“Malady can be dangerous for the lone traveler. But you can’t count on safety in numbers either unless the people supporting your journey are working together, and in your interest. You can be sure that a serious illness will rearrange some of your relationships. Fast friends will unfasten and pull away; others will surprise you with smart, concerned care. Let people help you. Assign them tasks if you can, duties during a doctor’s visit, flower arranging, shopping, walking your dog, a foot massage, medical research. Everyone can do something, most would like to, and many need guidance because they are simply unsure and afraid. Appoint a spouse, close friend, or colleague, who can act as a major domo and coordinate your "volunteer tour staff."

- Adapted from In The Country of Illness by Robert Lipsyte
While caring for your loved one, it is important not to forget about yourself. Try to make sure that you are attending to your emotional, social, physical, and spiritual needs by:

**Emotional:**
- Watching out for signs of emotional distress, such as depression and anxiety.
- Properly managing symptoms of emotional distress (e.g. anxiety, depression, anger, and stress).
- Seeking professional help when unable to cope with emotional distress.
- Talking with close friends or family about your feelings, or any changes in your mood that they have noticed.

**Social:**
- Visiting or talking with close friends and family.
- Doing something you enjoy.
- Maintaining other activities that are important to you, such as work, hobbies, etc.
- Trying to get out of the house at least once a day.
- Taking a break from caregiving at least once a week.

**Physical:**
- Eating at least 3 meals per day.
- Eating healthy, well-balanced meals.
- Drinking enough water every day.
- Cutting down on fatty foods, sugar, caffeine, and alcoholic beverages.
- Getting an average of 6-8 hours of uninterrupted sleep per night.
- Exercising for at least 20 minutes, 2-3 times per week.
- Taking time to relax daily.
- Seeing your own doctor and dentist according to schedule.

**Spiritual:**
- Taking time out to pray, meditate or practice another form of spiritual worship.
- Speaking to a chaplain or religious figure to make sense of the situation and your feelings.
- Attending services at your church, synagogue, mosque, or other place of worship.
- Reconnecting or establishing a connection with a religious community or group.
- Exploring your beliefs, even if you are not affiliated with a formal religion.
- Trying to find meaning in your role as a caregiver.
Though at times it may seem like your life revolves only around your loved one’s needs, you have a right to address your own needs, too.

CAREGIVER’S BILL OF RIGHTS
I have the right to:

▲ Take care of myself. This is not an act of selfishness. It will give me the capacity to take better care of my relative.
▲ Seek help from others even though my relatives may object. I recognize the limits of my own endurance and strength.
▲ Maintain facets of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person and I have the right to do some things just for myself.
▲ Get angry, be depressed, and express other difficult feelings occasionally.
▲ Reject any attempts by my relative (either conscious or unconscious) to manipulate me through guilt, and/or depression.
▲ Receive consideration, affection, forgiveness, and acceptance for what I do from my loved one for as long as I offer these qualities in return.
▲ Take pride in what I accomplish and applaud the courage it takes to meet the needs of my relative.
▲ Protect my individuality and my right to make a life for myself that will sustain me when my relative no longer needs my full-time help.

(Adapted from Today’s Caregiver Magazine Online)
EMOTIONAL NEEDS

Since so much energy and attention are focused on the patient, you may begin to feel invisible – like you don’t matter. In their concern for the patient, doctors, nurses, other family members, and friends may overlook how difficult the situation is for you. You must try not to let yourself get lost in caring for the patient. Always remember that you, too, have needs and desires. And, by addressing your needs, you can help ensure that your loved one will receive better care.

Paying Attention to Your Feelings

Caring for your loved one can bring with it a number of feelings and emotional reactions. You should not feel guilty or ashamed about any of your feelings. Being a caregiver and seeing someone you love suffer from a physical illness is difficult. You have the right to feel any emotion that you have. You may even experience different emotions over the course of the patient’s illness or in different caregiving situations. The following checklist can help you recognize whether you are feeling any of the emotions commonly felt by caregivers, and when you may need professional help to deal with these feelings:

Anxiety
- Worrying a lot.
- Feeling stressed out, edgy, or overwhelmed.
- Ruminating about little things.
- Having repetitive thoughts.
- Feeling short of breath.
- Having tense muscles.
- Feeling that something terrible is going to happen.

Sadness/Depression
- Feeling down in the dumps.
- Frequent crying and tearfulness.
- Poor appetite and significant weight loss.
- Increased appetite and significant weight gain.
- Sleeping too much or too little.
- Loss of interest or pleasure in usual activities.
- Loss of motivation or energy.
- Feeling worthless.
- Inability to think or concentrate.
- Thinking about death or suicide.

Anger/Frustration
- Feeling easily annoyed.
- Feeling irritable.
- Feeling powerless to change the situation.
- Feeling like you want to give up.
- Feeling helpless.
- Feeling like your loved one or the situation is not living up to your expectations.
- Acting aggressively toward others.
- Getting mad about little annoyances.
- Throwing or hitting objects.
- Experiencing increased heart beat/pulse and breathing, or clenching your jaws when confronting irritating incidents.
- Feeling hostile toward others.
- Displaying irrational behavior.
Tips for coping with your emotions

Anxiety:
- Prepare yourself as a caregiver by reading about caregiving in books or on the Internet.
- Make a list of all the things you are worried about and then try to come up with what you can do to reduce your anxiety about each concern.
- Learn about your loved one’s illness by talking to the doctor, reading books or patient materials about the disease, and using the Internet.
- Talk to other caregivers who are in a similar situation by joining a support group, joining chat rooms on the Internet, or linking up with other caregivers through advocacy groups.
- Watch a funny movie or television show, read a comic, or do something else that will help make you laugh.
- Distract yourself from anxious thoughts by using imagery (see “Learning How to Relax” section).
- Do some exercise. Doing physical activity can help relieve your tension and clear your mind.
- Take some slow, deep breaths and practice a relaxation exercise (see “Learning How to Relax” section).
- Realize that your worries may be exaggerated in your mind and take control of these thoughts by putting them in proper perspective.
- Consider whether it would be best to seek professional help.

Grief
- Experiencing emotional pain associated with the loss of anything that is an important part of your life.
- Feeling sad about changes in the person you love, and/or in your relationship with him/her.
- Being disappointed about lost hopes, dreams, and plans for the future.
- Feeling upset about changes in your social life, and relationships with friends and family members.
- Feeling disappointed about changes in your work/professional life and in your career goals.

Guilt
- Feeling like you have done something wrong.
- Feeling like you are not doing enough for the patient.
- Feeling like you should not enjoy yourself because the patient is unable to.
- Feeling bad about thoughts and feelings you are having.
- Having regrets about relationship problems you have with the patient now or in the past.
- Feeling like you could have done something to prevent the patient’s illness.
- Feeling like you should not be the healthy one.
- Feeling like you have neglected other friends or family members due to caregiving.
**Depression:**
- One of the best ways to ease depression is to get out and get your attention on something else. Though it may be hard to do, you will be surprised how helpful making plans and getting out of the house can be.
- Talk about your feelings to a close friend or family member, mental health professional, or support group.
- Try to make some positive changes in your life, which will make you feel better.
- Exercise. The natural chemicals that get released when you exercise can give you an emotional boost.
- Consider whether it would be best to seek professional help.

**Anger:**
- Don’t let anger bottle up. Express your feelings in a calm constructive way as you experience them.
- Question whether you are justified in being angry. Consider the evidence and determine if you have a valid reason to be angry.
- Think about whether getting angry will make a difference in the situation.
- Consider the other parties’ point of view before getting upset.
- Consider your expectations of the other party or the situation to see if they are realistic. If not, try to change your expectations so that you will not be so easily angered or disappointed.
- Use “I feel… ” language when expressing feelings to others rather than placing blame or accusing them. For example, instead of saying, “you never help me around the house,” you might say, “I feel upset because I think that I am not getting any help around the house.”
- Distract yourself from angry thoughts by using thought imagery or visualization (see “Learning How to Relax” section).
- Calm yourself down with relaxed breathing and other relaxation techniques (see “Learning How to Relax” section).
- It does not do you any good to hold onto angry feelings. Let go of your anger and move on by forgiving the person with whom you are angry.
- Talk to an objective, uninvolved party about your feelings to vent and get another perspective.
- Laugh... think of something funny when you feel your anger getting out of control. It is difficult to feel angry when you are laughing.
- Try to keep your focus on the present situation and don’t let old anger or pain get confused with your feelings about the present situation.


**Grief:**
- Allow yourself to grieve for changes in your life and plans for the future.
- Try to focus more on the positive things in your life, rather than the things you have lost.
- Do not isolate yourself from family and friends who care about you.
- Know that feelings of grief and loss are normal and that, given time, the acute pain will subside.
- Express your feelings to the patient or others close to you.
- Take control of the situation by transforming your expectations for the future.
- Make a new plan for the future based on the positive things that you have in your life.
- Talk to a mental health professional or join a support group.
Even short breaks can restore and renew your emotional energy. However, taking breaks requires planning so that you can feel secure and comfortable during your time away from the patient. You can begin by arranging for alternate care for the patient for a short amount of time. Do something that you enjoy and let yourself and the patient become comfortable with the idea of your absence. As you both become more comfortable, you can begin to increase the length of your outside activities.

**Tips for planning time for yourself:**
- Don’t feel guilty about wanting or needing time away from the patient or from your duties as a caregiver.
- Know that it is okay and necessary for you to have some time for yourself.
- Make a list of people whom you trust to care for or stay with the patient during your absence. Then ask someone.
- If you don’t have anyone in your social circle, you can obtain a volunteer or hire someone for a short time. You may be able to locate such people through local agencies, churches, or synagogues (see Appendix D).
- Start off slowly, by making plans to spend a short time away from the patient.
- Don’t let the patient make you feel bad about leaving. Having some time apart can empower both you and the patient, making you each feel a little more independent.
- Remember that as long as the patient has proper supervision, your absence will not put the patient at risk.
- Try to enjoy yourself and not worry too much while you are away. Allow yourself time to focus on you.

**Making Time for You**

Everyone gets stressed out and needs a break sometimes—most of all, caregivers! It is difficult to confront all of the feelings that you are having when you are constantly with the patient. It is vital for you to take some time away so that you do not become overwhelmed by the stress that caregiving can bring.
Expressing Your Feelings

It is common to spend so much of your energy supporting the patient that you end up ignoring, holding back, or failing to recognize your own feelings about the situation. Continuously ignoring your own feelings can be very dangerous because it does not usually make them go away. Instead, they can keep building up inside of you until you become so emotionally stressed that you can no longer handle the situation. For this reason, it is extremely important for you to identify and address the feelings that you are having. Here are some specific, appropriate ways to express and cope with your emotions.

Tips for expressing your feelings:

- Identify what it is that you are feeling and allow yourself to accept the emotions as a natural response to caregiving.
- Do not bottle up your feelings.
- Share what you are feeling with the patient, if you feel it’s appropriate.
- Call a close friend or family member with whom you can discuss your feelings.
- Write down your thoughts and feelings in a private journal.
- Join a local support group for caregivers or families of ill patients.
- Get a referral to speak to a professional therapist who can help you understand and deal with your emotions.
- Speak to a chaplain, priest, rabbi, minister, or other religious figure.
in your way. Much of this can be changed through proper communication, and allowing yourself some time to spend with friends. You need the support and love of your friends and family to feel less alone and to cope better with the challenges of caregiving.

Tips for maintaining social relationships:

■ Reassure your friends and family that although you may be busy, you do need and appreciate their support.
■ Be open and share your experiences as a caregiver with your friends and family so that they can try to understand what it is like for you.
■ Explain the patient’s diagnosis with those who are not familiar with it.
■ Invite friends and family over to visit or help while you are caring for the patient.
■ Take the time to call and catch up with those friends and relatives with whom you have lost touch. Be sure to ask them about their lives rather than just talking about your situation. This can serve as a great form of distraction.

SOCIAL NEEDS

One of the most common complaints of caregivers has to do with the reduction in their social contacts and activities. Caregivers find that they are unable to visit with friends and relatives, go out, or do the things they enjoy as much as they would like. As a result, caregivers often begin to feel socially isolated.

The Power of Social Support

As the primary caregiver of your loved one, most of your attention is probably spent on him/her. You may find that you rearrange other commitments and areas of your life to be with the patient. Often, friends and relatives are neglected because you are too busy, don’t want to burden others with your problems, or don’t think they will understand. You may also feel as though friends have limited their calls or visits, which may be the result of their own discomfort with the patient’s illness, not knowing what to say to you, or feeling like they will be
**Maintaining a Life of Your Own**

It is not healthy to spend all of your time with the patient, which can lead to resentment of him/her if you don’t feel like you are able to live your own life. Just as it was normal for you to do things without your loved one before he/she got ill, it is also okay now. You are an individual with your own interests, thoughts, and desires. At least some of these need to be expressed and fulfilled so that caregiving does not consume your life. Though work can sometimes be an additional burden, it is a good way for you to maintain a sense of purpose outside of caregiving. If you are retired or unable to hold a job because of your caregiving responsibilities, there are plenty of other things you can try.

**Tips for maintaining your own life:**
- Don’t feel guilty about asking or hiring someone else to take care of the patient while you do something on your own.
- If you don’t work, look into jobs that would allow you to work from home.
- Accept invitations to social gatherings.
- Find a hobby or activity that you like and do a little every day.
- Do something once a week that you enjoy.

**It’s Okay to Do Something You Enjoy**

If the thought of going out and enjoying yourself makes you feel guilty, you are not alone. Many caregivers feel that enjoying themselves implies that they are abandoning the patient. Taking a break and having fun do not make you a bad person, and certainly don’t mean that you don’t care about the patient. On the contrary, outside activities will help you maintain your sense of self and independence, clear your head, reduce stress, and improve your relationship with the patient.

**Tips for leisure:**
- Plan an enjoyable activity to which you look forward at least once a week.
- Remind yourself that getting out does not mean that you are abandoning your loved one.
- Get a beeper or cell phone so you can check on your loved one or be reached in an emergency.
- If you cannot get away from the house, invite a friend to spend some time with you at home.

**Why not try...**
- Going to a movie.
- Going out to lunch with a friend.
- Renting a movie.
- Inviting a friend over to play a game of cards.
- Taking a walk in a nearby park.
- Borrowing a good book from a friend and discussing it after you have read it.
- Taking a class you are interested in.
- Joining a club or group activity.
- Attending a sporting event.
Tips for proper eating:
- Eat 3 well-balanced meals per day, including breads and cereals, milk and cheese, fruits and vegetables, and lean meat, poultry, fish, and eggs.
- Cut down on fatty foods, sugar, and alcoholic beverages.
- Eat healthy snacks in between meals (e.g. fruit, vegetables, low-fat cheese, yogurt, cereals, and crackers).
- Drink enough water (6-8 glasses per day).
- Avoid drinking too much caffeine, such as soda, coffee, and tea.

For more information on nutrition or a referral to a dietician in your area, contact:
The American Dietetic Association/National Center for Nutrition and Dietetics
216 West Jackson Boulevard, Chicago, IL 60606
(800) 336-1655 (Consumer Hotline)
www.eatright.org

Fighting Fatigue
Waking up numerous times in the middle of the night to help your ill relative... Getting up early and going to bed late in order to get everything done... Staying up all night with a patient who can’t sleep... All of these situations can cause serious disruptions to your sleep and can lead you to become exhausted. When you do not get enough sleep for an extended period of time, you can lose energy, have trouble concentrating and remembering things, and generally feel fatigued. Sleep restores your body and mind. So, it is important for you to get enough rest in order to be able to maintain proper physical and emotional functioning. Ideally, you should be getting at least 6-8 hours of uninterrupted sleep per night.
The Benefits of Exercise

Though you may be very active during the day while caring for your relative, there is no substitute for regular aerobic exercise. Studies show that exercise has many benefits, including lowering blood pressure, easing depression and anxiety, and decreasing physical and mental tension. Exercise can help you ease your mind, take a break from the patient, and stay in shape to foster good health. As a caregiver, you confront a great deal of physical and emotional stress that can build up if not properly addressed. Exercise is one of the best ways to prevent yourself from becoming overwhelmed by the burdens of caregiving.

Tips for exercising:

■ Consult with your doctor to determine an exercise regimen that will be right for you. Walking and swimming are two great forms of low-impact exercise.
■ No amount of exercise is too little, but it is suggested that you work out at least 3 times per week for at least 20 minutes each time.
■ Be sure to stretch your muscles before and after you work out.
■ If possible, try to work out with a partner (especially the patient) who can help keep you motivated.
■ Pick a form of exercise that you enjoy.
■ Listen to your favorite music to keep you going while you are working out.
■ Choose a workout that is convenient so that you are more likely to stick with it.

Tips to fight fatigue:

■ Try to schedule your sleep around the patient’s sleeping pattern (e.g. if the patient sleeps during the day, take a nap at the same time).
■ Rest when you get tired and after high-energy activities.
■ Avoid caffeine before bedtime so that you don’t have trouble falling asleep.
■ Get outside help for the evenings if you are unable to sleep because your relative is up a lot during the night.
■ Every so often, recruit a friend or family member to stay over and care for the patient while you get some uninterrupted sleep.
Finding Time to Relax

Taking a little time to relax can help reduce the physical and emotional stress that come with caregiving. Your body and mind can function only up until the point where they become completely tense and overwhelmed. As little as 10 minutes of relaxation per day can help you feel more calm, rested, and able to cope with the stresses in your life. See the “Learning How to Relax” section to learn some helpful relaxation techniques.

Tips for relaxation:

■ Practice! Learning how to relax is a skill that takes time and practice — try to do it as often as you can until you feel comfortable with the technique.
■ Take time out at least once per day to relax, do something you enjoy, and just get your mind off the illness.
■ Do relaxation exercises in a quiet place where you will not be disturbed.
■ Practice relaxation at times when the patient is asleep or does not need you.
■ Take the phone off the hook and put a “Do Not Disturb” sign on the door.
■ Read a book, watch TV, or listen to music. These can serve as relaxing breaks from the demands of caregiving.
■ Schedule some time to pamper yourself by getting a massage, facial, or something else you enjoy.
Spirituality means different things to different people. It may include faith or what provides a sense of personal meaning in life (and death). Spiritual health can be sought through formal religion, prayer not associated with any religion, meditation, soul searching, and social ties with family, friends and others. When dealing with illness, spiritual issues often come to the forefront of the patient’s life, as well as your own. Illness and other adversity disrupt your sense of meaning, your values, and even your faith. Addressing your own spiritual needs can help you deal with these concerns and open the possibility of growth from the situation. In doing so, you may be better able to accept the situation, and even find some positive aspects in your role as a caregiver.

**Why?**

When something like illness happens to you or someone you love, there is a need to make sense of the situation in order to come to terms with it. In this search for understanding, you may find yourself asking and wanting to know “Why?” “Why has God done this to someone I love?”... “Why am I being punished like this?”... “What did the patient or I do to deserve this?” Often, there is no reason or logical explanation. Rather than spending your energy trying to understand why bad things happen, it may help to focus on trying to accept the situation, cope with it, and allow yourself to learn and grow from it. Accepting the situation as it is may involve transforming some of your core beliefs about God, religion, spirituality, and your future. Whether you are religious or not, you may be able to find faith in your existing beliefs about life and God. Use any spiritual distress you feel to find meaning in the situation. Looking at the situation as offering you the opportunity for personal growth may be of some comfort.

**Tips for dealing with spiritual issues:**

- Take time out to pray, meditate or practice spiritual rituals to nurture yourself.
- Speak to a chaplain or religious figure.
- Attend services at your church, synagogue, mosque, etc.
- Find faith in what you believe, even if you are not affiliated with a religion.
- Try to find meaning in your role as a caregiver.
- See if you can identify anything positive that can or has come out of the situation.
- Think about what you can learn from the situation and how it can make you a stronger person.
Whenever you feel yourself getting angry or upset about the situation, take a step back, look at the bigger picture, and reflect on these positive thoughts.

**Tips for making the best of the situation:**

- Think about ways that caregiving has made you a stronger person.
- Think about why you have accepted this role and any positive aspects of caregiving.
- Think about the positive ways in which caregiving and the patient’s illness have changed your relationship with the patient.
- Consider if caregiving has brought you closer to the patient and/or other relatives or friends.
- Make a list of positive aspects of your relationship with the patient, shared memories, and what the patient means to you. Look at the list whenever you find yourself getting upset about the situation.

**Making the Best Out of a Bad Situation**

Of course you are not expected to be happy about your situation as a caregiver, or about the patient’s illness. Chances are, becoming a caregiver has led to many changes in your life, about which you are not happy. Also, facing the prospect of the patient’s health deteriorating and having to watch him/her suffer may be of concern to you. You could probably spend the whole day thinking about all of the bad things about the situation without a second thought. However, where would that get you? While it is perfectly normal and expected for you to mourn for your losses, there is always another side of the coin. Try to take some time to look at the bigger picture and focus on any positive aspects of the situation. Think about the good times you have shared with the patient, how you feel about having the patient in your life, and how much would be missing if the patient were not in your life.
Or, maybe you will find solace in meditation or prayer if you give it a try. Even if you are skeptical or hesitant, it may be worth it for you to seek help from a spiritual advisor, such as a chaplain or other religious figure. You might be surprised to find that sharing your doubts about God may make you confront deeper feelings, which can transform your perspective. You may even find that the situation reestablishes your spirituality or faith in God. Use your faith to help you cope with any obstacles along the way.

**Tips for keeping your faith:**

- Speak to a chaplain or religious figure who has experience with illness. He/she may be able to help you make sense of your feelings and the situation.
- Give prayer, meditation, or other forms of spiritual worship a chance.
- Explore your beliefs and try to use them to accept the situation.
- Talk to others in similar situations and see how they have integrated spirituality and caregiving.
- Reconnect or establish a connection with a religious community or group. Even when you have lost faith, this can turn out to be a great source of comfort.
As we all know, caregiving by itself can be a full-time commitment. Add in work, family, and other responsibilities and it can be enough to drive you crazy. Unfortunately, those other areas of your life do not just disappear while you concentrate on caring for your loved one. As a result, caregiving can interfere with your performance at work, your relationship with your partner, or the care of your children. Your life can become a very shaky balancing act, which could come crashing down if you don’t work out conflicts and make a plan to attend to other areas of your life.

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**Work**

Doctors’ appointments, patient needs at home, and unexpected crises make it nearly impossible for you as a caregiver to maintain a regular work schedule. However, keeping your job may be very important to you for any number of reasons. Whether it’s for the salary, medical benefits, or personal satisfaction of working, you should not give up your job without first trying to make it work. With some convincing of your boss, you may be able to work more flexible hours, where you could come and go at different times, but work the same amount of hours. Another option would be to ask if you could work from home on some days or at certain times. Also, if you are able to afford cutting down on your hours, you might be able to switch to a part-time position. Finally, “job sharing” may be an alternative for you, which would entail sharing the responsibilities of one job with other employees.

Unfortunately, not all employers are flexible and/or understanding about the plight of family caregivers. That is where the Family and Medical Leave Act (FMLA) comes in to protect working caregivers. This law states that every U.S. employee working for a company that employs 50 or more people is entitled to 12 weeks of annual unpaid leave in order to care for a family member. This leave can be taken in one block of time, or in days at a time. Though employees do not get paid during this time, they continue to receive health insurance and other benefits, and are assured that their jobs will be there when they return. In any case, you need to decide what you can handle as an employee and a caregiver.
Tips for coping with work:

- Talk to your supervisor about your situation and needs in a way that expresses your concerns, both as a caregiver and a dedicated employee.
- Be understanding about your employer’s needs and work with him/her to agree on a plan that works for everyone.
- If possible, ask family members or friends to stay with or check in on the patient when you are at work.
- Look into home care options for the time when you are at work (See Appendix F).
- Try to view your job as respite time away from caregiving. It is time for you to focus on concerns other than the patient, and have time to yourself.
- If on leave, you should check in with your employer frequently to stay aware of what is happening at work, and to keep the employer informed about your situation.
- If you feel that you are unable to handle your job, resign before there are any hard feelings.

To find out if you qualify under the FMLA or to learn more about it call:
(1-800-959-FMLA)
http://www.dol.gov/dol/esa/fmla.htm

Family

The stress and time involved in caregiving can take a toll on your relationships with family members. You may find that you have less time to spend with your healthy loved ones, less energy to play with your children, less intimacy with your spouse, or less patience with your siblings. Such changes can create feelings of resentment, abandonment, and tension within family members, which can lead to conflict. It is not uncommon to experience short tempers, disagreements, fights, isolation and withdrawal within the family.

You may also notice transitions in the dynamics and roles of your family. Suddenly, you may be making important decisions that your spouse/partner used to make, you may feel like a parent to the mother or father who has always taken care of you, or you may be responsible for household duties for the first time. These personal and family shifts can be uncomfortable. It takes time for you and other family members to get used to filling roles and responsibilities that are different than the ones you held in the past.

If you have a spouse/partner, other than the patient, here are some tips for preserving a positive relationship:

- Talk openly with your partner about your concerns and emotions.
- Try not to take your frustrations out on your partner.
- If you spend a lot of time away from your partner due to caregiving, make sure to express your feelings about being away from him/her. Make the most of the time you do have together.
If need help and you think that your partner can assist you, ask him/her.

Reassure your partner about how you feel about him/her by telling and showing him/her.

Schedule periodic “dates” with your partner when you can be alone and spend some time away from the house.

Seek professional counseling if you and your partner are not able to communicate effectively, such as arguing frequently.

If sex is an important aspect of your relationship, you need to protect this. If you or your partner have lost interest in sex, this may be due to exhaustion, stress, or depression. Seek professional help if you are having problems with intimacy in your relationship.

If you have children, or there are children being affected by the illness, here are some tips for helping children adjust:

- Talk to children about the situation, giving them a clear explanation without scaring them.
- Involve children in caregiving by telling them how they can help out.
- Try to keep things as normal as possible in your children’s lives. Stick to a routine so that they do not feel like their world is suddenly being turned upside down.
- Make time to do something with your children as often as possible, so that they do not feel neglected.

Pay attention to your children’s behavior. If they are acting different, this may be a sign that they are looking for attention.

Make sure children know that they are loved by showing them affection and praise.

Try not to take out your frustrations on children when they have done nothing wrong.

Many times, young children have unrealistic notions that they are responsible for their parents’ distress. Be sure to explain to children that they are not to blame for any of the emotional or physical distress that they may be witnessing in the family.

Prepare children on how to talk to other kids about the situation, in case it comes up in conversation.

If you have siblings, here are tips for avoiding and dealing with sibling conflict:

- If caring for a parent, share the responsibilities of caregiving with your sibling(s) by dividing duties as evenly as possible.
- If necessary, ask your sibling(s) for help. Be clear and specific about how they can help you.
- Keep the lines of communication open with your sibling(s) and frequently update them about how the patient is doing.
- Have regular family meetings to discuss responsibilities and reassess the plan of care for the patient.
- Address any issues with your sibling(s) directly. If you feel that they are not giving you enough help or support, let them know.
- If you are unable to get help from your sibling(s), have the patient suggest to your sibling(s) ways in which they can help.

If sex is an important aspect of your relationship, you need to protect this. If you or your partner have lost interest in sex, this may be due to exhaustion, stress, or depression. Seek professional help if you are having problems with intimacy in your relationship.

If you have children, or there are children being affected by the illness, here are some tips for helping children adjust:

- Talk to children about the situation, giving them a clear explanation without scaring them.
- Involve children in caregiving by telling them how they can help out.
- Try to keep things as normal as possible in your children’s lives. Stick to a routine so that they do not feel like their world is suddenly being turned upside down.
- Make time to do something with your children as often as possible, so that they do not feel neglected.

Pay attention to your children’s behavior. If they are acting different, this may be a sign that they are looking for attention.

Make sure children know that they are loved by showing them affection and praise.

Try not to take out your frustrations on children when they have done nothing wrong.

Many times, young children have unrealistic notions that they are responsible for their parents’ distress. Be sure to explain to children that they are not to blame for any of the emotional or physical distress that they may be witnessing in the family.

Prepare children on how to talk to other kids about the situation, in case it comes up in conversation.

If you have siblings, here are tips for avoiding and dealing with sibling conflict:

- If caring for a parent, share the responsibilities of caregiving with your sibling(s) by dividing duties as evenly as possible.
- If necessary, ask your sibling(s) for help. Be clear and specific about how they can help you.
- Keep the lines of communication open with your sibling(s) and frequently update them about how the patient is doing.
- Have regular family meetings to discuss responsibilities and reassess the plan of care for the patient.
- Address any issues with your sibling(s) directly. If you feel that they are not giving you enough help or support, let them know.
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If you have children, or there are children being affected by the illness, here are some tips for helping children adjust:

- Talk to children about the situation, giving them a clear explanation without scaring them.
- Involve children in caregiving by telling them how they can help out.
- Try to keep things as normal as possible in your children’s lives. Stick to a routine so that they do not feel like their world is suddenly being turned upside down.
- Make time to do something with your children as often as possible, so that they do not feel neglected.
If you are not satisfied with your sibling’s help, try to accept whatever they do offer and seek help from other relatives or friends.

Recognize if old sibling rivalries are re-emerging and address them before they get out of control.

Express your anger, resentment, jealousy, or other emotions regarding your sibling(s) by talking to a close friend, family member, or therapist.

If you have in-laws, here are some tips for coping with possible problems:

- Remember that the patient is the foremost concern and try to work with your in-laws to ensure that the patient feels that way.
- If your in-laws would like to be involved in caregiving, let them know how they can help in a clear and specific way.
- Keep in mind that people can act out of character when they are stressed. Try not to take it personally if your in-laws act differently toward you or take things out on you as they try to cope with the patient’s illness.

- Communicate openly with your in-laws about the patient’s illness and treatment.
- Make sure your in-laws are aware of the patient’s wishes/advance directives to avoid disagreements if the time comes that decisions must be made for the patient.
- Talk through issues that arise between you and your in-laws. Be respectful, but do not be afraid to express how you are feeling.
- Do not bring up past conflicts between you and your in-laws. Airing old dirty laundry will only serve to make the situation more sensitive between you and your in-laws.
- Try to be forgiving and not hold on to hurt feelings, anger, or resentment.
- Remember that regardless of how you feel about them, your in-laws are still family. If you need to vent, talk to someone other than the patient about your feelings.
Tips for multiple caregiving:

- Do not attempt to do everything yourself. Frequently evaluate whether you can handle everything that you are taking on before you continue.
- Recruit other family members or professionals to help with some of the caregiving duties.
- Look into services that might help reduce your strain, such as getting a baby sitter to watch the kids, hiring a night sitter so that you can get some sleep, or getting a home health aide for a few hours a day to help with the patient. Some of these services may even be covered by the patient’s insurance plan.
- Force yourself to take breaks to renew your energy.
- Don’t carry the emotional burden of caregiving by yourself. Share what you are feeling with close friends and/or family.
- Don’t push yourself too hard. Slow down if you feel like you are doing too much.
- Change the situation if you find that you can’t handle everything that needs to be done.
- Look into other options for help at home (see Appendices D and F).
- Remember that your health is of utmost importance if you are going to be able to continue caring for others.

Other Caregiving Duties

If you are a caregiver who is responsible for caring for more than one person, you face demands above and beyond those of other caregivers. Whether it’s caring for children or an additional ill relative(s), multiple caregiving makes it almost impossible for you to attend to your own needs. However, the added burden of caring for more than one person makes it all the more important for you take care of yourself. You must take some time to address the emotional strain and physical toll of caregiving.
Relaxation exercises are useful techniques to help relieve tension, decrease worry, improve sleep, and make you feel generally more at ease. These exercises use physical and mental activities, which focus attention on calming the body and mind, creating feelings of comfort.

Provided are descriptions of different relaxation exercises. It is not necessary to use all the forms of relaxation that are described. Instead, you should choose a form that is easiest and most comfortable for you. It is a good idea to try each and decide which you like best. However, all relaxation should begin with relaxed breathing. This will help prepare you for deeper relaxation. Once you master relaxed breathing, you can continue to add other relaxation exercises to your routine. You can also combine a few relaxation exercises, such as beginning with relaxed breathing, doing some muscle relaxation, and then using imagery.
Relaxed Breathing
The best way to begin relaxed breathing is lying down on your back. Once you are comfortable breathing in this position, you can then try it sitting and standing.

▲ Find a comfortable place and lie down on your back, or sit in a chair.
▲ Breathe in through your nose slowly, in a natural, gentle way.
▲ At the same time that you take in each breath, gently expand your belly to fill with air. Keep your shoulders and chest as still as possible. Imagine that you are filling a small balloon inside your belly with air each time you inhale.
▲ Breathe out through your mouth, emptying your belly and letting it relax. As you breathe out, purse your lips to create a little resistance to the exhale to keep it slow, like gently blowing on a candle to make it flicker. Breathe out as slowly as you can, making each exhale last.
▲ When you finish your exhale, wait quietly until your body naturally takes its next breath. Take your time.
▲ Each time you breathe in, imagine a balloon filling with air, and each time you breathe out, imagine the balloon deflating.
▲ Be sure to breathe in a slow, gentle, and natural way. If you become dizzy or light-headed, take smaller breaths and slow down.
▲ It may help to put one hand on your stomach (over your belly button) and one hand on your breastbone. Watch to see which hand is moving more when you breathe in and out. Try to get the hand on your stomach to move more as you breathe, without forcing it.

You should practice diaphragmatic breathing frequently for short periods of time. At first, maybe 10-15 times per day for 1-2 minutes each time. Try to practice in different situations, such as lying down, sitting, standing, on a bus/subway. With practice, relaxed breathing can become a quick and easy tool to combat stress.

Relaxed (Diaphragmatic) Breathing
Since breathing is second nature to us, we rarely think about the way that we breathe. Learning to breathe abdominally (through the diaphragm) can promote relaxation, which improves physical and mental health. Over time, most people begin to breathe by moving their chest and/or shoulders. However, if you watch a baby breathe, you will see that they breathe by moving their belly, which is the most efficient way to take in oxygen and remove carbon dioxide with the least effort. The diaphragm is the muscle that controls breathing. It is a dome-shaped muscle that sits beneath the lungs, above the abdominal cavity. When a breath is taken, the diaphragm flattens out, allowing the lungs more room to expand with air. When air is exhaled from the lungs, the diaphragm returns to its domed shape. Though breathing is an automatic function, the movements of the diaphragm can be controlled voluntarily with training. Learning how to control the diaphragm and the way we breathe can be beneficial in many ways:

■ Allows the most efficient exchange of oxygen and carbon dioxide with the least effort
■ Promotes general relaxation
■ Improves circulation
■ Removes waste products from the blood
■ Slows down heart rate and breathing rate
■ Frees the mind
Muscle Relaxation

Muscle tightness/tension is the body’s signal that we are under stress. When we experience stress for prolonged periods of time, we may develop chronic tension in our shoulders, back, head, or other areas of our bodies. However, because we are so focused on external concerns, most of us are not usually aware of the tension in our bodies, unless it becomes painful.

Learning to relax your body not only helps prevent muscle tension from turning to pain, but can calm you mentally as well. Muscle relaxation trains you to be aware of tension in your body and control tight muscles that respond to stress. Relaxing your muscles is a skill that takes practice, but once you know how to do it, you can use it to reduce your emotional and bodily tension quickly and easily.

There are two types of muscle relaxation: Passive relaxation involves relaxing different muscle groups by thinking about them, while progressive muscle relaxation allows you to focus on and relax your muscles by first tensing them, which automatically forces your muscles to relax. The following is a relaxation exercise that you can use to relax the muscles in your body. You may want to have someone else read it to you, or you can tape yourself reading it, so that you can concentrate on relaxing.

Body Scan

▲ Begin by getting into a comfortable position and closing your eyes. Use some relaxed breathing to calm yourself. Take about 4 slow, deep breaths.
▲ Relax your whole face. Start with your jaw and tongue. Are you clenching your teeth? Are you pressing with your tongue? Let all the muscles of your jaw and tongue relax. Allow your teeth to be slightly parted in a natural, unforced way. Your tongue should be loose inside your mouth, resting against the back of your teeth. Next, pay attention to your eyes and forehead. Make sure that you are not squeezing your eyes shut or furrowing your eyebrows. Let your eyes close so that your eyelids barely touch. Your whole face is completely relaxed.
▲ Now, relax your shoulders. Let go of all of the tension in your shoulders and let them drop. Let any feelings of tension in your neck flow away. Let your shoulders and neck muscles sink into a pleasant state of comfortable relaxation.
▲ Relax your arms, hands, and fingers. Are you flexing a muscle? Are you gripping anything with your hands? Let your arms feel heavy and relaxed, like a floppy rag doll.
▲ Let any feelings of tension in your back, chest, or abdomen dissolve and flow away. Let yourself become more and more limp and relaxed with every breath you take.
▲ Relax your legs, feet and toes. Let go of any tension from your legs. Let your leg muscles sink into a deeper and deeper state of pleasant comfort. Make sure you are not pressing your feet or toes. Let your feet and toes become completely relaxed.

For the next minute or so, let your entire body become more and more relaxed. Enjoy this feeling of comfort and relaxation, and when you are ready, open your eyes slowly and remain quiet for another moment or two.
Imagery/Visualization

Imagery, or visualization, is a technique that uses your imagination to create mental pictures. It is used to focus your mind on something pleasant and comforting in order to ease stress and anxiety, and reduce muscle tension and pain. Imagery incorporates all of your 5 senses – sight, smell, hearing, taste, and touch. You should try to practice visualization 1-2 times per day until it becomes natural for you. If you are a very visual person, this may only take a few practice sessions. For others, you may need to practice for a couple of weeks before you feel comfortable with it. The easiest way to practice imagery is in bed in the morning when you wake up and at night before you go to sleep. With practice, you will be able to go to your special place just by closing your eyes. Try it using the following exercise.

Your Special Place

To begin, lie down, get comfortable, and close your eyes. Use some relaxed breathing to calm yourself. Take about 4 slow, deep breaths.

Now, picture yourself in a quiet, special place. A place that is very beautiful and feels peaceful and safe. You are all by yourself and feel totally relaxed, safe, and at peace in this quiet, special place. It can be a place in nature, such as a beach... a lake... a forest... a field... a mountain. Or it can be somewhere else, like a garden... a church... a favorite room... somewhere you have been in the past.

Picture yourself in this quiet, special place as vividly as you can, using all of your senses. Look around. Notice what you see. The colors... shapes... what the light is like. Perhaps the blue of the sky, or the reflection of the light upon the water. Notice what you see in your special place.

Notice the sounds, what you hear. Perhaps the lapping of water against the shore, or the sound of wind rustling in the leaves. Listen to the sounds in your quiet, special place.

Notice the smells in the air. Perhaps the smell of the salt water... or the fresh clean smell of country air... or the smell of pine needles in the forest. Notice the smells.

Feel how warm, or cool the air is against your skin. And picture where you are. Are you lying down? ... sitting? ... leaning against something? ... standing?

Use all of your senses to make this special place as vivid and real as you can. Memorize the smells, sounds, and sights. Continue to enjoy being in your special place for a minute or two longer. Allow yourself to relax even more deeply. Remind yourself that you can come back and relax here whenever you want. When you are ready, open your eyes slowly and continue to remain still and enjoy your relaxation for another moment or two.
Meditation Exercise

Sit comfortably in a chair with your legs apart and your hands in your lap.

Keep your back straight and keep your head up with your chin tucked in slightly.

Close your mouth and breathe through your nose. Position your tongue softly on the roof of your mouth.

Close your eyes or focus on a spot on the floor about 4 feet away.

Take deep abdominal breaths, but do not force them. As you breathe, focus completely on your breathing. Pay attention to the feelings of the inhale, the point at which you stop inhaling, the pause between inhaling and exhaling, and the exhale.

As you exhale, say “one” to yourself. Continue counting each time you exhale by saying “two… three… four.” Then begin again with “one.” If you lose count, start over with “one” again.

When you notice that your mind has wandered, note this, then gently return to counting your breathing.

If a particular sensation in your body catches your attention, focus on the sensation until it goes away. Then return your attention to breathing and counting your breaths.

When you first begin to practice, maintain the meditation only for as long as is comfortable, even if this is only for 5 minutes per day. As you practice and meditation becomes easier, you will find yourself wanting to extend your time. In terms of relaxation, 20-30 minutes once or twice a day is adequate.


There are many other forms of muscle relaxation, visualization, and meditation that might be right for you. If you would like more training in any of these techniques, you can ask your physician for a referral to a cognitive behavioral psychologist or therapist. You can locate classes on meditation and stress management in the community. Or you can learn some more on your own through self-help books (see Stress Management Fact Sheet).