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The Caregiver Helpbook

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CHAPTER ONE



Taking Care of You

Caregiving involves many challenges. You often need to master new skills. You may need to develop new ways of relating to a family member if his or her ability to communicate or remember is compromised by illness. You may have to make tough decisions. But often one of the greatest challenges is taking care of yourself.

Too often caregivers neglect their own health and well-being, and put their own needs "on the back burner." Sometimes caregivers become a second victim of the disease that afflicts their family member. It's sad when someone says, "My mother was the ill person, but her illness destroyed my father." Usually, we cannot stop the impact

of a chronic illness on a family member. However, we are responsible for our own self-care.

When you board an airplane, the flight attendant gives several safety instructions. One of them is, "If oxygen masks drop down, put on your oxygen mask first before helping others." This is because if you don't take care of yourself first, you may not be able to help those who need your help. It's the same thing with caregiving. When you take care of yourself, everyone benefits. Ignoring your own needs is not only potentially detrimental to you, but it can also be harmful to the person who depends on you.

THE CAREGIVER HELPBOOK

The *Caregiver Helpbook* was designed to help you maintain personal well-being while providing quality care to your family member. The first half of the book focuses on several tools to help you to take care of you. These tools will help you to:

- ◆ set goals and make action plans.
- ◆ identify and reduce personal stress.
- ◆ make your thoughts and feelings work for you, not against you.
- ◆ communicate your feelings, needs, and concerns in positive ways.
- ◆ cope with difficult situations, including asking for help and setting limits.
- ◆ deal with emotions, especially feelings of anger, guilt, and depression.
- ◆ make tough caregiving decisions.

Chapters in the second half of the book address special concerns and decisions you may face as a caregiver. These include what to do when a family member is no longer a safe driver, hiring in-home help, using community services, how to communicate with and respond to a family member who is memory impaired, options available when a family member is having problems managing his money, coping with depression, and making a decision about a care facility. You can turn to these chapters for guidance and resources when you face a specific decision or concern.



MANAGING SELF-CARE

Managing our self-care means that as caregivers we:

- ◆ **Take responsibility.** We realize we are responsible for our personal well-being and for getting our needs met. This includes maintaining activities and relationships that are meaningful to us.
- ◆ **Have realistic expectations.** We fully understand our family member's medical condition and we are realistic about what our family member can and cannot do.

Ask yourself the following questions about your caregiving:

Yes No

- | | | |
|--------------------------|--------------------------|---|
| <input type="checkbox"/> | <input type="checkbox"/> | Do you ever find yourself trying "to do it all?" |
| <input type="checkbox"/> | <input type="checkbox"/> | Do you ever say to yourself "I should be able to...", "I can never...", or similar statements? |
| <input type="checkbox"/> | <input type="checkbox"/> | Do you ever ignore your feelings or find that they are overwhelming? |
| <input type="checkbox"/> | <input type="checkbox"/> | Do you ever get frustrated because of something you can't change or someone who won't change? |
| <input type="checkbox"/> | <input type="checkbox"/> | Do you resist seeking, asking for, or accepting help? |
| <input type="checkbox"/> | <input type="checkbox"/> | Do you feel that your family or others just don't understand what you are going through as a caregiver? |

A "yes" answer to any of these questions indicates an area of self-care you might want to work on.

The more you know about your family member's medical condition, the better you will be able to plan successful caregiving strategies. Knowledge is power.

It's also important to look at your definition of a "good caregiver." Unrealistic expectations can set you up for feelings of failure, resentment, and guilt. Placing burdensome expectations on yourself does not make you a better caregiver. In fact, you are much more likely to become an exhausted, irritable, and resentful caregiver...and then to feel guilty!

- ◆ **Focus on what we can do.** It's important to be clear about what you can and cannot change. For example, you will not be able to change a person who has always been demanding and inflexible, but you can control how you respond to that person's demands. You can accept—"let go" of—the things you cannot change. Managing your self-care also means you seek solutions to what you can change.
- ◆ **Communicate effectively with others.** These include family members, friends, health care professionals, and the care receiver. Don't expect others to know what you need. Recognize it is your responsibility to tell others about your needs and concerns. Communicate in ways that are positive and avoid being demanding, manipulative, or guilt-provoking when you make requests.
- ◆ **Learn from our emotions.** Realize there will be emotional ups and downs. Listen to your emotions and what they are telling you. Don't bottle up your emotions. Repressing or denying feelings decreases

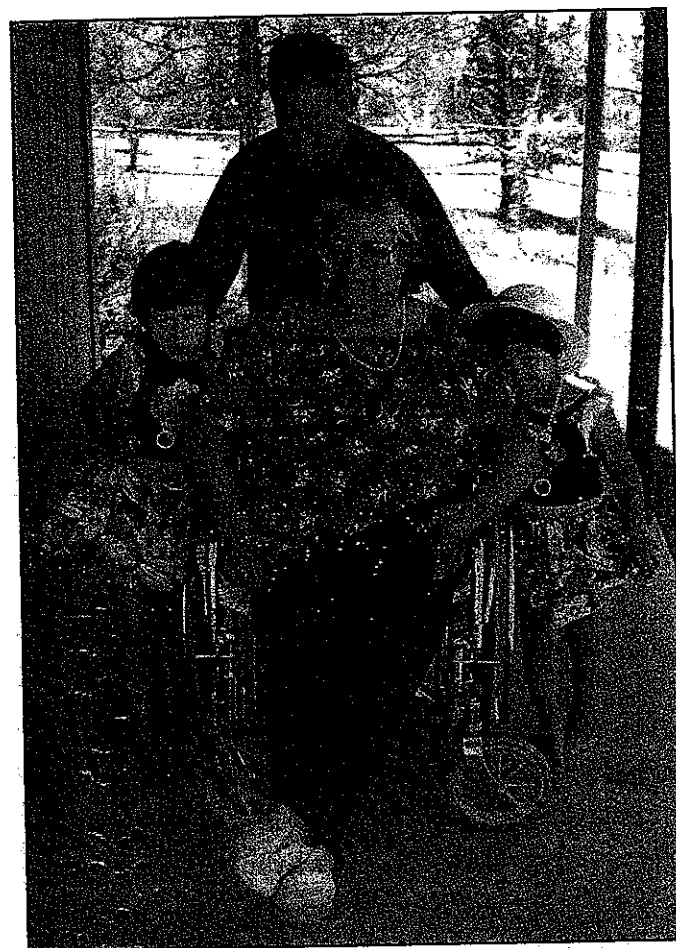
energy; causes irritability, depression, and physical problems; and affects your judgment and ability to make the best decisions. Also, don't strike out at others. You are in control of your emotions; your emotions don't control you.

- ◆ **Get help when needed.** An important part of self-care is knowing when you need help and how to find it. Help can be from community resources, family and friends, or professionals. Most important is that you do not wait until you are "hanging at the end of your rope" before you get help. Don't wait until you are overwhelmed or exhausted, or your health fails. Reaching out for help, when needed, is a sign of personal strength.
- ◆ **Set goals and work toward them.** Be realistic in the goals that you set and take steps toward reaching those goals. Seek solutions to the problems that you experience. Changes do not need to be major to make a significant difference.

In summary, self-care means that you seek ways to take better care of yourself. As a caregiver, you don't just survive. You thrive!

Trying To Do It All

One problem that caregivers frequently experience is trying to do it all and doing it all alone. Is it possible to do it all? The answer to the question can be both "yes" and "no." It really depends on you. What is critical is how you define what it means to "do it all." And, whether or not your definition of "doing it all" includes taking care of yourself so that you thrive, and not just survive.



To Maxine, the answer to the question "Is it possible to do it all?" was "no." She says, "Mother's needs are endless and no matter what I do, I can never make her happy." Yet, at the same time, Maxine was trying to do it all. Her mother's care dominated Maxine's life.

Another caregiver, Maria, answered "yes" to the question, "Is it possible to do it all?" She explained that "All that needed to be done for my mother was done."

A major difference between Maxine and Maria was the rules by which they operated. Maxine operated by the rule, "I must do everything for my mother." The rule had

become, "I must help Mama at all costs." As a result, her relationships with other family members suffered and Maxine found herself becoming increasingly resentful. Maxine's feelings of wanting to do everything is legitimate, but the actions associated with her feelings usually are impossible to carry out. As a result, Maxine experiences feelings of failure and lack of success.

Maria was more realistic. She recognized that the things she wanted to be done—whether they were her desires, her mother's desires, or the desires of others—were not the same as the things that needed to be done. Maria's goal was to make her mother as comfortable as possible, without sacrificing herself and the other important relationships in her life. She also got help from family and a community agency in meeting her mother's needs. Maria said:

To some degree I recognized that caregiving was like a job and my goal was to find the best way to get the job done. A friend also told me that doing any job well—including the job of caregiving—requires four things:

1. Recognizing you can't do everything yourself—you work with others.
2. Taking daily breaks.
3. Taking vacations to renew oneself.
4. Being realistic about what you can do.

There was another difference between Maxine and Maria. Maxine felt it was selfish to think of herself. Maria, on the other hand, viewed that if she was going to be there for the long haul, she must take care of herself, and make sure that she had pleasurable moments in her life.

As a caregiver, you are more likely to "be there" for your family member who needs your care and to be a more loving and patient caregiver when you meet some of your own needs. It's important to "fill your own cup" and not allow it to "run dry."

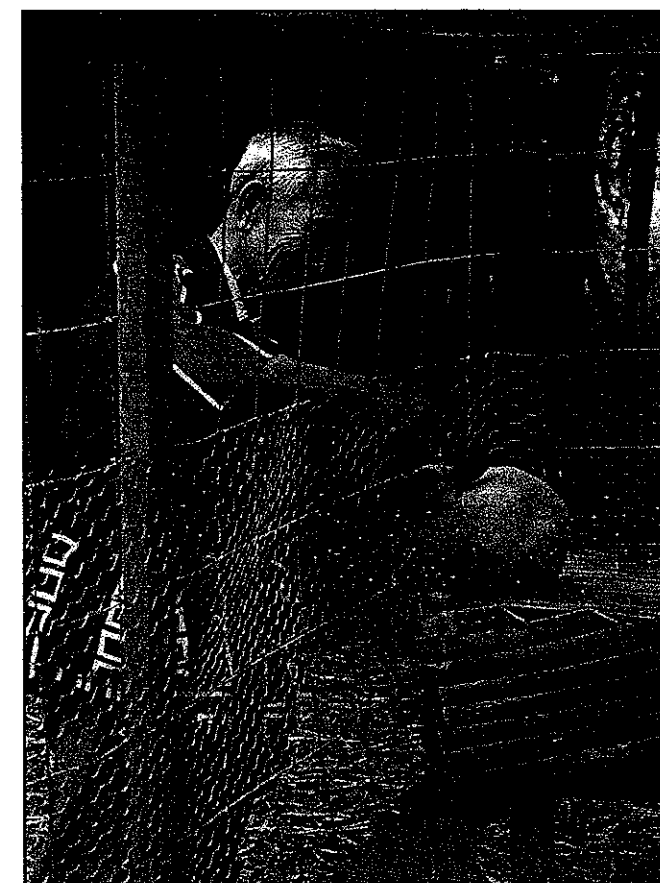
It's not being selfish to focus on your own needs and desires when you are a caregiver to a family member who has a chronic or progressive illness. It's important to ask yourself, "If my health deteriorates, or I die, what will happen to the person I provide care for? If I get emotionally drained, become deprived of sleep, or become isolated because I am trying to do it all, how loving am I likely to be to my family member?"

Taking Time for Yourself

Do you value yourself and your personal needs? What do you do for personal renewal? Do you save some time for yourself out of each day? Do you take occasional extended breaks? Or are you so involved with caregiving tasks that you have little or no time for yourself?

What activities do you enjoy? What would you like to do that would give you a lift? When was the last time you gave yourself a treat?

Breaks in caregiving are a must. They are as important to health as diet, sleep, rest, and exercise. It's important not to lose sight of your personal needs and interests. Studies show that sacrificing yourself in the care of another and removing pleasurable events from your life can lead to emotional exhaustion, depression, and physical illness. You have a right—even a responsibility—to take some time away from caregiving.



Regular breaks from the tasks of caregiving are essential. Decide on the time, date, and activity—then follow through. Breaks don't have to be long to make a positive difference. It's important to plan some time for yourself in every day, even if that time is only for 15 minutes or half an hour. Most important is to do something that "fills your cup" and helps you to feel better and thrive.

If you have difficulty taking breaks for yourself, consider taking them for your family member. Care receivers also benefit from caregivers getting breaks.



SETTING GOALS

An important tool in taking care of yourself is setting goals. A goal is something you would like to accomplish in the next three to six months: What would you like to do to take better care of yourself and to help yourself to thrive? This might be to get a break from caregiving for a week, get help with caregiving tasks, be able to walk three miles, or quit feeling guilty.

Goals often are difficult to accomplish because they may seem like dreams or they may be overwhelming. As a result, we may not even try to accomplish them or we may give up shortly after we get started. We will address this problem shortly. For now, take a moment and write your goals here:

Goal 1 _____

Goal 2 _____

Goal 3 _____

Put an asterisk () next to the goal you would like to work on first.*

After identifying a goal, the first step is to brainstorm all of the different things you might do to reach your goal. Identify and write down all possible options.

Option 1 _____

Option 2 _____



Option 3 _____

Option 4 _____

Option 5 _____

The second step is to evaluate the options you have identified. Which options seem like possibilities to you? It's important not to assume that an option is unworkable or doesn't exist until you have thoroughly investigated it or given it a try. Assumptions are major self-care enemies.

Put an asterisk () next to two or three options you would like to try. Select one to try.*

The third step is to turn your option into a short-term plan, which we call *making an action plan*.

MAKING ACTION PLANS

An action plan is a specific action that you are confident you can accomplish within the next week. It's an agreement or contract with yourself.

Action plans are one of your most important self-care tools. An action plan is a step toward reaching your long-term goal. It is to be something you want to do. It is *not* to be something you feel you *should* do, *have* to do, or *need* to do. The intent of making an action plan is to help you to feel better and to take better care of yourself. Remember, an action plan is a "want to do."

Here are the five steps for making an action plan:

1. Decide what you want to do.
2. Make your plan behavior-specific.
3. Make a specific plan.
4. Determine your confidence level.
5. Write down your action plan.

Decide What You Want To Do

Think about what is realistic for you to accomplish within the next week. It's important that an action plan is reachable; otherwise, you are likely to experience frustration. An action plan is to help you experience success—not frustration, increased stress, or failure. An action plan starts with the words, "I will..." If you find yourself saying "I will try to...", "I have to...", or "I should..." then re-examine your action plan. It probably is not something that you truly want to do.

Make Your Plan Behavior-Specific

The more specific your action plan, the greater your chances of accomplishing it. For example, "taking better care of myself"

PARTS OF AN ACTION PLAN

1. It's something you want to do.
2. It's reachable (something you believe you will be able to accomplish during the next week).
3. It answers these questions:
—What?
—How much?
—When?
—How often?
4. It has a high confidence level.
(You are certain that you will be able to complete your *entire* action plan during the next week.)

is not a specific behavior. However, making an appointment for a physical check-up, walking three times a week, getting a massage on Thursday afternoon, or asking someone to stay with your family member for one morning are all specific behaviors. "I will relax" also is not a specific behavior; however, reading a book, listening to your favorite music, or putting in the garden are specific behaviors.

Make a Specific Plan

Making a specific plan is often difficult, yet it is the most important part of making an action plan. A specific plan answers these four questions:

1. **What are you going to do?**
Examples: I will read (*book name*) for pleasure. Or, I will walk.
2. **How much will you do?**
Examples: Will you read one chapter or will you read for a half hour? Will you walk two blocks or for 20 minutes?



3. When will you do this?

Examples: Will you read the first thing in the morning when you awaken, before you go to bed, when the care receiver is sleeping, or...? If your plan is to walk, when during the day will you do it?

4. How often will you do this activity?

Example: Three times a week on Monday, Wednesday, and Friday.

A common mistake is to make an action plan that is unreachable within the time frame. For example, if you plan to do something every day, you might fail. Caregiving, and life in general, has its surprises. Although well-intentioned, it's often not possible to do something every day. It's better to plan to do something once or twice a week and

exceed your action plan than to plan to do something every day and fail because you only did it six days, rather than seven. Remember, an action plan is meant to help you to take better care of yourself and to experience success. The last thing you need is additional pressure, disappointment, and stress.

Here are two recommendations for writing an action plan that can help you achieve success.

1. Start where you are or start slowly. If there's a book you've been wanting to read, but just haven't found the time, it may not be realistic to expect to read the entire book in the next week. Instead, try reading for a half hour twice during the week. If you haven't been physically

active, it may be unrealistic to make an action plan to start walking three miles. It is better to make your action plan for something that you believe you can accomplish. For example, make your plan for walking three blocks or a half mile, rather than three miles.

2. Give yourself time off. We all have days when we don't feel like doing anything. That's the advantage of saying you will do something three days a week, rather than every day. That way, if you don't feel like doing something on one day, or something develops that prevents you from doing it, you can still achieve your action plan.

Determine Your Confidence Level

Once you've made your action plan, ask yourself the following question: On a scale of 0 to 10, with 0 being not at all confident and 10 being totally confident, how confident am I that I can complete my action plan?

If your answer is 7 or above, your action plan is probably realistic and reachable. However, if your answer is 6 or below, it's important to take another look at your action plan. Something probably needs to be adjusted.

Ask yourself, "What makes me uncertain about accomplishing my action plan? What problems do I foresee?" Then, see if you can either find a solution to the problems you identified or change your action plan to one in which you feel greater confidence.

Write Down Your Action Plan

Once you are satisfied with your action plan, write it down. Putting an action plan in writing helps us to remember, keep track of, and accomplish the agreement we have made with ourselves. Keep track of how you are doing. Write down the problems you encounter in carrying out your action plan. Check off activities as you accomplish them. If you made an adjustment in your action plan, make a note of what you did.

At the end of the week, review your action plan. Ask yourself, "Am I nearer to accomplishing my goal?" "How do I feel about what I did?" What obstacles or problems, if any, did I encounter?" Taking stock is important. If you are having problems, this is the time to seek solutions.

See page 12 for a sample action plan.

See page 13 for an action plan form that you can duplicate and use to develop your own action plans.



PROBLEM-SOLVING: A SOLUTION-SEEKING APPROACH

Sometimes you may find that your action plan is not workable. You may encounter unusual circumstances that week and need to give the plan a try for at least another week. Or you may need to make adjustments in your original plan. The following solution-seeking approach can help you identify solutions to problems.

- ◆ **Clearly identify the problem.** This is the first and most important step in the solution-seeking approach. It also can be the most difficult step.
- ◆ **List ideas to solve the problem.** Family, friends, and others may be helpful in giving ideas. When you ask for ideas, just listen to each suggestion. It's best not to respond as to why an idea is or isn't likely to work. Just focus on getting the ideas.
- ◆ **Select one to try.** When trying a new idea, give it a fair trial before deciding that it won't work.
- ◆ **Assess the results.** Ask yourself, "How well did what I chose work?" If all went well, congratulate yourself for finding a solution to the identified problem. If the first idea didn't work, try another idea. Sometimes an idea just needs fine-tuning. It's important not to give up on an idea just because it didn't work the first time.

If you have difficulty finding a solution that works, utilize other resources. Share your problem with family, friends, and professionals and ask them for possible ideas. If you still find that suggested solutions do not work, you may need to accept that the problem is not solvable right now.

Remember, just because there doesn't seem to be a workable solution right now doesn't mean that a problem can't be solved later, or that other problems can't be solved in the same way. It may be helpful to go back to the first step and consider if the problem needs to be redefined. For example, a caregiver had thought that her problem was

"I am tired all of the time." However, the real problem was the caregiver's beliefs that "No one can care for John like I can," and "I have to do everything myself." As a result of these beliefs, the caregiver was doing everything herself and getting worn out. When she redefined the problem and focused on changing her beliefs and view of the caregiving situation, she found a workable solution. Sometimes, too, a problem may be easier to work on if you break it down into smaller problems.

Most of the time if you follow these steps, you will find a solution that solves the problem. It's important to avoid making the mistake of jumping from step 1 to step 7 and thinking "nothing can be done."

SUMMARY OF THE SOLUTION-SEEKING APPROACH

1. Identify the problem.
2. List ideas to solve the problem.
3. Select one idea to try.
4. Assess the results.
5. Substitute another idea if the first one didn't work.
6. Utilize other resources if your solutions don't work.
7. Accept that the problem may not be solvable now.

REWARD YOURSELF

Accomplishing action plans is often a reward in itself. However, it's also important to find healthy pleasures that add enjoyment to your life. Rewards don't have to be fancy or expensive or take a lot of time. One caregiver, for example, regularly goes to a movie or a play as a gift to herself from her husband. She said:

When my husband was well, he would take me out Friday nights to a movie or a play at least twice a month. Because of his medical condition, he is no longer able to do so. Now a friend and I go to a movie or a play at least once a month. I consider this is a treat that my husband is still giving to me.

Another caregiver said:

Before my wife's illness, I would go golfing with my buddies on Saturday morning. When Carmela needed more care, I quit golfing. I now treat myself to Saturday golfing, while my daughter or a friend visits with Carmela. This gives me something to look forward to each week and I feel more alive when I return home. I'm also finding I am more patient with Carmela. My daughter says I am always happier and calmer when I return home. So, I look at Saturday golfing as my treat not only to me, but also to Carmela.



SUMMARY

In review, a caregiver who practices self-care does the following:

1. Sets goals.
2. Identifies a variety of options for reaching a goal.
3. Makes an action plan toward accomplishing the goal.
4. Carries out the action plan.
5. Assesses how well the action plan is working.
6. Makes adjustments, as necessary, in the action plan.
7. Rewards himself or herself.

Not all goals are achievable. Sometimes we must accept that what we want to do is not possible at this time, and we must let go of the idea. Be realistic about goals and don't dwell on what can't be done.

Consider what is likely to happen to the caregiver who is driven by a goal to make her mother happy. Given her mother's personality, this goal may be completely unachievable. Such a goal creates a heavy burden and a caregiver is not likely to achieve it. However, an achievable goal might be to provide a pleasurable activity for her mother at least once a week—perhaps taking her to get her hair done, visiting a friend, watching a comedy on television, or working together on a project her mother enjoys.

Remember, what is important in caregiving is not just to survive, but to thrive! This book is designed to give you a set of tools to help you take care of yourself. This in turn will help you provide better care.



Overview Chapter Two

The Stress of Caregiving Factors That Affect Stress

Steps to Maintain and Avoid Stress

Step 1: Recognize Your Warning Signs of Stress

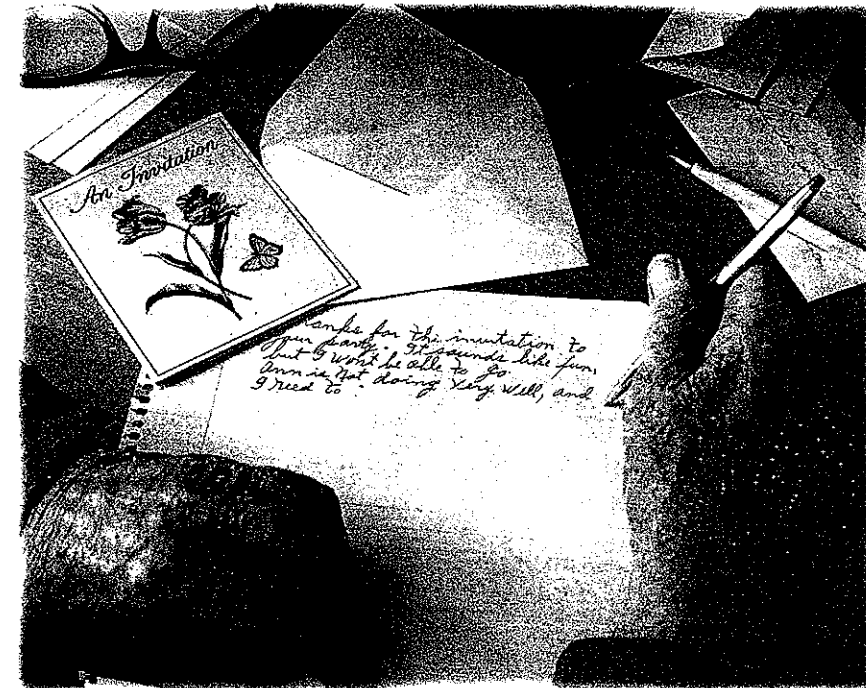
Step 2: Identify Your Sources of Caregiving Stress

Step 3: Identify What You Can and Cannot Change

Step 4: Take Action to Manage Your Stress

Summary

CHAPTER TWO



Reducing Personal Stress

The philosophy of Virginia Satir, noted family therapist, sets the tone for this chapter on the stresses and challenges of caregiving. She reminds us that how we perceive and respond to an event is a significant factor in how we adjust and cope with it.

This chapter explores the stress of caregiving. It will help you identify and understand your particular stressors, challenges, and strengths. You can then plan strategies that help you cope, change, and reduce stress. A basic premise of this chapter is that each of us has a reservoir of strength. The challenge is to identify our strengths and build on them.

*Life is not the way it's supposed to be.
It's the way it is. The way you cope
with it is what makes the difference.
I think if I have one message, one thing
before I die that most of the world
would know, it would be that the event does
not determine how to respond to the event.
That is a purely personal matter.
The way in which we respond will
direct and influence the event more
than the event itself.*

Virginia Satir

THE STRESS OF CAREGIVING

There has been so much written about stress it has become a household word. Studies show that a certain amount of stress is helpful. It can challenge us to change and motivate us to do things we might not do otherwise. However, when the amount of stress overwhelms our ability to cope with it, we feel "distress" or "burnout."

According to Webster's Dictionary, distress is "suffering of mind or body; severe physical or mental strain." As a caregiver, you no doubt have increased stress in your life, whether you are caring for a mother with early Parkinson's disease, who is still able to care for her personal needs, or a spouse who doesn't recognize you because of advanced Alzheimer's disease.

Each caregiving situation is unique. What is stressful for you may not be stressful for someone else. In his book *The Survivor Personality*, Al Siebert says, "there is no stress until you feel a strain." Since the feeling of stress is subjective and unique to each individual, it is difficult to define objectively. The stress you feel is not only the result of your caregiving situation, it is also your perception of it. Your stress will increase or decrease depending on how you perceive your circumstances. And your perception will affect how you respond.

Factors That Affect Stress

Your level of stress is influenced by many factors, including:

- ◆ whether your caregiving is voluntary or not.
- ◆ your relationship with the care receiver.

- ◆ your coping abilities.
- ◆ your caregiving situation.
- ◆ whether support is available.

Whether your caregiving is voluntary or not

Many people become caregivers voluntarily. Others acquire the role because no one else is available. When you become a caregiver voluntarily, you are making a choice. However, if you "inherited" the job and feel you had no choice, the chances are greater for experiencing strain, distress, and resentment. Nancy became a caregiver because no one else was available.

Nancy couldn't have been more surprised when the visiting nurse asked her if she was the primary caregiver for her mother-in-law, Joan. Nancy was fond of Joan. She called and stopped by frequently to see how Joan was managing, but hadn't thought of herself as the primary caregiver. It was apparent that Joan's medical condition was worsening and she was becoming increasingly weak. Nancy realized there were no other children or relatives available, so she agreed, although somewhat reluctantly, to be Joan's caregiver. Nancy felt anxious and uncertain about what it meant to be a primary caregiver and whether she had the necessary skills to perform the role.

Luckily, Nancy and Joan had a good relationship and they were able to communicate openly, minimizing some of the potential for stress. You can't always think about a caregiving relationship in advance, but if you can, it has greater potential for success.

Your relationship with the care receiver

If your relationship with the care receiver has been difficult, becoming a caregiver is more of a challenge. If the care receiver has always been demanding and controlling, you will probably feel more stress, anger, and resentment.

Sometimes people are caregiving with the hope of healing a relationship. The healing may or may not happen. If healing doesn't happen, the caregiver may feel regret, depressed, and discouraged. A professional counselor, spiritual advisor, or trusted friend can help deal with such feelings and emotions.

Your coping abilities

How you have coped with stress in the past predicts how you will cope now. Did you find constructive ways to manage your stress? Perhaps you were able to find time to exercise regularly and generally take care of yourself. Or did you rely on alcohol or drugs to help you cope? Sometimes people rely on medications and alcohol in times of stress, which only makes matters worse.

It is important to identify your current coping strengths and build on them. Learning new coping skills also will help make your caregiving situation less stressful.

The caregiving situation

What does your caregiving situation require of you? Does it require 24-hour-a-day availability? Or do you just need to make an occasional telephone call to check on the person? What disease does the care receiver have? Does he have a mental or physical disability, or both?

Certain caregiving situations are more stressful than others. For example, caring

for someone who has a dementia such as Alzheimer's disease is often more stressful than caring for someone with a physical limitation. Also, stress tends to be highest when:

- ◆ the caregiving situation continues for a long time.
- ◆ the care receiver's needs gradually increase.
- ◆ caregivers feel they have limited or no support.
- ◆ caregivers have their own health/physical problems.

Whether support is available

Caregivers who feel isolated and without adequate support usually experience a higher level of stress. Support may be lacking for several reasons:

- ◆ The caregiver may resist accepting help, even when he or she needs it.
- ◆ Others may be willing to help but don't offer because they are uncomfortable around the ill person, frightened of the illness, or don't know what they can do.
- ◆ Others don't want to interfere, especially if the caregiver seems to have everything under control and has refused help in the past.

Caregiver stress is influenced by many factors, including the need to adapt to ongoing changes and losses caused by the care receiver's illness. These changes cause you to redefine your life. What was normal has changed. You are living with a new reality.



STEPS TO MAINTAIN HEALTH AND AVOID DISTRESS

Whatever causes stress in your life, too much of it can lower your resistance to disease and lead to "burnout." Current research shows that there is a close connection between stress and health. Unrelieved stress is one of many factors that cause illness. Research also shows that thoughts and emotions affect the immune system, which is the first line of defense against disease. It is possible to strengthen the immune system by reducing stress. The following four steps will help you maintain your health and avoid distress:

1. Recognize your warning signs of stress.
2. Identify your sources of stress.

3. Identify what you can and cannot change.

4. Take action to manage your stress.

Each of these steps will be discussed in detail.

Step 1: Recognize Your Warning Signs of Stress

The first step in managing stress is to be aware of how it affects you. What are your warning signs and symptoms of stress?

The following are signs that may occur when you experience an unusual amount of stress. Answering these questions can help you identify your own warning signs.

What is usually your earliest sign of stress? It's important to recognize stress early and do something about it, before it

Yes No

- ☐ ☐ Do you feel a loss of energy or zest for life?
- ☐ ☐ Do you feel tired or exhausted much of the time?
- ☐ ☐ Do you feel out of control, exhibiting uncharacteristic emotions or actions?
- ☐ ☐ Do you feel tense, nervous, or anxious much of the time?
- ☐ ☐ Do you lack interest in people or things that were formerly pleasurable?
- ☐ ☐ Are you becoming increasingly isolated?
- ☐ ☐ Are you consuming more sleeping pills, medications, alcohol, caffeine, or cigarettes?
- ☐ ☐ Are you having increased health problems: for example, high blood pressure, headaches, ulcers, upset stomach, or other difficulties with digestion?

Yes No

- ☐ ☐ Do you have sleep problems, such as difficulty falling asleep at night, awakening early, or sleeping excessively?
- ☐ ☐ Are you experiencing appetite changes?
- ☐ ☐ Do you have problems with concentration or memory?
- ☐ ☐ Are you increasingly irritable or impatient with others?
- ☐ ☐ Do you have feelings of helplessness or hopelessness?
- ☐ ☐ Are you abusing or neglecting to provide care to the care receiver?
- ☐ ☐ Do you have thoughts of suicide?

A "yes" answer to even one or two of these questions can indicate stress that has become debilitating.

causes you serious problems. For one caregiver, the early sign might be increased irritability. For another, it might be lying awake for hours before falling asleep. For another, it might be fatigue and a lack of energy.

Sometimes, too, when we are involved in a situation, we may not listen to our early warning signs, but they are voiced in the words of others: "You look so tired," "You get upset so easily lately," "Why are you snapping at me?" If you hear such statements, it is a "red light" warning sign. Just as a flashing red light on your car's dashboard warns you that something is wrong with your car, we also display warning signals. What happens if we ignore the early red flashing light on the car's dashboard? What happens if we ignore our personal early warning signals?

Do you listen to your early warning signals? What are they? And what do you do about them? Warning signs usually mean we need to stop, evaluate what's happening, and make some changes. The earlier warning signals are recognized, the greater the chance of avoiding or reducing the destructive effects of stress.

Step 2: Identify Your Sources of Caregiving Stress

The second step in managing stress is to recognize what causes your stress. Not all stressors are the result of caregiving. Other sources can affect your ability to be a caregiver. The following questions include many common sources of stress. Answering these questions can help you recognize some of your own sources.

Yes No

- ☐ ☐ Are you experiencing many demands on your time, energy, or money? What are they?
- ☐ ☐ Do you feel you have conflicting responsibilities? Which ones?
- ☐ ☐ Are there differences in expectations between your family, your boss, the care receiver, and yourself? What are they?
- ☐ ☐ Do you feel others don't understand the care receiver's mental or physical condition?
- ☐ ☐ Do you have difficulty meeting the care receiver's physical or emotional needs?
- ☐ ☐ Are you pressured by financial decisions and lack of resources?
- ☐ ☐ Do you feel a loss of freedom, to the point of feeling trapped?
- ☐ ☐ Is there disagreement among family members?
- ☐ ☐ Do you feel that other family members aren't doing their share?
- ☐ ☐ Does the care receiver place unrealistic demands and expectations on you?
- ☐ ☐ Is there a lack of open communication between you and the care receiver?
- ☐ ☐ Do other family members have negative attitudes that create difficulty for you?
- ☐ ☐ Is it painful to watch the care receiver's condition get worse?
- ☐ ☐ Are there other problems with children, marriage, job, finances, or health? What are they?

Consider your "yes" answers carefully. The sources of stress you have identified are indicators for change. Use the awareness you have gained in the first two steps to make helpful changes.

The following story is an example of a caregiver who recognized the source of her distress and made changes to better manage the situation.

Ernestine was increasingly fatigued, irritable, and depressed with the responsibility of caring for her husband, Richard, who had Parkinson's disease. Richard's condition was steadily getting worse. He was bedbound and needed help with many functions. Other family members hadn't offered to help, and Ernestine felt abandoned, alone, angry, and overwhelmed. A few friends and neighbors had offered to help but Ernestine refused. When she started having health problems, it became clear that something had to change. She had to have help.

Because Ernestine had difficulty asking for help, she devised a simple plan that would give others an opportunity to help without having to be asked. She made a list of tasks she needed help with and posted it on the refrigerator. The list included such things as vacuuming the living room, grocery shopping, staying with Richard so she could go to church, weeding the garden, picking up audio books at the library, picking up medications at the pharmacy, and preparing food. When visitors offered to help, Ernestine referred them to the list, suggesting they choose a task that suited them. This proved to be a successful plan for everyone.

It's important to identify the causes of your stress before they overwhelm you. Don't wait until you develop health problems, as Ernestine did. Many caregivers keep going until they become ill. You can only be an effective caregiver if you are healthy. Self-sacrifice to the point of illness benefits no one and is not required or recommended.

Step 3: Identify What You Can and Cannot Change

A major challenge of caregiving is to not only survive, but to rebuild your life and thrive. This is possible once you know the sources and signs of your stress. Then you can determine those you can do something about and those that are beyond your control. Step three is to identify what you can and cannot change.

Identifying what you can change gives you a sense of control over events. However, it isn't easy to determine what can and cannot be changed. Too often people try to change things they have no control over. For example, someone who focuses on trying to change another person usually ends up more frustrated. The only person you can change is yourself. You may be able to change a situation, how you respond to it, or your perception of it, but you can't change another person. It wastes valuable time and energy trying to change what is outside of your control.

Some situations can't be changed. However, you may be able to manage them better if you change your outlook about a situation, or decide to "roll with the punches."

The frustration and hopelessness that result from trying to change the unchangeable are self-defeating and can adversely affect a relationship, as in the case of Hal and Sue.

Sue and Hal had been a socially active couple. Sue was diagnosed with early Parkinson's disease and gradually started backing out of social plans because she didn't feel up to it. Since the beginning of the disease Sue has been on a roller coaster of having good days and bad days. Hal encourages Sue to go out when she doesn't feel like it, urging her to "snap out of it." He wants things to remain as they were.

Hal is frustrated in his attempts to change the effect of the disease on their lives. By not accepting Sue's feelings, he is adding stress to their relationship. But recently he has learned more about Parkinson's disease and is trying to be more realistic and flexible about what he can and cannot change. Flexibility is crucial. A Japanese saying is:

In a storm, it is the bamboo, the flexible tree, that can bend with the wind and survive. The rigid tree that resists the wind falls, victim of its own insistence on control.

Bending with the wind is crucial to surviving the winds of change, including those involved in caregiving. At times, both you and the care receiver may feel a loss of control over your lives. While feeling in control is important, sometimes it can become a problem because the more we try to control, the less control we seem to have. Being flexible can help us keep a positive attitude, despite hardships.

Use the following guidelines to look at your situation and to determine what can and cannot be changed:

1. Accept the reality of your caregiving situation.
2. Educate yourself about the care receiver's disease.
3. Identify unrealistic expectations, especially your own.
4. Seek and accept support.
5. Identify what you still have, rather than focus on what is lost.
6. Let go of what cannot be changed.

Accept the reality of your caregiving situation

When making changes it is necessary, but not always easy, to accept reality. We often deny things that hurt, and that can keep us from seeing a situation as it really is.

Jane heard the doctor tell Joe that he had a serious illness. He also told Joe he would need more rest and help with certain daily activities. Still, Jane found herself feeling annoyed when Joe took frequent naps, especially since she was taking on more responsibility for managing things at home. It took time for Jane to stop denying, and start accepting, the full impact of the disease. It was then that she was able to see realistically what could and couldn't be changed.

Jane is coping in a more adaptive way. However, Joe's mother denied the seriousness of the disease long after Jane came to terms with it. Family members may take different lengths of time to accept reality, which can add to the stress of caregiving.