

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 is linked to the Internet, you can find a wealth of current information on 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 "shoulds" 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 constructive changes 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

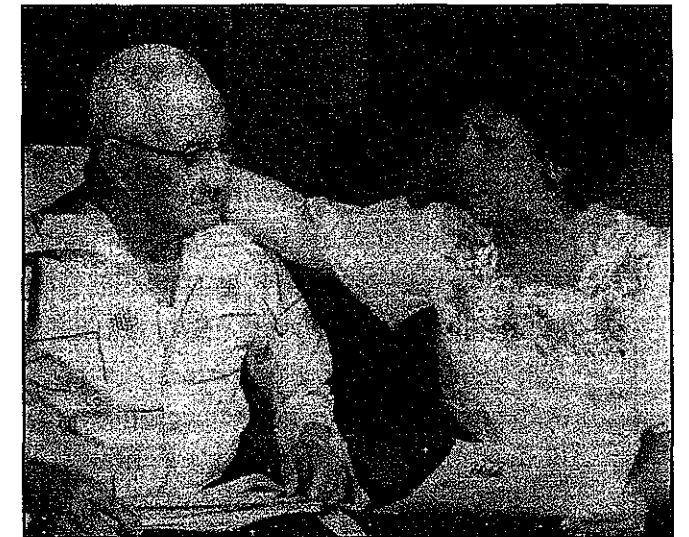
Many caregivers find it difficult to ask for help. Rosa initially refused help from friends and neighbors. She did everything herself until she started feeling distressed. The expectations she had for herself were overwhelming and unrealistic. It wasn't until she began seeking support from the visiting 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's 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."

Marsha's unhappiness caused a strain in their relationship. It was only when she and Bud were having a good time playing cards with friends one 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 questions. What

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

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.

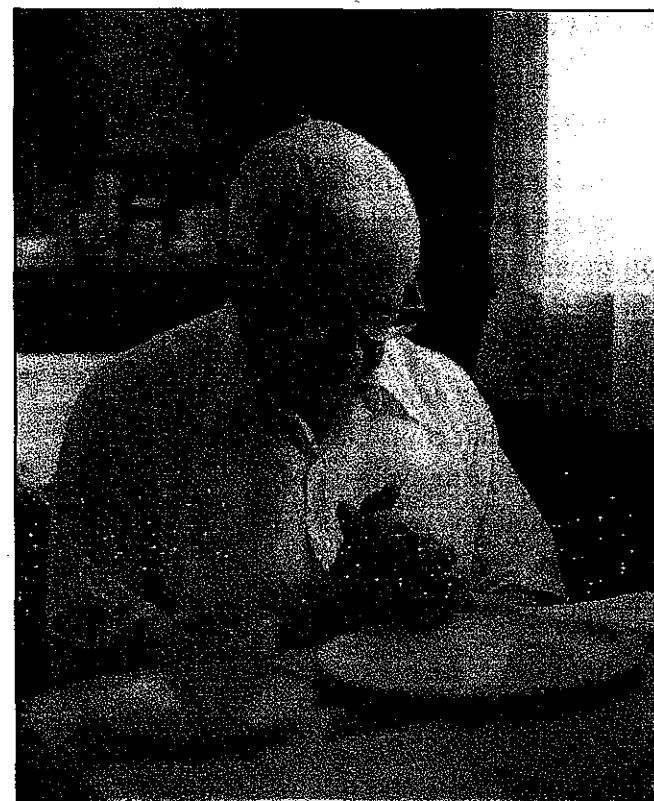
Managing your thoughts, beliefs, and perceptions

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 thing 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 became 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.

- ◆ are aware of available community resources.
- ◆ 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 is 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 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.

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.

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 your 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 at times?
- ☐ ☐ Do you think you should always meet the needs of other people before your own?
- ☐ ☐ Do you feel you should be a "perfect caregiver"?
- ☐ ☐ 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 well-being 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."
- ◆ change the negative ways you view situations.
- ◆ set goals and prioritize.

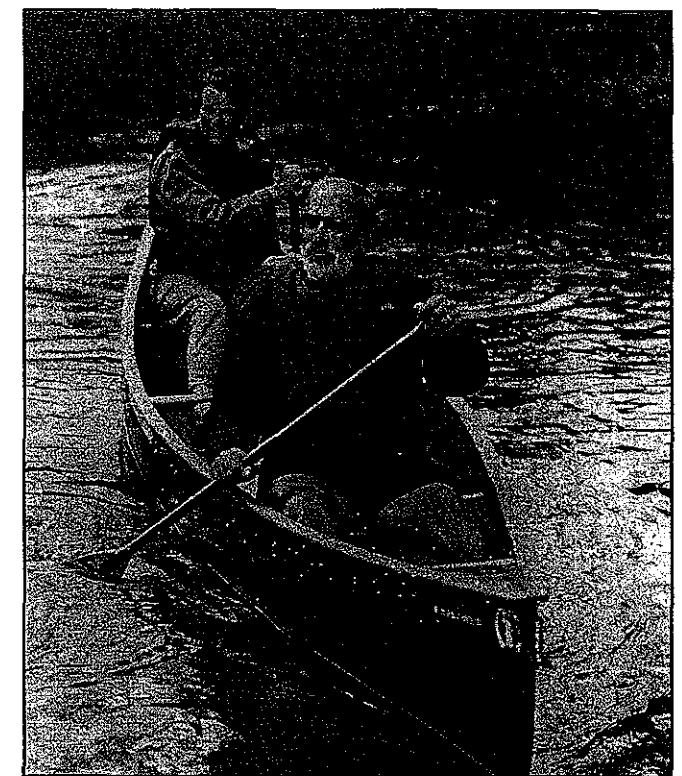
Reflect on what it means to practice self-care. Consider the items above. How do you fare? Are you caring for yourself as well as you are caring for another? Remember, it is only when we love and nurture ourselves that we are able to love and nurture another.

As a caregiver, appreciation and "thank you" 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.



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.

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

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. We offer some quick and easy ones that you can fit into your busy life.

Basic wellness practices. It is vital to maintain your health and well-being. Ask yourself the questions in the box below.

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 your own physical health (e.g., get regular medical check-ups and take care of yourself when you are ill)?
- ☐ ☐ 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/drugs, 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 feel, the more shallow our 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.

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.

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 well-being.

Meditation

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

—Dag Hammarskjöld

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.

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 often used specifically for healing and decreasing stress and 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 week-night 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

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. Be aware 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.

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 meditating 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.



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.

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).

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 accomplishment 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 news on TV when 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.

See pages 7–9 for more information on action plans.

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

The ability to 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*, psychiatrist Viktor Frankl 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

REFRAMING YOUR 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. (See pages 7–9 for more information.)

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 than 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 universal.

The need to find hope and meaning is also important when you are a caregiver

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

Robert Randall

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?" Questioning 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 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't 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:

*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.*



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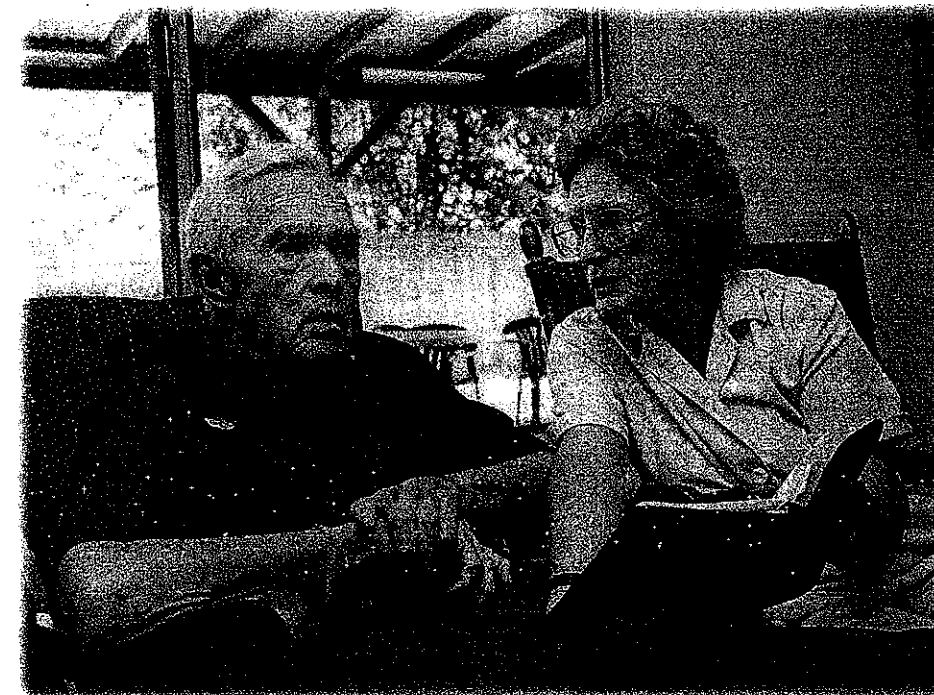
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Summary

CHAPTER FOUR



Communicating Effectively in Challenging Situations

Many caregivers say one of their biggest challenges involves uttering the word no. The feeling is that saying no is somehow not permissible. If you feel this way, ask yourself, "Is there

courage and nobility in saying nothing and burning out? Or does true courage and nobility lie in taking care of yourself so you can be a caring helper longer?"

As no, uttered from the deepest conviction, is better and greater than a yes, merely uttered to please or, what is worse, to avoid trouble.

Mahatma Gandhi

Keep those questions in mind as we discuss in this chapter tools for dealing with these caregiving challenges:

- ♦ setting limits
- ♦ asking for help
- ♦ expressing and responding to criticism
- ♦ expressing anger

We will also discuss how to communicate more effectively under special circumstances and with people who use the following communication styles:

- ♦ Passive/peacekeeping
- ♦ Aggressive/pitbull
- ♦ Factual/computer

COMMUNICATING TO TAKE CARE OF YOU

Caregivers frequently report they have difficulty setting limits and asking for help. Yet, these are critical tools for avoiding burnout, maintaining your well-being, and getting the support you need. It's equally important to express your feelings and give criticism in constructive ways. You want others to hear what you have to say, *not* to focus on how you said something.

Setting Limits

If you have never set limits, it can take time to feel good about doing so and to communicate your limits in positive ways. At first people may not take you seriously and you might back down a few times. But with time and practice, you can do it. You might be surprised at your family's reaction. Many caregivers discovered that their relatives were pleased and relieved when they began setting limits. It seems family members worried less knowing that caregivers were taking care of themselves.

Because only you know what your limits are, setting your limits is up to you. Setting limits is a form of self-respect and honesty. It's realizing that you can't do everything and that's okay. It also shows consideration for family and friends. It helps take the guesswork out of planning and problem solving when you tell others what you are able and unable to do.

Remember, your limits are not engraved in stone. You can be flexible and change them when your priorities change and when time, place, people, and circumstances demand it.

What happens if you don't set limits

As a caregiver, do you think setting limits is selfish? Do you believe people who set limits are uncaring? If so, think about what can happen if you don't set limits. Not setting limits can lead to:

- ◆ feelings of resentment on your part.
- ◆ caregiver burnout, and possibly, the inability to provide the help needed.
- ◆ concern by family about your health and even your survival.
- ◆ health problems related to stress and fatigue, or even death.

Limits carry risks

Relationships suffer when they are based on someone doing whatever another person wants or needs. If you lose closeness with a person because you set limits, ask yourself, "Am I better off without a relationship completely defined by what the other person wants?" Then weigh the risks, to yourself and the care receiver, of not setting limits. Think about the serious effects on you and the care receiver if your health fails.

Consider the consequences of setting limits

Before saying or doing anything about setting limits, review possible consequences of what you want to do. Ask yourself:

- ◆ What would be the worst outcome? How would I handle it?
- ◆ What are the chances the worst outcome will happen? Could I live with it?
- ◆ What are the consequences if I do nothing? Can I live with those?
- ◆ What is the best thing that could happen?

Some limits are not negotiable

Look carefully at limits you cannot exceed. These are your non-negotiable limits. What is the most you can give to others? This has to be clear, "I am able to help two days a week. That is all I can do."

Look at how you set limits now

Evaluate your current style of setting limits, particularly with the care receiver and other family members. Check the boxes that most closely describe how you set limits.

Yes No

- ☐ ☐ Do I set limits so seldom that people don't pay attention when I do?
- ☐ ☐ Am I so meek about setting limits that people don't take me seriously?
- ☐ ☐ Do I usually wait too long—until I can't continue—before I set limits?
- ☐ ☐ Do I hint or expect people to read my mind about what I can and can't do?
- ☐ ☐ Do I complain instead of setting clear caregiving limits with those who need to know my limits?
- ☐ ☐ Do I set limits and flip-flop by not sticking to them?
- ☐ ☐ Do I try setting limits once and then quit if people ignore them?

Did you check "yes" in answering any questions? If so, the following suggestions will help you set and communicate your limits.

Start small. If you have trouble setting limits, start with people outside your family and start with small matters, like telling a caller you can visit for only five minutes.

Start with the easy people. This means practicing saying a polite, firm "no" to someone either unrelated to you or that you don't even know, such as telephone sales solicitors, fund-raisers for questionable charities, or pollsters in the local mall. A simple "Thank you for your call, but I cannot donate to your cause" (or whatever the request is) is all you need to say. If the person persists, just keep repeating your statement and soon he will give up.

Start with easy situations. It's a good idea to warm up on situations or tasks that are impersonal or that you don't like. For example, if you enjoy volunteering but you don't care for the schedule or the assignment, try saying, "I enjoy volunteering but I must cut back. I'd be glad to help one Thursday a month at this time with..." Then work up to family situations, such as who will host the holiday dinners.

Communicating your limits

The following tools will help you communicate what you can and cannot do.

Be clear about your limits

Use "I" statements and be as specific about your limits as possible. "I am happy to stop by after work tonight but I have to leave by 6:30." (The formula is: "Up to this point I can do _____. Beyond this point I will do _____," or "_____ happens.")

Offer choices within your limits

This is a way to replace what you can't do with a choice of what you can and are willing to do. "I can't take you shopping today, but I can do it either on Thursday afternoon or Saturday morning. Which is best for you?" (The formula is: "I am

unable to do _____, but I can do _____ or _____. Which do you prefer?”). Sharon said to her son:

I've enjoyed having the grandchildren stay at the house over the holidays every year. Because Grandpa needs more help these days, I can't ask them to stay with us this year. I would like to have them over to sing carols and decorate Christmas cookies with Grandpa. Let's talk during Thanksgiving.

Make no excuses

Giving factual reasons for setting limits aids understanding and is different from making excuses. Offering excuses sounds apologetic. Notice that the following statements contain no excuses or self-criticism:

- ◆ “I'd like to do that, but for now I can only handle these three things.” (You are being factual and specific, and suggesting the limits are not permanent ones.)
- ◆ “I appreciate your suggestions. Right now I can't fit them into my day.” (This is a good response to unsolicited advice.)
- ◆ “I need some time to think about it. I'll let you know tomorrow.” (This gives you time if you feel like making excuses or if flattery or “guilt trips” undermine your resolve.)

If you want to make it easier, you can prepare people over the phone or in writing that you have to rethink how much you can do. You also can mention that your doctor advises you to cut down.

Some people may respond negatively to your limits. This doesn't mean you are wrong. It usually means things are changing that other people wish would stay the same.

Asking for Help

Some caregivers feel that by asking for help they are somehow falling short. But asking for help may be the only way they can continue to provide care at home. They are not falling short; they are adapting to changing care needs that cannot be met without help. It is a caregiver's responsibility to ask for help. If you feel uncomfortable asking for it, consider the following questions about asking for salt.

Yes No

- ☐ ☐ Do you expect people to pass the salt before you ask for it?
- ☐ ☐ Do you blame people for not knowing you want salt?
- ☐ ☐ Would you plead, hint, or whine to get the salt?

You probably answered “no” to the salt questions. Just as we expect to ask for salt in order to receive it, we also need to ask for the help we need in caregiving. As you ask for help, remember to use the tone of voice you use when asking for salt. It's probably pleasant and matter-of-fact, without blaming and hinting.

Prepare yourself to ask for help

Before you ask for help, consider the following suggestions.

Consider the person's special abilities and interests. Before approaching someone with a request, consider their likes, dislikes, areas of interest, experience, abilities, and knowledge. For instance, if someone enjoys cooking but dislikes driving, your chances improve if you ask for help with cooking.

Your chances for success also improve if you ask the person to help you with tasks he feels comfortable with and knows how to do. Tasks unrelated to caregiving are easier for some people.

Note: When one family member has a medical or nursing background, it is natural to expect that he is the best one to help with caregiving. Take care that other relatives are not automatically excused from responsibility because there is a health professional in the family.

Resist asking the same person repeatedly. Ask yourself if you are requesting help from a certain person because he or she has difficulty saying no. It is important to capitalize on your stronger speaking skills rather than on someone else's inability to set limits.

Consider the person's special needs.

Personal, private time is hard to come by. As a caregiver, no one knows this better than you. Other obligations in people's lives may limit the time and energy they have to give. Consider these matters before asking for help and talk them over. “I need more help with the _____. I know you are very busy and I'm concerned about asking too much of you. Would helping me a few hours during the week be more than you can do comfortably?” Out of concern for everyone's needs, you may decide it's time to inquire about hiring in-home help.

Decide the best time to make a request. Timing is important. A person who is tired, hungry, stressed, or busy is not a good candidate for a request.

Prepare a list of things that need doing. If you are unsure what people prefer to do, and relatives say they don't know how to

help, make a list of tasks you need help with (cooking, errands, yard work, someone to visit with the care receiver) and let them choose.

Some caregivers turn providing help into gifts given. The idea is that when people give their time and energy to help, they are giving the caregiver a valuable gift. They may call their list “Gifts of Help” or “Gifts You Can Share/Give.”

Be prepared for hesitance or refusal.

Your request might be answered with a simple no or silence. The person may be unable or unwilling to help and is setting personal limits. Sometimes refusals upset caregivers. Realizing the refusal has hurt the caregiver's feelings, the person may change his mind and decide to help, but the relationship will suffer. If the person hesitates, ask, “Would you like time to think about it?”

Suggestions for asking for help

The following communication tools may help if you feel uncomfortable putting your request into words.

Use your please-pass-the-salt style to make requests. This is the tone you want to use when you ask someone for help. Practice making a request: “I would like to go to church on Sunday. Would you mind staying with Grandma?” in the same tone you would use to ask for the salt.

Use “I” statements to make clear, specific requests. A statement like “I need more help” is vague. A specific request sounds like, “I would like to go to church this Sunday. Would you stay with Grandma from 9:00 a.m. to noon?”