

# TAKING CARE OF YOURSELF

A Guide For  
Family  
Caregivers





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## Introduction

### WHO IS A CAREGIVER?

Most of us, at some point in our lives, are caregivers. We may care for children, for grandparents, for parents, for other family members such as brothers or sisters or aunts or uncles, for friends, or we may care for our husband or wife. The word “caregiving” covers many different relationships and responsibilities. Many of the tasks that are part of caregiving may seem so much a part of daily life that we don’t even recognize them as caregiving. But you are a caregiver if you regularly help someone in need.

There are more than 45 million people in the United States who are providing care for someone over 18 years old. About 1 out of every 5 adults in the US is providing care for another adult. The money value of the services family caregivers provide is estimated to be \$306 billion per year. So, if you are a caregiver, you are not alone!

### RISKS OF BEING A CAREGIVER

As a caregiver, you are aware of the rewards and satisfaction that can come with giving a loved one the help that he or she needs, making them comfortable and letting them know that they are not alone. What many caregivers don’t think about and they often put at the bottom of their “To Do” list, are their own needs.

#### You are a caregiver if you regularly help someone with:

- Housekeeping, shopping, yard work
- Daily personal care such as bathing, dressing, eating, toileting
- Preparing meals
- Making medical decisions
- Driving to appointments, shopping, etc.
- Financial tasks, such as paying bills, making bank deposits
- Checking in on a regular basis

## Introduction Continued

While caregiving may be rewarding, it can also be very stressful. Caregivers may be juggling several different roles. In addition to providing care for a loved one, they may work outside their home. They may be caring for more than one family member including children, older family members, family members with a disability. The people they are caring for may live in different places. They may have responsibilities in the community that require their time. And the needs of the person or people needing care may seem endless. No matter how we might try, it often seems that it is impossible to do everything that needs doing.

It is not surprising, then, that almost all caregivers feel stressed. And it is very well known that the stress experienced by caregivers, especially if it lasts for a long time, can have some very harmful effects on the caregiver's health and well-being.

But caregivers often are so focused on their loved one that they don't realize that they may be risking their own health and well-being. Some of the effects that stress can have on your body include aches and pains, heart problems, digestive problems. Stress can also affect your immunity and make it more likely you will get sick.

## Signs of Caregiver Stress

**You may have Caregiver Stress if you frequently:**

- **Feel tired**
- **Are more emotional than usual (e.g., find that you cry or get angry more often than you normally would)**
- **Resent the person for whom you are providing care**
- **Find that you either are sleeping "all the time" or have trouble getting enough sleep**
- **Have eating problems and have gained or lost a lot of weight**
- **Don't feel like doing the things you enjoy**
- **Are worried about the future**
- **Can't concentrate**

## Introduction Continued

### DESCRIPTION OF THE PROGRAM

In light of the impact that caregiving can have on the life and health of the caregiver, it is not surprising that many health care experts and social service professionals have been focusing on how to make sure that caregivers take care of themselves as well as their loved one.

This program is meant to help you do that. The program has two aims. The first is to make sure that caregivers know and remember how important they are and how important it is that they take good care of themselves. There are four messages that we hope you will take away from the program to remind you of these truths. These messages are: Believe in yourself; Protect your health; Reach out for help; and Speak up.

The second goal of the program is to offer you tips and steps that you can take to help you act on the four messages.

This Workbook will explore these messages further, explaining what they mean, why they are important, and how they can help you be an effective caregiver for a loved one while also taking care of your own mind, body and spirit. You can return to the Workbook and re-read it whenever you feel a need to remind yourself of these messages. We hope you find the Workbook a valuable companion on your journey as a caregiver.

**Four Messages:**  
*Believe in Yourself*  
*Protect Your Health*  
*Reach out for Help*  
*Speak Up*



## Part I: Believe In Yourself

### TRUST YOUR INSTINCTS

As a caregiver, you may have many occasions to talk with professionals – doctors, nurses, social workers, therapists. But remember, *no one knows you and your loved one better than you do*. No one knows as well as you do what your loved one likes, what has been important to you both, what has filled the days of your life together, what your days together are like now, or what your other responsibilities are. So trust yourself. Trust your instincts about what you and your loved one need. When your “gut” is telling you something different from what others are saying, don’t assume they are right and you are wrong. While professionals may have important technical information, you are the expert about who you and your loved one *are* and how well things are going for you both.

#### Believe in Yourself

- Trust your instincts
- Take charge of your life
- Don’t judge your feelings
- Give yourself a break
- Recognize the Caregiver’s Bill of Rights

If you are like most caregivers, you are probably exhausted much of the time and questioning how good a job you are doing. Don’t doubt yourself and don’t let others’ comments or opinions undermine your confidence in the good job you are doing. You are doing a great job!



## Part I: Believe In Yourself Continued

### TAKE CHARGE OF YOUR LIFE

The responsibilities of caregiving often come upon us suddenly, without warning, as when a loved one has a stroke or a serious accident. Other times, caregiving responsibilities increase slowly over time so that we hardly notice until one day we turn around and realize that caregiving seems to have become our whole life.

In either case, whether caregiving makes a sudden change in the life you have known or increases gradually as your loved one becomes more frail, you may come to feel that you no longer have any control over your days and that all of your time is spent tending to the needs of your loved one. Remember that as long as you are alive and have your wits about you, you have the freedom to decide what you can and cannot do and to choose how you will live with your loved one's needs. You may not be able to choose the direction your loved one's illness will take, but *you can choose to take charge of your life.*



**Part I: Believe In Yourself  
Continued****TAKE SMALL STEPS**

“But”, you might ask, “How can I take charge of my life when I’m the only one who can take care of my loved one and he (or she) has so many needs?” Start by taking small steps.

- 1st. Make at least one decision each day about *something you choose to do* that is not for the care of your loved one. It can be for pleasure, or to take care of other responsibilities, or simply to share your feelings with someone who is a good listener. The important thing is that you continue to make decisions for your own life.
  
- 2nd. Use “positive talk” – don’t focus on what you can’t do but on what you *can do*. Notice how well you are taking care of your loved one. Remind yourself that caregiving is demanding and difficult. Appreciate what a good job you are doing!

**Take Charge of Your Life**

- Make (at least) one decision a day that is for YOU
- Use “positive talk”
- Set priorities
- Recognize you need and deserve help

**Part I: Believe In Yourself**  
**Continued**

3rd. Decide what is most important. It sometimes feels like there is no end to caregiving, that your job is never done. Make a priority list, putting at the top of the list the tasks that are the most important to get done during a day or a week and then listing further down the things that, even though they need to be done, can wait a bit longer. Crossing off those “important” items at the top of your list will give you a sense of accomplishment. And being able to look at a list helps to make the number of tasks you have seem more manageable. No matter how many items are on it, *there is an end to the list!*

4th. Recognize that you need and deserve help. One of the barriers that may keep a caregiver from really taking charge of his or her life is the belief that they must do everything themselves. We will explore the importance of reaching out for help later in this Workbook. But for now, just try to think of a family member, friend, neighbor or community member who might be able to relieve you of some of the burdens of being a caregiver by taking on tasks that are difficult for you to get to. Some examples of ways that other people might be able to help you:

- Doing the marketing
- Preparing a meal
- Running an errand (for example, getting stamps at the post office so you can mail your bills or dropping the mail in a mailbox)
- Just “sitting” with your loved one to give you time to get out
- Taking your loved one for a ride



## Part I: Believe In Yourself Continued

### DON'T JUDGE YOUR FEELINGS

Caregivers often have mixed emotions. Sometimes, just a look from the person being care for, or a smile, or a word, can bring feelings of deep satisfaction and even pride for how well you are doing difficult work.

Caring for a loved one who is ill can also bring more difficult feelings. You may grieve for the losses both you and your loved one are experiencing. You may fear what's ahead. You may at times find yourself angry and resentful over the effects that age and/or illness are having on your loved one. You may feel anger and resentment for the burdens of the responsibilities you now have, and for the burdens others do not have.

Caregivers often feel guilty, either over something they have done or not done in the past or over the fact that they can't change the present. Caregivers sometimes experience guilt because they are healthy and their loved one is so ill. Sometimes guilt comes as the result of well-meaning friends and family who keep making suggestions about what you should or should not do without knowing the details or considering the entire situation. Someone once described this kind of help this way: "It's like being hungry and having someone throw sandwiches at you. It's intended to feed you, but it feels like an assault."



**Part I: Believe In Yourself  
Continued****Pay Attention to Your Emotions**

*Keep a daily record of the feelings you experience each day for one week. At the end of each day, write down the feelings you remember having and what prompted them. At first you might be tempted to write down just one feeling as if you experienced it for the whole day.*

*Think a little harder:*

- *Was there a moment when you were happy or pleased at some time during the day, when you had reason to smile or laugh?*
- *What was it that caused you happiness or gave you pleasure?*
- *Were you impatient?*
- *What was it that tested your patience today?*
- *Were you afraid?*
- *What thoughts or events made you afraid?*

*At the end of the week, review the daily log.*

- *What does it tell you?*
- *Can you see what brings some “sunshine” into your days?*
- *Do you look at the list and find that you have very few times when you felt good?*



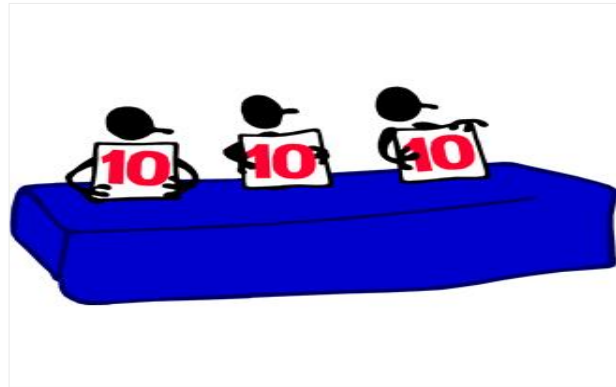
*By looking over the log, you should be able to learn a great deal about yourself and what you might need to help you feel good while you provide care for your loved one. As time allows, continue to keep a log and use it as a way of recognizing when you need to balance the difficult feelings with some of those things that put a smile on your face!*

**Part I: Believe In Yourself  
Continued****DON'T JUDGE YOUR FEELINGS (CONTINUED)**

All of these feelings of love, pride, sadness, anger, guilt are natural and normal. It would be strange if you were caring for a frail loved one and didn't feel some or all of these and more. Acknowledge your feelings without passing judgment on them. Allow yourself the freedom to experience these emotions without trying to push them down.

If you find that your feelings of grief or anger or guilt are interfering with your relationships with other people, especially those close to you, or with your ability to engage in the activities of your day-to-day life, consider talking with a counselor. You might seek out a clergy person from your church or spiritual community, or you can ask a doctor, social worker or other professional to refer you to someone who will listen.

Keep in mind that your feelings – including love, sadness, frustration, and others – show how much you care about the work of caregiving, how difficult this time is for you, and the effort you are making to do right by your loved one.



**Part I: Believe In Yourself  
Continued****GIVE YOURSELF A BREAK - PHYSICALLY AND EMOTIONALLY**

Every caregiver has physical and emotional limits. When you reach your limits, it is very important, for you, your loved one, and for others who care and might worry about you, that you recharge your batteries. There are a number of steps you can take when you feel yourself approaching your own particular physical or emotional “breaking point.” All of us, even the busiest of caregivers, can find 10 or 15 minutes from time to time to take care of ourselves. These are some suggestions for ways to give yourself a little break from the stress of the demands of caregiving. Consider practicing at least one relaxation aid on the list every day.

**Walk away!** Take a moment to step back and get some perspective. Sometimes just walking into the next room for a few moments is enough for your body to relax and for you to get your emotions under control before you go back and continue doing what needs to be done

**Breathe!** Taking a few slow breaths does wonders for reducing tension in your body. If your hands are clenched, unclench them. Relax your shoulders. Let the blood flow.

**Call a friend!** The sound of the voice of someone who cares about *you* is so important when you are giving such effort to caring for someone else. You may need a shoulder to cry on, or a person to vent your frustrations or sadness with or someone who will make you laugh. Being able to express your feelings with someone you trust, rather than holding your feelings inside, is absolutely essential to your own emotional and physical well-being.

**Give Yourself a Break**

- Walk away
- Breathe
- Call a friend
- Relax
- Have a cup of tea
- Go for a walk
- Listen to music

**Part I: Believe In Yourself  
Continued****GIVE YOURSELF A BREAK - PHYSICALLY AND EMOTIONALLY (CONTINUED)**

**Relax!** What do you do when your loved one is taking a nap or not needing your care for a time? Do you always take that time to do housework or other chores? Why not take that time and treat yourself to a warm bath? Or simply sit in a favorite chair and look outside at the changing leaves or the clouds in the sky? In the long run, you may be accomplishing more by taking the time to recharge your batteries rather than by doing household tasks. The dishes in the sink will get done eventually, the laundry will get sorted. Take a moment of quiet for yourself!

**Have a cup of tea!** Make yourself a cup of herbal or calming tea. Maybe you can pour it into a cup from your “good” dishes. Treat yourself like you would an honored guest. You have earned the honor!



**Go for a walk!** Getting outside can change your outlook and your mood. It will remind you that there is a world beyond your responsibilities, one filled with both familiar and new people and things to see. And walking is not only good for clearing out those cobwebs in your head – it is wonderful exercise!

**Listen to music!** Music has so many benefits. It can be relaxing. It can lift the spirits and get your feet dancing. It can be a reminder of past times and places, of the life and good times you and your loved one have shared. So turn on the radio or put a phonograph record or CD on. Allow yourself to float away on the music!

**Part I: Believe In Yourself  
Continued****A Caregiver Bill of Rights**

**I have the right:**

- ✧ **To take care of myself as well as my loved one**
- ✧ **To seek help from others**
- ✧ **To have parts of my life that are separate from caregiving and from the loved one I am caring for, just as I would if he or she were well**
- ✧ **To get angry, be depressed and express other difficult feelings occasionally**
- ✧ **To take pride in what I am doing and to applaud the courage it sometimes takes to meet the needs of my loved one**
- ✧ **To not be made to feel guilty by others, even if they are well-intentioned**
- ✧ **To be treated well and with respect by the loved one I am caring for and to be appreciated for what I do**

## Part II. Protect Your Health

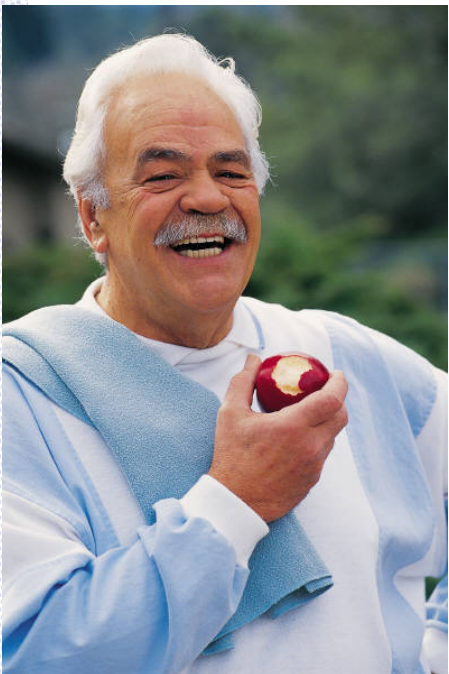
### YOUR HEALTH IS IMPORTANT

Researchers know a lot about the effect of caregiving on health and well-being. The combination of loss, long-term stress, the physical demands of caregiving and your own aging place you at risk of significant health problems and possibly even an earlier death.

Despite these risks, family caregivers are less likely to practice preventive health care than are people who are not caregivers. Caregivers have a tendency to ignore their own health. The best reason for paying attention to your own health is because you are entitled to the greatest well-being and the longest life that you can have. But as a caregiver, you have a second reason for safeguarding your health. Your health benefits not only you, but your loved one as well. There is no question that by being well and strong you are able to provide the best care for someone else.

Even so, caregivers often do not pay enough attention to keeping themselves healthy. There are several reasons for this. First, caregivers often live from crisis to crisis. They feel they need to put the more immediate needs of their loved one

ahead of their own. They postpone making doctors' appointments or don't keep the ones they have, don't eat well, don't get enough exercise. When someone gives unasked for advice that they should take better care of themselves, caregivers may say (somewhat impatiently) that they will get to it when they have some time!



## Part II: Protect Your Health Continued

### EAT WELL

To be an effective caregiver, you must take care of yourself, too. Giving your body the nourishment it needs is important if you are to have the stamina and energy it takes to do all that caregiving requires. A good place to begin is with healthful nutrition. Food choices affect how we look, feel, think and act. Good choices provide needed nutrition and energy. Poor choices cause us to feel badly, and can make a difficult situation seem worse.



There are lots of feelings associated with food. The very act of cooking for yourself, or even enjoying a good meal can make you feel guilty or even a bit selfish. If you are in an overwhelming situation, you may lose your appetite or not feel you have time to eat.

### Follow these suggestions to make sure you continue to eat well:

- **Don't rely on false energy from caffeine or sugar.** They can give you a quick burst of energy that will fade just as quickly, leaving you craving more of either or both. Whole grains give you energy that is more consistent and lasts longer. Also, water or juices have the advantage of providing better hydration, an absolute necessity for your body to operate at its best.
- **Be aware of the food you buy.** The food you bring into the house is the food you will eat. Include more fresh fruit and vegetables in your diet. Try to cut back on salty and fatty snacks. Keep sweets as special treats.

**Part II: Protect Your Health  
Continued****EAT WELL (CONTINUED)**

- **Don't skip meals.** Being overworked and over-stressed can lead to a loss of appetite. Sometimes you may feel “too tired to eat”. Even a light meal can be nutritious.
- **Accept offers from friends or family to help.** Having someone else prepare a meal for you and/or your loved one can be more satisfying. Better yet, share a meal with them. Social time at meals makes it easier and more enjoyable to eat.
- **Get others to help by running errands for you.** Give family or friends a grocery list so they can pick up some food for you.
- **Eating well involves not only eating the right food, but eating in the right way.** Take the time to eat slowly, letting your food digest.
- **Eating quickly can lead to eating too much.** Your body doesn't have time to register when you have had enough. Grabbing some food from the refrigerator and eating on the run generally leads to eating high calorie, low nutrition foods. A result of these habits can be eating too much and gaining weight. And, of course, we know from news reports that overweight is one of the most serious health risks we face.

**Part II: Protect Your Health  
Continued****A Story**

Eleanor, a 66 year old woman, was the caregiver for Paul, her 81-year old husband who had dementia. Eleanor was having trouble accepting the changes in Paul and the loss of the strong partner she'd had for over forty years. She wasn't sleeping, worried all the time that something would happen to Paul or that he would do something to embarrass himself (and her), but she refused to have anyone else care for Paul.

Eleanor mentioned to her daughter Brenda that she thought she was getting an ulcer. Brenda replied, "Please see a doctor, Mom. I'm losing one parent; I don't want to lose two!" Eleanor said that she would go to the doctor "when I get your father settled." So Eleanor didn't go to the doctor and a couple of months passed.

One morning, Eleanor noticed that the whites of her eyes looked a little yellow. This was frightening, so she made an appointment with her family doctor. When all the tests came back, they showed that Eleanor had pancreatic cancer and that the cancer had spread. The doctors gave her three months to live. Because Brenda had small children and couldn't give her father the attention he required, and Paul went to live in a nursing home. Eleanor's family wonders what might have been possible if Eleanor had seen a doctor earlier, if she had taken care of her own health as well as she took care of Paul.

## Part II: Protect Your Health Continued

### EXERCISE

As a caregiver, you probably have little time for yourself. Of all the things you might like or want to do in your spare time, exercise may be last on your list. And yet, exercise can be very rewarding and definitely is very good for you. It can keep you healthier, increase your resistance to disease, help you sleep better, and give you greater energy.

Discover exercise you enjoy. No matter how good our intentions are, if exercise is *only* a chore, we won't continue to do it. This is especially true for caregivers, who often need to make special arrangements and make a greater effort in order to be able to have an opportunity to exercise. Any kind of movement can be exercise. Dancing, walking, chair calisthenics, yoga - any kind of movement that will get your blood moving, get you breathing more deeply, and strengthen your muscles is terrific.

Choosing an activity that is fun for you is one way to enjoy exercise. But exercise can also be enjoyed as a social time. Set up a plan with a friend to have a regular meeting time to go for a walk. Take a Senior Center exercise class together. If you can't leave the house, perhaps your friend can visit in the morning or afternoon several times a week and the two of you can exercise together, maybe along with a television exercise program or an exercise tape if you find that helpful.



## Part II: Protect Your Health Continued

### SLEEP

It should be no surprise that research shows that lack of enough sleep is widespread among caregivers. Yet caregivers especially need to get proper rest. Being well-rested is essential for meeting the challenges you face each day. It will allow you to be more patient with your loved one. Getting enough sleep improves your mood so you feel better throughout the day. And sleep is critical for your good health. It supports your immune system so you don't get sick. Then, too, being tired contributes to accidents and injuries.

It may be hard to settle down from the constant activity of the day. Worry can keep you from falling asleep; anxiety may also cause you to wake up in the middle of the night and stare at the ceiling for hours, unable to get back to sleep. There are things you can do when you find you are having trouble getting enough sleep.



#### Here are some tips to help you get a good night's rest:

- Try to exercise regularly; exercise can improve sleep.
- Avoid drinks with caffeine for several hours before bedtime.
- Alcohol can disrupt sleep so don't drink or drink lightly just before going to bed.
- Drink warm, caffeine-free drinks, such as warm milk with honey or decaffeinated or chamomile tea, before sleep.
- Eat a light snack at bedtime.
- Experiment with aromatherapy, trying scents like lavender that are known to encourage relaxation.
- Keep your room dark and quiet during sleep times.
- Rest when your loved one does

## Part III. Reach Out For Help

### I'M FINE!

When people ask if they can be of help, is your first reaction to say, “Thank you but I’m fine”? Many caregivers don’t know how to invite others to help them and may be reluctant to accept help when it’s offered.

You can often hear the word “support” used in connection with caregiving. Without question, finding sources of support as a caregiver is important and at some points can be a real lifeline. Membership in a support group offers an opportunity to talk with others who have walked, and are walking, the path you are on. Even though each caregiver’s experience is unique, there are challenges and rewards that are common to caregiving, challenges and rewards that most caregivers know. Sharing your feelings with others who understand, really *understand* in their bones, what you are talking about can help you manage the stress and loneliness that too often come with being a caregiver for an ill family member.

However, as vital as support is, it is different from *help*. Help from another person can actually relieve you of some of the responsibilities of caregiving, for a time at least. Just as you need to be willing and able to seek out and receive support, you need to be able and willing to ask for help and be open to accepting help when it’s offered.

Help can come from community resources, family, friends and professionals. Ask them. There’s no reason to wait until you are overwhelmed and exhausted to seek help .



### Part III: Reach Out For Help Continued

#### ASKING FOR HELP

- Make a list of the things that would be helpful to you. The list might include running errands (for example, picking up medicine at the drug store, buying groceries), fixing meals, making phone calls, filling out forms, or just sitting with you loved one while you go out for a time. Delegate to family friends, neighbors, professionals whatever can be delegated
- Think about the particular skills and availability of family members, friends and neighbors. Who might be available during the daytime on weekdays? Who might be available evenings? Who may be able to help out on weekends?
- Consider how you might politely but firmly turn down help you don't need without discouraging further offers or willingness to help.
- Hold family meetings to share with family members what's happening, talk about what needs to be done, and enlist family members' participation in the care of their loved one.



### Part III: Reach Out For Help Continued

#### CHALLENGING OUR BELIEFS

Caregivers are often kept from seeking the help they need because of beliefs they hold about caregiving. The truth does not always support these beliefs, however. Consider the following:

**Belief:** I *should* be able to do everything myself; needing help is a sign of weakness or failure.

**Truth:** Understanding that caregiving is not a one-person job and being able to identify the specific areas where you can use help are signs of strength, not weakness. It means you understand your situation and you are able to plan to make things better for you and your loved one.



**Belief:** I am the only one who loves and is concerned about my loved one enough to give him or her the quality of care he/she deserves; no one else will make the effort I do.

**Truth:** There is almost always more than one approach to meeting any challenge. Try to be open to different perspectives. Although another person may provide help to your loved one differently than you, they may be able to handle the situation effectively, especially if it's for a short time (for example, a couple of hours).

**Part III: Reach Out For Help  
Continued****CHALLENGING OUR BELIEFS (CONTINUED)**

**Belief:** I am the only one who is competent enough to give my loved one excellent care

**Truth:** Maybe no one can do everything you do, but there are probably people around you who can do one or two of the many things you do each day. Consider individual family members', friends' and neighbors' abilities and interests. Match the person to the task. Who is around during the day and may be available to stay with your loved one while you run errands? Who can drive and may be able to run those errands for you occasionally? Who loves to cook and might make some extra to share with you?

**Belief:** I need to have much control of this situation as I can; having a bunch of people involved will just make things harder.

**Truth:** Giving yourself a break will allow you to maintain more control, not less, by providing a way to manage your feelings and the emotional rollercoaster of being a full-time caregiver. Even when others are involved in caregiving for your loved one, you can still take the lead in deciding what needs to be done and who should do it. You know better than anyone how your loved one likes things done and who he or she would be comfortable getting help from with particular tasks. Those providing help want to do things right and will welcome respectful directions.

**Belief:** I don't want to burden others with my problems

**Truth:** Many people want to help a friend, neighbor or family member who has become a caregiver but hesitate to intrude or are afraid of offending you. You can help them be helpful to you by letting them know what you need.

## Part III. Reach Out For Help

### SUGGESTIONS FOR ASKING OTHERS FOR HELP:

- Be clear and specific. Don't just hint or hope that the person will guess what you need.
- Be a good listener. Hear what others' needs are. Good communication depends upon good listening skills as much as it does on expressing your feelings and needs.
- Try not to ask the same person all the time. Even if a particular family member or friend never says no when you ask, keep in mind he or she may have other competing demands on their time.
- Prepare a list of things that need doing. This will give you a ready answer when someone asks how they can help. Second, it can provide a person who wants to help with an opportunity to choose the task they feel most able to do.
- Realize that someone you ask for help may not say "yes" right away or may not be willing or able to help. Try not to take a refusal personally. The person may feel very uncomfortable having to turn you down. One way to respond so that it doesn't affect your relationship is to simply say, "Thanks anyway – maybe another time." That way, you let the person know you're not angry with them and you leave the door open to the possibility of help in the future.

### Arranging to Get the Help I Need:

#### Tasks that I would like some help with:

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

#### Family, friends or neighbors who might be willing to help:

Name	Task
_____	_____
_____	_____
_____	_____

**Part III: Reach Out For Help  
Continued****A STORY**

Betty was a caregiver for her mother who had a stroke leaving her with limited use of her left arm and leg and limited ability to speak. Betty was overwhelmed with caregiving but had trouble asking for help. She joined a stroke caregiver support group. One day at a meeting Betty was feeling especially worn down and was complaining that her husband Charlie didn't help her at all. Bill, another member of the group, asked her what kind of help she would like from Charlie. Betty said, "I'd like him to wash the dinner dishes." Bill replied, "You provide care for your mother from the minute you wake up until you go to bed and all you want from Charlie is for him to wash the dishes?" Betty heard the disbelief in Bill's voice and began to reel off a long list of things she'd like Charlie to do, from cooking breakfast, to getting her mother up, to doing the laundry all before he left for work in the morning. Bill responded, "And Charlie might say, 'I can't do that, Betty, but I can bring you a cup of tea.'" At that , Betty felt tears spring to her eyes. Charlie's offer to bring her a cup of tea, showing concern and care for *her*, would mean the world to her. Sometimes those we ask for help may not be able to do exactly what we ask of them. But by asking, we give others the chance to express their care for us in their own way, and help in whatever way they can.

## Part IV. Speak Up For Your Rights

### YOU ARE NOT ALONE

As a family caregiver for a frail loved one, you are part of a group whose numbers are ever growing. As noted at the beginning of this Workbook, there are over 44 million caregivers in the United States providing care to an adult over 18 years of age. In other words, about 1/5 of the adult population in the country are caregiver. Almost 1/3 of all caregivers provide care for more than one person.

Because caregivers represent such a large portion of the population of the United States, you would think that they have a lot of power and can influence politicians to make sure that caregivers get the support that they need. The truth is, though, that caregivers are a silent group. They do not speak up to those in power to let them know what they need and what is needed to provide quality care for those who are the receivers of their care.

One reason, no doubt, is that caregivers are simply too busy to take on the role of advocates for themselves and other caregivers. Then, too, caregivers hesitate to “make trouble” for fear that they won’t get whatever resources are available for them. All of us share a responsibility to “speak truth to power.” That is, we need to tell those who have the ability to make changes in society about the changes that are needed. We need to recognize the importance of caregivers’ voices in letting others know the truth about the experience of providing care for an ill loved one. If caregivers don’t speak up for themselves, who can they expect to speak up for them?

Helen Keller, a woman who was both blind and deaf, summed it up best when she said “If we all do a little it will add up to a lot.” More than forty million caregivers in the United States add up to a lot of voices. If each person contributed her or his voice it would make a sound hard to ignore. Your voice is important – let it be heard!

**Part IV: Speak Up For Your Rights  
Continued****BEING AN EFFECTIVE ADVOCATE FOR YOURSELF AND OTHER CAREGIVERS CALLS FOR:**

**Confidence.** There is no one who knows more about your situation than you do. Trust in the truth of what you know and in your ability to talk about your experience. Your voice is valuable and those who are in positions to make change in the system or to make what you and your loved one need available to you want to hear what you have to say.

**Knowledge.** People listen better to those who sound like they know what they are talking about. You have the experience to allow you to talk with authority about what being a caregiver is like; you are familiar with the stresses, the rewards, things that have been helpful or that have made caregiving more difficult than it needs to be. Don't hesitate to ask questions of anyone you think may have information that you need or that would be helpful in sharing your experiences with others.



**Self-awareness.** It is not easy for caregivers to find the time and opportunity to speak up for themselves. Caregivers are already balancing many responsibilities and do not have a lot of time to spend on the telephone or attending community meetings where they can speak with representatives directly. It is really important, therefore, that you recognize how important it is to add your own voice to those of other caregivers so that caregivers' needs can indeed be heard by those who make decisions about how available government dollars will be spent.

## Part IV: Speak Up For Your Rights Continued

### BEING AN EFFECTIVE ADVOCATE FOR YOURSELF AND OTHER CAREGIVERS CALLS FOR: (CONTINUED)

**Impatience.** Impatience is often regarded as something to be controlled or overcome. But impatience can be an advocate's friend. It is what motivates advocates to keep the pressure on when others might drag their feet or put the concerns of caregivers on a back burner. Impatience is a motivator. Advocacy offers a way to use the impatience and frustration that caregivers can experience to improve conditions for both caregivers and care receivers.

**Limits.** You may not be able to be as involved in advocacy as you would like since you are a busy caregiver. However, you should decide, based on your ability, what you *are* able to do. You can be helpful by just sharing your story with another advocate, signing your name to a petition or a letter prepared by others, or by making a quick phone call.



## Part IV: Speak Up For Your Rights Continued

### Contacting Your Government Representatives

If an elected official invited you to educate her about what caregivers need from government programs, what are the top three things would you tell her or him are needed:

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

You can make your voice heard by letting your representatives know of the ways that government programs can support caregiving and improve the lives of both those who give and receive care.

#### City/County Council Representative:

Name: \_\_\_\_\_  
 Office Address: \_\_\_\_\_  
 Office Telephone: \_\_\_\_\_  
 Email: \_\_\_\_\_

#### State Representative:

Name: \_\_\_\_\_  
 Office Address: \_\_\_\_\_  
 Office Telephone: \_\_\_\_\_  
 Email: \_\_\_\_\_

#### State Senator:

Name: \_\_\_\_\_  
 Office Address: \_\_\_\_\_  
 Office Telephone: \_\_\_\_\_  
 Email: \_\_\_\_\_

#### United States Representative:

Name: \_\_\_\_\_  
 Office Address: \_\_\_\_\_  
 Office Telephone: \_\_\_\_\_  
 Email: \_\_\_\_\_

#### United States Senators:

Name: \_\_\_\_\_  
 Office Address: \_\_\_\_\_  
 Office Telephone: \_\_\_\_\_  
 Email: \_\_\_\_\_

Name: \_\_\_\_\_  
 Office Address: \_\_\_\_\_  
 Office Telephone: \_\_\_\_\_  
 Email: \_\_\_\_\_

## Summing Up

### THE FOUR IMPORTANT MESSAGES OF THIS WORKBOOK HAVE BEEN:

- **Believe in yourself**
- **Protect your health**
- **Reach out for help**
- **Speak up for your rights**

While each one of the four is essential both for your well-being and for the quality of care that you are able to provide to your loved one, the most important message is the first: *Believe in yourself!* When you believe in yourself and the significance of the work that you are doing the other messages naturally follow. You will recognize the importance of taking care of yourself and your health, you will feel entitled to ask for help from others around you, and you will understand the need to speak out for changes to assure that services and financial support are more broadly available for all caregivers.

It may be unrealistic to expect that we can put each of the four messages into practice all the time. However, the four messages remind us of a truth about caregiving we might be tempted to overlook. *Being good to yourself is one of the very best ways to be good to your loved one!*



## Resources

### **FAMILY CAREGIVER SUPPORT PROGRAM**

The Family Caregiver Support Program offers assistance to primary unpaid caregivers who are providing daily hands-on care to a friend or relative. This support comes in many forms—financial assistance to help families who qualify financially pay for caregiving supplies and services; access to resources and information; and reduction of emotional stress through our care management and respite care services. Our goal is to assist caregivers with the resources they need to continue providing vitally needed care. There are also services available for relatives over age 60 who are raising a child age 18 or younger.

### **RESPIRE CARE**

Respite services such as in-home care, adult day care services and overnight care allow caregivers to have time for themselves or work at a job outside the home knowing their loved one is in good hands.

### **SUPPORT, COUNSELING & EDUCATION**

There are many organizations that provide information about coping with chronic and terminal illnesses, what to expect, and how to meet the challenges of serving as a caregiver to someone who has one of these illnesses. There are also support groups that offer caregivers an opportunity to meet and share experiences with others facing similar challenges.

### **PHILADELPHIA CORPORATION FOR AGING**

215-765-9000

642 North Broad Street

Philadelphia, PA 19130-3424

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

## Resources

### **ALZHEIMER'S ASSOCIATION**

215-561-2919  
399 Market Street/Suite 102  
Philadelphia, PA 19106  
[www.alz.org](http://www.alz.org)

### **AMERICAN CANCER SOCIETY**

888-227-5445  
1626 Locust Street  
Philadelphia, PA 19103  
[www.cancer.org](http://www.cancer.org)

### **CENTER FOR ADVOCACY FOR THE RIGHTS AND INTERESTS OF THE ELDERLY**

215-545-5728  
100 South Broad Street—Suite 1500  
Philadelphia, PA 19110  
[www.carie.org](http://www.carie.org)

### **PENNSYLVANIA DEPARTMENT OF AGING**

717-783-1550  
555 Walnut Street—5th Floor  
Harrisburg, PA 17101-1919  
[www.aging.state.pa.us](http://www.aging.state.pa.us)





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A Guide For Family  
Caregivers

2011

