. For some survivors, not being able to perform normal, everyday physical activities creates the



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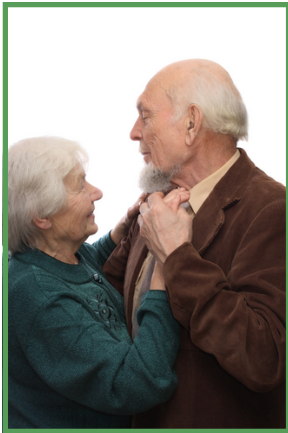
perception that others view the survivor as a weak person. These perceptions make some survivors feel they are no longer the head of the family or in charge. This can greatly affect the survivor's feelings, creating a feeling of insecurity and self doubt. He may begin to think he is less of a man than before. Caregivers face the challenge of helping keep the veteran's view of himself as a worthwhile and contributing member of the family. If the stroke survivor you care for is depressed and feels bad about himself for more than a week or two, it might help to talk to a doctor and get help.

Men often relate being manly with being sexual. It is common for stroke survivors to lose ability to be sexual after having a stroke. This is often related to survivors' feeling like they are not 'men' after the stroke. Some survivors seek medical treatment to increase sexual activities with their partners, while other men accept their

**“You’re supposed to be pretty straight and pretty macho... but I am not that any more. I miss being that...Being in the Marine Corps...I don’t like to be stooped over shrivelin.”**

**Quote by a stroke survivor**





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inability to function sexually and find new ways of being intimate and remaining close to their partner.

**For example, we found many stroke survivors shared hugs and kisses to bond with their partner. Caregivers can help stroke survivors show their feelings by showing their own feelings.**

As a result of recovery over time, some survivors notice an increase in intimacy with their sexual partner after the first year of recovery. If this aspect of recovery is important for the stroke survivor you care for, you can help by asking his VA doctor about options to help regain sexual function. Sometimes survivors just need to talk about what they are going through and how they feel - this helps survivors feel better about themselves. In the next section we discuss the emotions stroke survivors often go through. We also provide tips

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for caregivers and family members helping a stroke survivor deal with these emotions.

### **3. Coping with feelings**

Dealing with emotions can be hard for stroke survivors. Having uncontrolled emotions and being lonely or depressed are common after stroke. In this section we talk about these three feelings.

#### **Uncontrolled emotions**

Stroke survivors often find themselves laughing or crying at the wrong times. This is fairly common after a stroke and often leads to feelings of embarrassment, frustration and anger. Uncontrolled emotional responses can prevent stroke survivors from wanting to go into public places and can increase their feelings of loneliness. Caregivers can help stroke survivors find ways to manage these uncontrolled emotions. Sometimes distractions can help. When the survivor feels an outburst coming on,

**“Once I even  
thought of killing  
myself...I thought  
of taking my life,  
I thought of a lot  
of things.”**

**Quote by a  
stroke survivor**

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About 1 out of 2 survivors are depressed after having a stroke.



they can focus on something else that is unrelated to prevent the response. Trying some breathing exercises to relax or changing posture may also help. Openly talking about managing uncontrolled emotions is often helpful.

### **Depression**

It is common for stroke survivors to be depressed after having a stroke. Being able to recognize the signs of depression is important during stroke recovery. Feelings of anger, fear, anxiety, and loneliness lead to and are common signs of depression. It is important to detect and treat the depression in the early stage. If untreated depression can get worse during stroke recovery and even delay the recovery process. Below are signs you might see if the person you care for is depressed:

- Looking sad for longer than two weeks
- Making statements about feeling hopeless or useless

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- Crying often or feeling overly emotional
  - Feeling tired often (fatigue)
  - Not being responsive to events or people
  - Spending much time alone
  - Loss of interest in hobbies and activities that were once enjoyed, including sex
  - Change in sleeping patterns
  - Not eating or eating too much
  - Change in weight
  - Poor hygiene
  - Talking about death or suicide

If you have observed any of these signs in the stroke survivor you care for, consult with a VA doctor. Feelings of loneliness and depression can be intense for some stroke survivors. Often the loneliness felt by stroke survivors is a result of being alone at home. Being alone too much can lead to depression and illness. Having friends and family to talk to about their feelings is good for stroke survivors. However, talking with a friend can be harder after a stroke for some people.



**“My life has changed 100%. Before I used to exercise and play sports. And now nothing. Life is full of unhappiness.”**

**Quote by a stroke survivor**



**“She helps out a lot, thank God.”**

**Quote by stroke survivor**

#### **4. Changes in communication**

A common problem that some stroke survivors face is that they can't speak clearly or understand what others say. Stroke survivors who have these problems are often left feeling frustrated. It can also cause a stroke survivor to spend too much time alone, resulting in depression. Telephone calls are a good way to support survivors who can speak and understand well. If the survivor cannot hold the phone by himself, he can use a speakerphone or have someone hold the phone while he talks with others. Family members and friends can help set him up with a computer and an e-mail account, or if he already has one he can continue using it to keep in touch with people on the internet. Sending letters through the mail is also an option.

Sometimes family and friends need to be shown how to communicate with veterans. If the veteran has memory problems simply saying to

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visitors that reminders are helpful can relieve discomfort in communication.

### **5. Feeling isolated from others**

In our study, many survivors talked about strong family bonds as helpful during their recovery. In hard times, stroke survivors feel most comforted when they are around family. These values help survivors, caregivers and other family members as they manage stroke recovery at home. Having someone to trust and knowing that if he needs help his family will be there for him is a great comfort. The support and love of family and friends are vital to living well after a stroke.

Having a social life and enjoying different events with friends and family are a very important part of life. Many veterans enjoy watching sports on the TV with friends, fishing, and going to church and neighborhood events. However, after a stroke many survivors do not

**“I’m alone. No one takes care of me. If I need to do something...I have family, but they all have their own things to do...”**

**Quote by stroke survivor**

**Stroke survivors who have less than 3 people visit them are more likely to have poorer health than those with more visitors.**

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About 1 of 2 stroke survivors feel lonely after a stroke.

continue these activities. Often stroke survivors spend much time alone at home. Being alone often leads to feelings of isolation and depression. Family and friends can help by encouraging the veteran to continue activities as much as possible after their stroke.

**For example, for some survivors it can be exciting to go shopping or pick up the mail at the post office. He can sit for a short wait in the car or sit on a bench outside. Caregivers can help veterans increase their activity level as they are ready to take steps toward recovery.**



Being involved with social groups can get stroke survivors out of the home and help them connect with others. Being in a support group or involved in a church group are often helpful for those who are often home alone. Family and caregivers can also help veterans by encouraging neighbors, church members or



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other friends to visit often. In our study, feelings of loneliness was common for many survivors despite the company of their caregiver. Being social and getting out of the house is good for stroke survivors and can prevent feelings of loneliness. In the next section, we discuss how veterans in our study dealt with getting out of the home after stroke. We also provide tips for caregivers and family members to help stroke survivors get out of the home.

## 6. Getting out of the house

During the first month after discharge home, most survivors in our study expressed they were not comfortable going out in public. Often survivors did not want to go out because:

- They were unable to do it physically
- They lacked transportation
- They feared having another stroke
- They feared falling
- They were embarrassed using a walker, cane, or wheelchair

“My boys have never had a day go by that they were with me that they never knew and heard me say that I love them. They say that to me a lot, and they hug me a lot. . . ‘I want you to know that I love you’ . . .”



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“I feel bad because, I am not the same...I used to do everything, and now I can't move from my house or do nothing.”

Quote by stroke survivor

3 out of 4 post stroke patients stop most of the activities they did before the stroke, and some never resume their social activities.

These feelings often prevent stroke survivors from leaving the house. According to our study most of the survivors had problems walking, being active or driving. Many veterans from our study chose to stay at home; just going out for medical appointments. Caregivers, family and friends need to provide extra support to these survivors after returning home to help them get involved after having a stroke. Encourage small steps at first.

**For example, riding in the car to go to a store. Survivors may enjoy pushing the grocery cart, which they can also lean on for balance. He may prefer to wait in the car rather than getting out and going into the store. Some stores offer motor scooters to use in the store.**

Caregivers can tell what the veteran is able to do and help them recognize their abilities and limits. Caregivers and family can help survivors take small steps in getting involved in

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social events and offer support along the way. Veterans need more social contact and caregivers can help them with this. This may be a good time to offer assistive devices such as a walker or cane.

It is helpful to be aware of the social needs of stroke survivors and bring the family together often. Caregivers can let friends and family know that visiting is a very important way of helping the survivor maintain a healthy and happy life. Visiting with others can help the survivor avoid feeling alone and depressed. Family and friends visiting may help relieve some of the stress on caregivers. Some of the ways the friends and family can help are:

- Visit at least once a week
- Talk to him, even if he has problems with speech
- Get him out of the house, even for a short walk or cup of coffee
- Offer him a ride if he cannot drive

**“I can't go out. I want to go places. It makes me want to go places. I want to get dressed, put my nice clothes on and, I just feel lonesome. I feel trapped. I can't get out.”**

**Quote by stroke survivor**



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**“I belong to a Church and a Club and they have music and food once a month...I might go to the store over there, I might go to the community center, I belong there. Friday nights I usually go to the VFW fish fry, have a couple of drinks...I belong to both Eagle's and Elk's...”**



Some survivors feel frustrated that they cannot drive after their stroke. They want the control that they used to have and will not feel satisfied without it. A few survivors reported they could drive after having their stroke but chose not to because they worried about the dangers of their limits – they did not want to harm other people on the road. Most of the survivors in our study said they felt their freedom was taken away because they were not able to drive. They were frustrated because they could not enjoy all the activities they used to do. The ability to leave the house by themselves or with another person gives them the chance to have more freedom. Caregivers can support stroke survivors by offering to drive them somewhere or get others to go out with him. Supporting the survivor and helping him get out in public will help him recover quicker and get back into life!

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### **What Can You Do as a Caregiver to Help a Survivor After a Stroke?**

- If the stroke survivor you care for lost communication skills due to the stroke you can help by using photos of common things they may be likely to ask for. It is a way to express their needs and practice recognition and memory of different objects, persons and words. Simple games with memory cards can help improve lost skills.
- Family and friends should use short, commonly used words when speaking or writing a survivor who has lost communication skills. Also, it helps to give messages slowly and clearly with gestures. Make sure the survivor can see the speaker's face.
- Family and friends may need to talk openly about their frustrations to remain patient when helping stroke survivors.
- Swallowing can be hard after a stroke. Providers usually check to see if patients can swallow after a stroke, but you can also give the stroke survivor a "sip test." Give him or her a sip of water and see if he or she can swallow it without choking. If he or she chokes while doing the sip test, contact his or her doctor and ask for Speech therapy for swallowing problems. If you see him or her choking often, contact his or her VA doctor and ask for help.

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## **EVERYTHING HAS A PURPOSE**

While the general view of stroke is negative, it is possible to regain a good quality of life after a stroke. For example, some survivors become healthier and more involved with their family after their stroke. Many survivors talk about being grateful for their family more than ever. Husbands and wives may become closer. Grandchildren are often special visitors to brighten the days. For some, every day that they wake up and see the sun is a blessing that they celebrate. If given the chance, something good can often emerge from the pain and anguish of surviving a stroke event. Caregivers can help veterans see some of the good changes that happen along the way.





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## RESOURCES

You can get educational material on all aspects of stroke information, heart disease, blood pressure, cholesterol and blood sugar control, and prevention with the websites and addresses listed below. Check your local VA medical center library for free access to a computer and internet.

### Information about stroke, warning signs and prevention

#### **American Stroke Association (ASA):**

**<http://www.strokeassociation.org>**

ASA's "Life after Stroke" campaign provides resources focusing on prevention and recovery.

#### **American Heart Association (English/Spanish)**

**<http://www.americanheart.org>**

You can get free brochures and information in Spanish or English. For information in Spanish click on **Español** on the left column.



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## Caregiver support groups

### **Family Caregiver Alliance**

690 Market Street, Suite 600  
San Francisco, CA 94104  
(800) 445-8106  
(415) 434-3388  
[www.caregiver.org](http://www.caregiver.org)

### **Friend's Health Connection**

P.O. Box 114  
New Brunswick, NJ 08903  
(800) 48-FRIEND (483-7436)  
(732) 418-1811  
[www.48friend.org](http://www.48friend.org)

### **National Alliance for Caregiving**

4720 Montgomery Lane, Suite 642  
Bethesda, MD 20814-3425  
(301) 718-8444  
[www.caregiving.org](http://www.caregiving.org)

### **National Caregiving Foundation**

801 North Pitt Street, #116  
Alexandria, VA 22314  
(800) 930-1357  
(703) 299-9300  
[www.caregivingfoundation.org](http://www.caregivingfoundation.org)

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**National Family Caregivers Association**

10400 Connecticut Avenue, Suite 500

Kensington, MD 20895

(800) 896-3650

(301) 942-6430

**[www.nfcacares.org](http://www.nfcacares.org)**

**Rainbows**

2100 Golf Road, #370

Rolling Meadows, IL 60008

(800) 266-3206

(847) 952-1770

**[www.rainbows.org](http://www.rainbows.org)**

**Rosalynn Carter Institute of Georgia**

**Southwestern College**

800 Wheatley Street

Americus, GA 31709

(912) 928-1234

**[rci.gsw.edu](http://rci.gsw.edu)**

**The Compassionate Friends, Inc.**

P.O. Box 3696

Oak Brook, IL 60522-3696

(630) 990-0010

**[www.compassionatefriends.org](http://www.compassionatefriends.org)**

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**Well Spouse Foundation**

30 East 40th Street, PH

New York, NY 10016

(800) 838-0879

(212) 685-8815

[www.wellspouse.org](http://www.wellspouse.org)

**Caregiver websites**

**AARP – American Association of Retired Persons:**

[www.aarp.org/indexes/life.html](http://www.aarp.org/indexes/life.html)

**Caregiver Network, Inc.:**

[www.caregiver.on.ca](http://www.caregiver.on.ca)

**Caregiver Survival Resources:**

[www.caregiver911.com](http://www.caregiver911.com)

**Caregivers.com:**

[www.caregivers.com](http://www.caregivers.com)

**Caregiving.com:**

[www.caregiving.com](http://www.caregiving.com)

**Eldercare Online:**

[www.ec-online.net](http://www.ec-online.net)

**Empowering Caregivers:**

[www.care-givers.com](http://www.care-givers.com)

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**Family Caregiving 101 Site:**  
<http://www.familycaregiving101.org/>

**Familycare America:**  
[www.familycareamerica.com](http://www.familycareamerica.com)

**Friend's Health Connection:**  
[www.48friend.org](http://www.48friend.org)

**Healthy Caregiver.com:**  
[www.healthycaregiver.com](http://www.healthycaregiver.com)

**National Partnership for Women and Families:**  
[www.nationalpartnership.org](http://www.nationalpartnership.org)

**Stroke Net Caregiver Manual:**  
<http://www.strokecaregiver.org/handbook.htm>

**The Family Caregiver Site:**  
[www.thefamilycaregiver.org](http://www.thefamilycaregiver.org)

**Today's Caregiver Magazine Online:**  
[www.caregiver.com](http://www.caregiver.com)

**U.S. Administration on Aging:**  
[www.aoa.dhhs.gov](http://www.aoa.dhhs.gov)

**Well Spouse Foundation:**  
[www.wellspouse.org](http://www.wellspouse.org)

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## VA websites

**VA Web Home Page:**

**[www.va.gov/](http://www.va.gov/)**

**VA Online Bulletin Board:**

**<http://vaonline.va.gov/>**

**VA My Healthvet:**

**<http://www.myhealth.va.gov/>**

MyHealthvet is the internet gateway to veterans health benefits and services.

**Veteran's Affairs 'Move' Exercise and Weight Control Program (English/Spanish)**

**<http://www.move.va.gov/>**

## Medical information

**Medline Plus (English only):**

**<http://www.nlm.nih.gov/medlineplus/stroke.html>**

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## THE STUDY

The information in Chapter 1 of this guidebook was obtained from the *National Stroke Association*; the *American Stroke Association* ; and the *Partnership for Clear Health Communication*. Chapters 2 & 3 of this guidebook are based on findings from a study entitled, “Culturally Sensitive Models of Stroke Recovery and Caregiving of Veterans After Discharge Home.” The study was funded by the VA Health Services Research and Development Program, Nursing Research Initiative. The purpose of the study was to describe the recovery process of veterans living in the US mainland. We collected information from veteran stroke survivors and their caregivers to learn about how caregivers provide care to veterans and what their needs are across two years after discharge. Though females were intended to be included in the study there were no female participants. Although we realize female veterans also have strokes and stroke recovery needs, our study participants were male and thus we feel we can only speak to the recovery needs of male stroke survivors and their caregivers.

Stroke survivors talked about their lives and changes they went through in their daily lives. We focused on their daily routines and needs, how they felt about themselves, how others react to them, and how their social lives are affected. We also collected information about

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their functional status and depression. Caregiver information included amount of time spent in providing care, tasks caregivers performed, caregiver burden, caregiver coping, and depression.

Our findings suggest that after having a stroke, many veterans have a physical impairment which gets better during the first two years of recovery. Therefore, there is often much stress placed on informal caregivers, family members and friends to help the veteran on a daily basis. The goal of this guidebook is to help prepare caregivers, stroke survivors, family and friends for the stroke recovery process after discharge. This book also promotes the strong family and social bonds that help sustain veterans to achieve a healthy and happy life after discharge home.

Stroke is the leading cause of serious long-term disability affecting more than 4 million people in the United States. Often stroke survivors and their caregivers are faced with changes that pose many problems during stroke recovery. This book was created from reports provided by more than 100 stroke survivors and their caregivers within the Veteran Healthcare System to provide insight into the mental, emotional and social aspects of stroke recovery and caregiving. This book provides information and support for caregivers of stroke survivors. Caregivers and stroke survivors can use this book to better understand the healing process and pave a road to recovery together.

