

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.

Like 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 increase 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. 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.

Caregivers stress is influenced by many factors, including the need to adopt 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 show 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.

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.

Yes No

- | | | |
|--------------------------|--------------------------|---|
| <input type="checkbox"/> | <input type="checkbox"/> | Do you feel a loss of energy or zest for life? |
| <input type="checkbox"/> | <input type="checkbox"/> | Do you feel tired or exhausted much of the time? |
| <input type="checkbox"/> | <input type="checkbox"/> | Do you feel out of control, exhibiting uncharacteristic emotions or actions? |
| <input type="checkbox"/> | <input type="checkbox"/> | Do you feel tense, nervous, or anxious much of the time? |
| <input type="checkbox"/> | <input type="checkbox"/> | Do you lack interest in people or things that were formerly pleasurable? |
| <input type="checkbox"/> | <input type="checkbox"/> | Are you becoming increasingly isolated? |
| <input type="checkbox"/> | <input type="checkbox"/> | Are you consuming more sleeping pills, medications, alcohol, caffeine, or cigarette? |
| <input type="checkbox"/> | <input type="checkbox"/> | Are you having increased health problems: for example, high blood pressure headaches, ulcer, upset stomach, or other difficulties with digestion? |
| <input type="checkbox"/> | <input type="checkbox"/> | Do you have sleep problems, such as difficulty falling asleep at night, awakening early, or sleeping excessively? |
| <input type="checkbox"/> | <input type="checkbox"/> | Are you experiencing appetite changes? |
| <input type="checkbox"/> | <input type="checkbox"/> | Do you have problems with concentration or memory? |
| <input type="checkbox"/> | <input type="checkbox"/> | Are you increasingly irritable or impatient with others? |
| <input type="checkbox"/> | <input type="checkbox"/> | Do you have feelings of helplessness or hopelessness? |
| <input type="checkbox"/> | <input type="checkbox"/> | Are you abusing or neglecting to provide care to the care receiver? |
| <input type="checkbox"/> | <input type="checkbox"/> | Do you have thoughts of suicide? |

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

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

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, our boss, the care receiver, and yourself? What are they?
___	___	Do you feel others don't understand the care receiver's physical or emotional needs?
___	___	Are you pressured by financial decisions and lack of resources?

Yes	No	
___	___	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?

common sources of stress. Answering these questions can help you recognize some of your own sources.

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 advised 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 the 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 is 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.

Educate yourself about the care receiver's disease

You will be better able to identify what you can and cannot change when you understand the disease. For example, without knowledge about the communication abilities of someone with Alzheimer's disease, you may try to reason with the person or expect him to tell someone something you consider easy to remember. This will probably frustrate both of you.

There are many sources of information about specific diseases, including your personal physician, medical libraries, and associations related to specific diseases, such as Alzheimer's and Parkinson's disease. If you have access to a computer that I linked to the Internet, you can find a wealth of current information on the diseases and disease-related associations.

Identify unrealistic expectations, especially your own

You can make changes successfully only when your expectations are realistic. How realistic are yours? Do you often feel anxious because you expect more of yourself than you can achieve? Many caregivers listen only to the "should" they have been raised with. Women, especially, often believe they "should" be able to do everything themselves, and when that isn't possible, they feel guilty or depressed. If you have unrealistic expectations of yourself, then your expectations of what can be changed probably will be unrealistic also. The following story is an example of a caregiver, Rosa, who with her husband, Dean made a constructive change in what was a difficult, stressful situation. Rosa was devastated when Dean, her husband of 40 years, suffered a sudden severe stroke that left him partially paralyzed on one side of his body and unable to speak. The stroke was a shock. Rosa's initial response was to become overly protective and do everything for Dean. She was afraid to leave him alone for fear something terrible would happen. Before the stroke, Rosa and Dean had been making retirement plans, which included extensive travel.

Those plans were forsaken as they both felt increasingly overwhelmed, fearful, isolated, and depressed.

Rosa became extremely fatigued and irritable as Dean became increasingly dependent on her. The visiting nurse talked with them about what Dean could and could not do for himself. She emphasized the importance of Dean maintaining as much independence as possible. It became apparent that Dean could do many things for himself, including writing letters to family and friends. Dean felt better as he became more independent. Rosa was able to be more realistic in her expectations. She realized that Dean's dependence on her was detrimental to their relationship. As Rosa and Dean gradually adapted to living with the stroke, they became less fearful and more hopeful. They began looking at the quality of their remaining life together. They wanted, more than anything, to travel together and decided to take a short trip to see how it would go. The first trip was successful and they felt encouraged to travel more. Rosa found a travel agent who helped them plan trips that accommodated Dean's disabilities. They enjoyed several trips before Dean's death 12 years later. Rosa and Dean responded to this challenge by gaining an understanding of the disease, accepting reality, setting realistic expectations, and changing what could be changed

Seek and accept support

Many caregivers find it difficult to ask for help. Rosa initially refused help from friends and neighbors. She did everything herself until she started feeling distressed. The expectations she had for herself were overwhelming and unrealistic. It wasn't until she began seeking support from the visiting nurse, travel agent, and others that she was able to find a way to make changes. Often you can make changes only with the help of others. Seeking and accepting support may be the single most important factor in making constructive changes.

Identify what you still have, rather than focus on what is lost.

When Rosa and Dean decided to look for "what remained" in their situation, they hoped that they still had quality in their life together. They looked at what they still had, rather than focusing on what had been lost, and they made changes that were still possible.

They found an unexpected "gift" as they made changes and adapted to the illness. Rosa said, "I never would have asked for the stroke to happen,

but it was because of it that Dean and I learned what love was all about. I am a different person than I was. I am more understanding, patient, caring, and sensitive to the pain of others."

Many caregivers, as they learn more about themselves, experience personal growth. That is the "gift that can often be found in difficult times.

Let go of what cannot be changed

It is natural to want to hold on to things as they were. But letting go of what you cannot change is accepting the situation as it is. It releases you from the need to control what you cannot change. Letting go is a way to cooperate with the inevitable. It releases new energy for accepting reality and seeing new possibilities. Sam is a prime example of someone who is learning to let go.

Sam had always been an intense athletic competitor, and sports had been the driving force in his life. At age 45 he had a slight stroke which left him mildly affected. Sam' problem wasn't that he had a stroke, the problem was that he couldn't let go of wishing that he hadn't had one. He continuously wanted things to be as they had been. This made him feel angry and frustrated. Fortunately, Sam reached a point of wanting to learn to live with the stroke and to let go of wanting life to be as it had been before.

Sam was unable to live in the present until he let go of his desire for things to be as they were. The "if onlys" and "what ifs" were a source of suffering. When Sam let go, he learned to live with the stroke and made changes that helped him develop a satisfying life. What Sam learned also applies to caregivers, as shown in the case of Marsha and Bud.

Marsha was the caregiver for her husband, Bud, who had Parkinson's disease. Bud's condition worsened and he and Marsha were unable to do many of the things they had done in the past. Marsha continually wanted things to be the way they had been. "If only" became her constant thought: "if only Bud could dress himself," "If only we could go dancing like we used to," "If only Bud had more energy," "If only he could still drive us places."

Marsh's unhappiness caused a strain in their relationship. It was only when she and Bud were having a good time playing cards with friends on day that she realized how much valuable time she was wasting by constantly wanting things to be different. She began to let go of "If only" and to accept "what is." In letting go, she found acceptance and peace of mind.

As you reflect on your challenges as a caregiver, consider these

The Serenity Prayer

*...grant me serenity to accept
the things I cannot change,
Courage to change the things
I can, and Wisdom to know
the difference.*

Reinhold Niebuhr 1934

questions. What can I change? What must I accept? What can I improve? The challenge is beautifully written in "The Serenity Prayer."

Step 4: Take Action to Manage Your Stress

The fourth step points the way for you to manage and reduce your stress.

There are many different tools for

managing stress. But you must find what is most effective for you. Proven ways to manage and reduce stress include:

- ❖ Managing your thoughts, beliefs, and perceptions.
- ❖ Practicing self-care.
- ❖ Getting social support.
- ❖ Using techniques that lower stress.
- ❖ Developing plans of action.
- ❖ Finding hope and meaning.

Managing your thoughts, beliefs, and perceptions

Thoughts and beliefs are the foundation of experience. They are not only reactions to events but our thoughts and beliefs can also influence

events. What we think and believe affects what happens. Managing our thoughts means we have control over how we view things. As a caregiver, there may be times when the only things you can change is how you view a situation.

There are several tools for managing thoughts, beliefs, and perceptions. Two that can be helpful are reframing and self-talk.

Reframing. Your frame of reference is the window through which you view the world. It gives meaning to your world. You see things one way, but someone else sees the same circumstances differently. Situations become more stressful when you view them in a negative way.

Reframing is learning to look at things in a different way, for example, finding something positive about a difficult situation. Some examples of reframing include:

- ❖ A caregiver who views the behavior of someone with Alzheimer's disease as "purposefully behaving that way to get to me" versus taking the view that "the behavior is a part of the disease."
- ❖ A caregiver who is angry at her brother for helping only once a month versus taking the view that "any help, no matter how little, will lighten my load."
- ❖ A caregiver who puts the situation into a religious or philosophical framework, such as "This is happening because God is angry with me" versus taking the view that "God is giving me an opportunity to learn and grow."

People who are able to reframe difficult situations generally feel less burden and more in control. Feeling a greater degree of control often leads to acting in control. Clara is a good example.

Clara had difficulty taking breaks from caregiving. Before becoming a caregiver, she had worked in a demanding position and had realized the importance of taking weekends off and vacations to refresh herself and cope better with work demands. When she started to view caregiving as a job, it made a difference in how she viewed breaks in caregiving. They become not only more acceptable, but a necessity.

Julie also found that reframing a difficult situation reduced her stress and helped her act in new ways.

Julie felt resentful and burdened with the increasing demands of caring for her mother. She had no help, feeling that as a good, dutiful daughter she should do it all. A social worker told her about available resources and suggested she think of herself as a personal care manager as a way to find help in caregiving. Julie gained a sense of control over the situation once she realized she didn't have to provide all of the care herself, but could oversee her mother's care.

As a caregiver, you may feel overwhelmed and burned out, especially if you are assuming responsibility for most of the caregiving. Changing your perception of your role from a caregiver to care manager is a way of reframing. As a care manager, you still get the job done, but you don't have to provide all the care yourself. The role of care manager means that you:

- ❖ coordinate and supervise another's care needs. This includes using available support.
- ❖ Plan and prioritize care.
- ❖ Understand the disease of the care receiver and what to expect.
- ❖ Participate as an equal partner with other health care professionals.
- ❖ Are knowledgeable about the health care system.

As a care manager, you assume an active role and reach beyond giving hands-on care, to planning and coordinating care and using available resources. You will feel an increased sense of mastery as a successful care manager.

Self-talk. Most stress management courses include learning how to use self-talk to promote health. Self-talk is what we say to ourselves. As Ralph Waldo Emerson said, "A man is what he thinks about all day long."

What do you think about all day long? What do you say to yourself? It's especially important to notice your self-talk when you suffer setbacks and when you feel anxious, angry, discouraged, or distressed. Negative self-talk statements often begin with the following phrases:

- ❖ I just can't do...
- ❖ If only I could (or didn't) do...
- ❖ I could never...
- ❖ I shouldn't have done...
- ❖ I should have...

Negative self-talk is defeating. It can lead to depression and a sense of failure, because with negative self-talk we tend to focus on:

- ❖ what we did not do versus what we have done.
- ❖ What we can't do versus what we can do.
- ❖ Our mistakes and failures versus our successes.

You want your self-talk to work for you, not against you. If your self-talk is negative or unhelpful, challenge it. Learn to change the negative things you say to yourself into positive statements, such as affirmations.

Affirmations are positive, supportive statements that counteract the effects of negative thinking. When positive statements are repeated several times a day, they begin to replace negative thoughts. This helps to change one's attitude, promote relaxation, and reduce stress. Karen's story is an example of changing negative self-talk to positive self-talk with the use of affirmations:

Karen felt angry and discouraged when her mother didn't eat the tasty, nutritious meals she prepared for her. She didn't accept the fact that her mother's lack of appetite was caused by the illness. Karen constantly told herself, "No matter what I cook, it is never good enough for mother."

This is an example of negative self-talk. Karen became aware that she often thought she was not doing good enough, especially in caring for her mother. These thoughts made her feel like a failure.

With determination, patience, and practice, you can change your self-talk from negative to positive. The following steps lead to change.

1. Identify your negative thoughts. Listen to what you say to yourself, especially during difficult times.
2. Write your negative thoughts down on paper. This helps to identify and clarify them.
3. Challenge your negative thoughts. Give them a good argument.
4. Write a simple, positive statement for each thought you want to change.
5. Memorize and repeat the chosen statements. This helps establish the habit of positive self-talk.
6. Put your written statements where you see them frequently. This is a helpful visual reminder.

Karen chose the affirmation, "I am preparing nutritious food. That is enough." In fact, the statements, "I am doing my best. It is good enough," became her frequent affirmation and counteracted her negative thoughts of "not doing good enough."

These statements have the dual purpose of affirming what Karen is doing and helping her let go of the idea that she has control over her mother's appetite. Accepting that was important. Telling herself that she is doing her best and it is enough of a positive way of saying she is changing what she can and letting go of what she cannot change. Karen's expectations for herself have become more realistic.

Practice over time will change negative, habitual thinking. Repeat this activity frequently to identify other negative self-talk. Remember, thoughts

CHALLENGING YOUR SELF-TALK

Identify an example of your negative self-talk and the situation when it is most likely to occur. Be as clear and as detailed as possible. Write it down.

1. My negative statement:

3. I will replace the negative thought with this positive statement:

2. I say this to myself when:

4. Repeat the chosen affirmation whenever the above situation occurs.

and attitudes create your reality. Changing your negative thoughts will help you focus on the positive things in your life, rather than on what you don't have.

There will be times when you will find it hard to shake off negative thoughts. This is normal. However, paying attention to the frequency and content of these thoughts is the beginning of self-awareness and the possibility of change.

Practicing self-care

To be an effective caregiver you need to maintain your own health and spirit, and to nurture yourself. All too often caregivers put their own needs last. Studies show that sacrificing yourself in giving care to another can lead to emotional exhaustion, depression, and illness.

Maintaining your health and spirit can reduce your level of stress. It is critical to find activities that help you to stay healthy and nurture yourself. These activities are different for each individual. What works for one person may not work for another. You must find stress-reducing methods that work best for you.

We can learn a lot from a self-care program in Florida called "Getting Well." This is a group of people who are supporting each other in learning to live and feel better. They take part in life-affirming activities such as 'laughing, juggling, playing, meditating, painting, journal writing, exercising, and eating nutritiously.' They demonstrate the necessity of associating with others who help you maintain your spirit and help you feel loved and supported.

To manage stress, it is essential to take breaks from caregiving. Plan them into our schedule, starting immediately, if you have not done so already. Studies show that caregivers often don't take breaks until they are at the "end of their rope" or burned out."

Are You Taking Care of Yourself?

Yes No

___ ___ Are you uncomfortable putting yourself first sometimes?

___ ___ Do you think you should always meet the needs of other people before your own?

___ ___ Do you feel you should be a perfect Caregiver?"

Yes No

___ ___ Do you minimize or deny that you have needs?

If you answered "yes" to any of these questions, you may be ignoring your own needs.

This serves no one's best interest as your ability to function can be seriously affected. To avoid problems, it is your responsibility to take time off from caregiving to refresh yourself.

It is important to the wellbeing of care receivers that you take breaks. If you don't they may become increasingly dependent on you. If you take breaks, they will be less isolated and will benefit from having contact with other people. They also need breaks from you. (This is an example of reframing your perception of a situation.)

You are responsible for your own self-care. Practicing self-care means that you:

- ❖ Learn and use stress reduction techniques.
- ❖ Attend to your own health care needs.
- ❖ Get proper rest and nutrition.
- ❖ Exercise regularly.
- ❖ Take time off without feeling guilty.
- ❖ Participate in pleasant, nurturing activities.
- ❖ Reward yourself.
- ❖ Seek and accept the support of others.
- ❖ Seek supportive counseling when you need to, or talk with a trusted counselor, religious advisor, or friend.
- ❖ Identify and acknowledge your feelings.
- ❖ Tell others what you need. Don't assume "they should know"
- ❖ Set goals and prioritize.

Reflect on what it means to practice self-care. Consider the items above. How do you fare? Are you caring for yourself as well as you are caring for another? Remember, it is only when we love and nurture ourselves that we are able to love and nurture another.

As a caregiver, appreciation and "thank yous" for what you do may be lacking. For example, a person with Alzheimer's disease may be unable to show appreciation for what is done. Everyone has a need for approval. It

motivates us to keep going. If you don't receive appreciation from other people, find a way to give it to yourself. What would be helpful for you? Consider the following suggestions:

- ❖ Acknowledge and take satisfaction in those things you do well.
- ❖ Reward yourself on a regular basis.
- ❖ Involve yourself in an activity that will provide positive feedback.

Carol found a creative way to reward herself for a job well done when her mother could no longer express appreciation. Carol's mother, Irene, had Alzheimer's disease. Irene often expressed frustration and anger at Carol, in spite of the fact that Carol was her mainstay. Carol understood the disease process and successfully avoided taking her mother's attacks personally. To give herself a gift of appreciation, Carol bought flowers regularly. She said, "I considered the flowers a gift from Mom to me. It's something she would have done for me if she were well."

Memories of past generosity and love from her mother sustained Carol. In buying herself flowers she reminded herself weekly that the gift of love and caring she gave to her mother had first been given to her. At a difficult time, she found a way to nurture herself.

What are you doing to nurture yourself? Are you choosing healthy activities? Or are you relying on drugs, alcohol, cigarettes, and tranquilizers to handle the emotional and physical burdens of caregiving? According to the National Institute on Drug Abuse, millions of people abuse these drugs to reduce tension and to relax. It is in your best interest to choose healthy, nurturing ways of coping with the difficulties of caregiving.

Getting social support

Caregiving can be a lonely experience. According to the National Family Caregivers Association, caregivers often report that they feel alone and isolated.

Support from family, friends, and others is an important stress buffer. Something as simple as a two-minute telephone call can make you feel cared about and supported. It helps to share your experiences and burdens with a person you trust- a friend, family member, counselor, religious advisor, or support group member- who will listen and understand.

Support groups can be helpful when you're going through a difficult time. Sharing with others who are going through similar experiences is a way to give and receive support, and take time out from caregiving duties

You can learn new ways of coping from others in the group, which may include learning to look at the light side of difficult situations with a bit of humor. Sharing lightens the load. A support group is a place to express thoughts and feelings in a confidential setting. Most important, you learn that you are not alone. This can be a wonderful relief.

Support groups are available for caregivers and for people with various chronic illnesses. Local hospitals and disease-related associations often have groups available.

Using techniques that lower stress

It is of little help to identify your stressors if you don't take action early to reduce them. Recognize obstacles to taking action.

These may include:

- ❖ Not giving yourself permission to take care of yourself.
- ❖ Lacking awareness of stress-reduction techniques.
- ❖ Choosing unrealistic stress-reduction techniques for example, those that are too complicated, lengthy, or difficult for you.
- ❖ Delaying or postponing a stress-reduction activity. For example, planning a break or trip too far into the future to be of help now, when you need it.

Take care of yourself daily. Use "tried and true" stress reduction tools that work for you. In addition, learn and incorporate new stress-reducing techniques into your life. There are many worthwhile techniques available.

Yes	No	
___	___	Do you participate in physical activity at least three times a week?
___	___	Do you get enough sleep daily so that you feel rested in the morning?
___	___	Do you eat balanced, nutritious meals?
___	___	Do you take time to sit down and eat your meals?
___	___	Do you take care of you own physical health (e.g., get regular medical check-ups and take care of yourself when you are ill)?

Yes	No	
___	___	Do you participate regularly in recreational/leisure activities?
___	___	Do you drink at least eight glasses of water or other liquid daily?
___	___	Do you limit alcoholic beverages to no more than two drinks a day? (One drink is 1.5 oz. of hard liquor, 12 oz. of beer, or 4 oz. of wine.)
___	___	Do you avoid using alcohol, medications/drug, or cigarettes to calm your nerves?
___	___	Do you maintain a healthy weight?

If you answered "yes" to all of these questions, congratulate yourself. A "no" response reflects areas to work on for better health.

Proper diet, adequate sleep, and regular exercise are necessary for all of us, and even more so when we are caregivers. These lifestyle factors increase our resistance to illness and our ability to cope with stressful situations.

Exercise promotes better sleep, reduces tension and depression, and increases energy and alertness. If finding time to exercise is a problem, try to incorporate it into your usual day. Perhaps the person receiving care can walk or do stretching exercises with you. If necessary, do frequent short exercises instead of using large blocks of time. Find activities you enjoy.

Walking is considered one of the best and easiest exercises. It helps to reduce psychological tension as well as having physical benefits. Walking 20 minutes a day, three times a week, is very beneficial. If you can't be away 20 minutes, 10-minute walks twice a day or even a five-minute walk are beneficial.

Work walking into your life. Walk whenever and wherever you can. Perhaps it is easiest to walk around your block, at the mall, or a nearby park. The next time a friend or family member comes to visit, take time for a short walk. When the care receiver is getting therapy take a walk around the medical facility.

Breathing for relaxation. Stressful situations or memories of those situations can cause changes in our breathing. Often the more tense we

BREATHING FOR RELAXATION

Follow these steps:

1. Close your eyes. If that isn't possible, quietly become aware of your breathing.
2. Inhale to the count of seven, slowly and deeply. Exhale to the count of seven, slowly and Deeply. Exhaling is "letting go."
3. Repeat-without forcing your breathing in any way. If your mind becomes distracted, refocus on your Breathing.
4. Continue for one to two minutes or longer if you Want. Notice how relaxed you feel overall.

feel, the more shallow your breathing becomes.

Stress management tools usually include a focus on breathing. The following breathing exercise takes only one or two minutes and you can easily

do it anywhere. Use it often to lower stress.

Meditation. The word "meditation" comes from the Sanskrit word *medha* which, when taken literally, means "doing the wisdom." Meditation aids in relaxation and in achieving physical and mental wellbeing. Meditation is keeping your attention focused in the moment to quiet the mind and hear your body's inner wisdom. You, too, can learn to meditate. See the "Process of Meditation" box on the next page.

Meditation

The more faithfully you listen to the voice within you, the better you will hear what is sounding outside.

Dag Hammarskjold

Music. Music is another tool for reducing stress. It can alter the body and the mind. It can induce deep relaxation, act as a stimulant, and take you into other states of consciousness. Music is other used specifically for healing and decreasing stress tension. Use the following steps as a guideline.

1. Choose soothing music you like.
2. Relax and close your eyes.

3. Breathe deeply and easily.
4. Lose yourself in the music, listening with your body, not your mind.
5. After the music is finished, open your eyes and notice how you feel.

Music is a universal language, listening to music can be healing for both you and the care receiver. Either together or alone. People with dementia, especially, respond to music when they may respond to little else.

Humor. Caregivers who maintain and foster their sense of humor do better. It is often hard to find much that is humorous in caregiving, but the secret to succeeding as a caregiver is to find humor in your daily routine. Finding humor does not deny the fact that, at times, your heart is heavy with the pain and sadness of caregiving. Those times will exist, but they can coexist with laughter and humor.

Tears and laughter are closely related. They each offer a release of tension and are often intermingled. Humor does not minimize the seriousness of a situation; rather, it helps you embrace it.

Humor can be a helpful tool in many ways, from making us laugh at our shortcomings and impossible situations, to reducing anxiety and stress. Laughter relaxes and helps calm emotions, allowing us to regain emotional balance and think more clearly. If you want to laugh, or want someone else to laugh, you may have to find a reason, as George and Alma do.

George and Alma watch their favorite comedy show on television every weeknight at 7 p.m. They look forward to it and anticipate laughing together. In addition, Alma and George look for humorous cartoons and jokes to share with each other. The fact that Alma has a disabling medical condition doesn't mean they can't appreciate laughter.

In his book *Anatomy of an Illness*, Norman Cousins wrote of his fight against a crippling disease. He credited his recovery to the use of laughter. He intentionally sought healing through watching videotapes of comedies, reading joke books, and listening to people tell jokes. He had read about the effects of stress and emotions on illness. He understood that disease was caused by chemical changes in the body, due to the stress of strong emotions such as fear and anger. He concluded that perhaps love, laughter, hope, and the will to live would counteract those effects. He was right in his belief. Recent studies show that laughter helps to stimulate breathing, muscular activity, and heart rate. This serves to reduce stress and strengthen the immune system.

Taken from the book "The Caregiver Helpbook"

Published: 2000 by Legacy Health System

Vicki L. Schmall, PH.D., Marilyn Cleland, R.N., & Marilyn Sturdevant, R.N., M.S.W., L.C.S.W.

Humor is important to health. It lifts the spirit and provides a way to connect with others. The following suggestions can help you make laughter and humor a larger part of your life:

- ❖ Seek out humor. Humorous tapes and books can be found at video stores and libraries. Spend time with friends or family members you enjoy and can laugh with.
- ❖ Surround yourself with humor. Put jokes, cartoons, funny pictures, and humorous sayings on the refrigerator or bulletin board where others can enjoy them with you.
- ❖ Laugh at yourself. Don't take yourself too seriously. Poke fun at yourself by making light of your shortcomings (which we all have).

PROCESS OF MEDITATION

1. Choose a quiet spot where you will not be disturbed. Ten to 20 minutes should suffice.
2. Sit in a comfortable position.
3. Close your eyes to better concentrate.
4. Relax your body by tightening, then relaxing, each of your major muscles from head to toe. This need not take long, only a minute or two.
5. Beware of your breathing without trying to change it. Your breathing may get slower as meditation proceeds, because of relaxation and your body's metabolism slowing down. Breathe naturally in and out.
6. If you like, choose a word for focus. This is sometimes called a mantra. It can be any word or words that mean something to you. Many people find that words like "love," "let go," and "peace" work well. Others may use a phrase from a favorite prayer. Repeat the chosen word or phrase silently with your breathing, on the in and out breaths. One caregiver's focus words are "I," on the in breath and "AM," on the out breath, "I AM." Together the breathing and words anchor the mind.
7. Don't judge your performance or wonder how you are doing. You will have distracting thoughts which you can let go of by returning to awareness of your breathing and focus. With repetition, awareness will continue to develop and carry over into the rest of your life, inducing a peaceful state of mind.
8. Practice a minimum of once a day for 10 to 20 minutes. Twice a day is even better. The best times to meditate are often in the early morning, after exercise and a shower but before breakfast, or before dinner. Since meditation is an exercise in concentration, avoid meditation when you're tired or you might fall asleep. However, if you have difficulty falling asleep at night, meditate while lying down to facilitate relaxation and sleep.

Developing action plans

Action plans are tools for change. They can be a useful way to identify and plan specific activities for reducing stress and making change. Feelings of accomplishments are necessary for thriving as a caregiver. Action plans can help you achieve these feelings. Even the smallest action can make a big difference. This was true for Evelyn.

Evelyn needed more time for herself during the day. She made a plan to take a leisurely, warm tub bath four-times a week instead of the always-hurried shower. Evelyn settled her father to watch the 5 o'clock news on television on the days she took her baths. This worked well for both of them and became an accepted part of their routine. Accomplishing the action plan encouraged Evelyn to make other action plans that made a big difference to her.

Feelings of mastery and confidence are usually the result of developing new ways of coping. Use the information presented in this chapter to help you identify your stressors, and improve coping skills. The activity in the box on the next page can be a useful tool for managing stress.

This activity can be useful on a regular basis. It will help you assess and cope with current stressors. Since your caregiving situation and stressors continually change, it is important to be aware of when you feel stress and to use stress-reducing tools that work for you. Most important, build stress reduction and nurturing activities into your daily life to prevent distress. Be proactive. And remember, what is good for you is good for the person receiving care!

Finding hope and meaning

In ability for find hope and meaning in the caregiving situation enables you not only to survive, but to thrive. Finding meaning and hope are what keeps us going. It is a way to make sense of our circumstances.

In his book *Man's Search For Meaning*, Dr. Viktor Frankl, author-psychiatrist, tells of his experience as a long-time prisoner in a prisoner of war camp during World War II. Many of his family members died in the camps. In spite of the fact that he faced death constantly and suffered severe punishment, Dr. Frankl was able to find meaning and hope in his life. He noted that the prisoners who were able to sustain even a flicker of hope were better able to survive the terrible circumstances that those who

felt hopeless. He concluded that what did remain, when all else was taken away, was "the last of the human freedoms." The ability to "choose one's attitude in a given set of circumstances." Out of that experience, Frankl's guiding philosophy was born: "To live is to suffer, to survive is to find meaning in the suffering." He also believed that man's need for meaning is

Reframing You Stress

Make a list of those things that you find most difficult or stressful. Be specific. Write at least two (more if you can).

1.

2.

Answer the following questions in relation to each item on your list.

Can I ignore this? Or can I let it go?

1.

2.

Can I change anything about this? If so, how can I change it?

1.

2.

If it can't be changed, can I change my perception of it? If so, how? What is a more helpful perception?

1.

2.

Select one stressor from your list to work on first. The stressor is:

Develop an action plan for addressing this stressor. Be specific and realistic.

Here are 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.

The need to find hope and meaning is also important when you are a caregiver for a person with a chronic illness. Uncertainty, loss and suffering may shake your foundation. After all, you have much at stake. Your world, as you have known it, has changed drastically and you may be left with questions such as, "Why me?" and perhaps, "Where is God?" Questions often leads to a search for meaning. No one else can tell you what the meaning is for you. It can be a lonely journey.

A sense of hope is knowing that your present moment has meaning.

Robert Randall

A search for meaning can be a conscious choice. There are ways to stimulate your search. The following can be helpful:

1. **Ask yourself questions like, what am I to learn from this?** What good can come from this? Am I a better person now? These types of questions can help you open up to possibilities for finding meaning.
2. **Reflect.** Periods of quiet reflection, especially after a difficult time, are important and offer opportunities to learn from the experience.
3. **Talk with a trusted person.** Whether this person is a counselor, religious advisor, or friend, sharing can help clarify your thoughts and feelings. As you tell your story, it often takes on meaning.
4. **Write.** This is also a way to clarify your thinking. Writing is a way to bring out your thoughts and feelings. Write freely and spontaneously. Don'ts concern yourself with proper sentence structure or punctuation. Writing is a way to talk to yourself. Re-reading your journal over time provides an understanding of where you were when you started and where you are now. You will probably see changes and find new understanding and meaning.

- 5. Seek spiritual renewal.** This is especially important when you are facing difficult times. Many caregivers report that faith and prayer help them find comfort, purpose, and meaning. It may be that even when you feel anger because of suffering and sorrow, your need for meaning is greatest.

Like Frankl, it is hopeful to believe that meaning can be found in difficult and painful experiences. Hope and meaning play a large part in the following story of Margaret and Tim.

Tim's frequent visits to his elderly mother, Margaret, in the nursing home, were meaningful to him. Years ago, when Margaret was healthy, she shared some of her beliefs with Tim. She had told him, "If there comes a time when I am not able to recognize you because of Alzheimer's disease, or for any other reason, I want you to know what I believe to be true. I believe that my true essence, my spirit, will always be present, even though my physical body and mind may not be the person you remember. Please know that I am with you. We may not be able to talk with each other as we did in the past, but if you play my favorite music, read poetry, hold my hand, or just be with me, I will feel your love and you will feel mine for you."

In sharing her beliefs, Margaret gave Tim the gift of finding meaning in what can be a most difficult and challenging situation. Meaning is all around us. It is the "stuff" of life. Meaning is personal. It is up to each person to find his or her own meaning.

SUMMARY

Are you better acquainted with your stress? Have you identified what you can do to reduce at least one stressor? Do you realize the potential strength in considering your needs and in practicing self-care? Can you find meaning in difficult experiences? Have you learned that often the compassion and care you give to another comes back to you as a gift of meaning?

Remember that your response to a situation will affect the situation itself. As much as possible, make it be what you want it to be. Reflect again on the words of Virginia Satir:

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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 even more than the event itself.