



THE CAREGIVER'S COMPANION



CARING FOR YOUR
Mind, Body & Spirit



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A Note to the Reader

— Introduction

As a caregiver, you have a job that changes constantly depending on your loved one's health and needs. You deal with expectations and feel many emotions. Being a caregiver can be a long journey with many challenges. Taking good care of yourself, also called self-care, is essential to your health and sense of being well. It also helps the loved one you are taking care of.

Your emotions may include feeling overlooked by the health care professionals caring for your loved one. You might feel alone and unable to talk to your loved one about how the situation makes you feel. And perhaps you feel misunderstood by friends, family and coworkers.

This guidebook is here to support you, whatever your relationship is to the person you care for. You are husbands and wives, parents and children, friends, relatives and acquaintances. And you are not alone on this journey.

So often you hear that it's important to take care of yourself. But for caregivers like you, who spend so much time and effort caring for someone else, how is that possible and what does it mean? Another important group of individuals reading this book are those coping with the loss of their loved ones.

This guidebook is based on scientific research and other caregivers' personal experiences. It walks you through the four areas of your life that are key to being at your best. These are your sense of self—who you are—your choices, your circle of support and your relationship with the outside world. You can read the guide whenever you have a few minutes to yourself or need help and advice.

As you work with this guide, you may find healing. But you may not find a cure. "Cure" means the signs and symptoms of disease, injury or loss are completely gone, and this is not always possible. For example, if your loved one was in combat, they may have permanent hearing loss or other changes. If you lose a child, you will always be conscious

of the loss. However, healing is a process of recovery, repair and renewal. It is personal, and it can continue throughout your life. Healing can help you and your loved ones live the best life possible.

In addition to the resources in this guidebook, you can find free videos, fact sheets and journal exercises online. Visit drwaynejonas.com/caregiver for more information and to download the journal companion.

Put Safety First

Although this guide helps you work through some of the challenges of being a caregiver, it is not meant to solve problems of abuse, neglect, someone using you or you hurting yourself. If you or your children are in danger, get help immediately. Don't wait until your situation becomes a crisis. Talk to a friend or family member, and make a plan to be safe when the problem happens again. Talk to a medical provider, crisis center or spiritual leader. If they do not help, talk to someone else until you do find help.

Physical and emotional abuse almost always gets worse and worse unless you get professional help. Even with professional help, it might not change, and you might need to simply get away to a safe place. You and the person you care for are worth the effort.

Part 1: The Body-Mind-Spirit Connection

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You are the caregiver, not the curegiver.

—Siegel & Yosaif

When you think of self-care, you might think of exercise and eating well. Those are two important topics that will be covered in the next chapter. But how well you feel in general comes from how you feel about yourself, your life and your relationships.

Your Sense of Self

Who you are includes the thoughts, feelings and wishes that come from the mind. It also includes your spiritual life and having a sense of meaning or purpose. You can lose this sense of self when you are caring for a loved one. Even as you love and want to help them, you might feel their illness or injury has taken over your life.

Acknowledging that who you were before and who you are now may not be the same can be a painful process. The goal is to work toward accepting your new self as a complete person who has grown from your experiences.

Find Power in Your New Role

Each day comes with new challenges that test and build your ability to bounce back, but this does not mean bouncing back to become the same person you were before. Instead, you become someone better, stronger and more aware than you ever were before.

Caring for someone else teaches you compassion, love and empathy as no other experience can. You also learn practical skills such as managing time, speaking up for the patient and yourself, listening and communicating.

Give yourself credit for bouncing back from challenges and becoming stronger. This can create new meaning in your life and work—and finding meaning is important for your mind, body and spirit.

Writing in a Journal

Writing in a journal is one way to take care of yourself. It can help you heal, grow and thrive. Here are some reasons why it helps:

- Journal writing helps bring order to your deepest thoughts and fears. Writing things down creates order out of chaos.
- A journal is free therapy. It helps you have a conversation with the person who knows you best—you!
- You can keep track of your progress. Read what you wrote earlier to learn how much progress you have made on your journey.
- Sharing your journal with others might bring you joy. But whether or not you share your work is up to you.
- A gratitude journal is a journal with lists of things you are thankful for. This kind of journal relieves stress. Writing about what you are happy for is a powerful reminder of the good in your life.

Faith and Healing Presence

For many, spirituality, faith and religion are central parts of who they are. They can influence how you cope with trauma and loss. They help you find happiness and meaning within rather than from external influences such as money, belongings, work, fame or food, which may leave you feeling empty, lost and alone.

The same mind and body practices that help you develop a sense of spirituality can help stop stress and its harmful effects. A mind and body practice can help you relax through mental focus, controlled breathing and body movements. The most important

thing to know is that the same practice does not work for everyone. However, all of them can break the train of everyday thoughts.

Consider these factors when picking a mind and body practice:

- **Physical energy**—Do you enjoy being physically active?
 - If yes, consider a moving meditation like tai chi, qi gong, yoga, walking and running, or an active meditation like art therapy or writing in a journal.
 - If no, consider breathing techniques, meditation, mindfulness-based stress reduction, loving-kindness meditation, guided imagery or progressive muscle relaxation. These can all be done when your body is quiet and still.
- **Self-based or Provider-based**—Practices such as acupuncture or massage require making time to see a provider. For some caregivers, that time-out can be relaxing. Other caregivers may find it stressful to go to one more appointment. Some practices, such as breathing techniques or repeating a meditation mantra, require nothing more than your attention and a few seconds. Other practices can be done alone after you learn them. These include acupressure, reiki, yoga or tai chi.
- **Time**—Consider what fits into your schedule. Do you have 30 seconds? Five minutes? An hour? There is a mind and body practice for every moment.
- **Belief and conviction**—Choose a practice that fits into your belief system. Whether you call it making time for prayer, meditation or quiet reflection, what's important is that you are practicing self-care. It is not important to be convinced that the practice will work for you. However, it is important to set your doubts aside and look at it as an experiment. Often taking that first step is the hardest, though the most important.

In Your Journal

Make a list of 3 qualities you have that you consider weaknesses. Then, write a sentence or 2 about how you can also consider them strengths. For instance, if you think a weakness is having to manage every detail of everything, you could also consider that you have the strength of being organized and responsible. Once you determine the strength for each "weakness," write about a time when you used that strength in a positive way. If you can't think of a recent example, write down how you might use this strength positively in the future.

Try to schedule this time regularly. Knowing that you have time set aside just for yourself can be helpful.

Stress and the Body's Response

Not all stress is bad. Small amounts of stress can increase your focus and help you perform better. However, too much stress has an opposite effect on the body. You are less efficient when you work or concentrate, and you become more anxious. A regular mind and body practice helps your body use its natural ability to overcome the harmful effects of long-term stress.

“Over time, continued strain on your body from routine stress may lead to serious health problems such as heart disease, high blood pressure, diabetes, depression, anxiety disorder and other illnesses.”

— National Institute of Mental Health, 2016

The saying “No pain, no gain” does not apply to stress. Pushing yourself through it may lead to physical and mental burnout. Your stress response can get stuck in the “on” position, so you are always in a stressed and anxious state. It is important to learn ways to reset it. Stress management skills can help you to recover faster from stress. They can also increase your ability to handle challenging experiences.

Take Action: Commit to developing a mind and body practice.

Healing Intent

Healing intent is a conscious choice to improve your health or another person's. It includes belief that you can feel better and reach the goal you want. Belief and hope help you prepare to heal.

Developing healing intent includes awareness, intent (also called intention) and reflection.

Awareness

You may frequently hear from friends or family, “How’s your [ill or injured] spouse or loved one?” But you may rarely hear, “How are you?” You may be very aware of how the person you take care of is feeling but less aware of how you are feeling.

Awareness addresses the question “How do I feel?” It helps you learn what your body is telling you and to connect what you think about to who you are.

You can become aware of your body’s subtle signals such as changes in energy level or mood. Bring these thoughts and feelings to your conscious mind. This allows you to change behaviors that don’t make you healthier. You can also learn new skills to change your automatic responses. Physical symptoms are messages from your body, telling you how it is doing and what it needs.

Some caregivers turn to active practices like jogging, yoga or even repeating a single word that makes them feel “centered.” Others use religious prayer, practices and services. You can also just take a few moments to be quiet or to meditate.

Intent

Once you know how you feel, it’s essential to know what you want. If being a caregiver has changed your life from what you planned, this can be challenging. But it is important to create new goals and plans. These may be different, but they can also be meaningful and fulfilling.

On a spiritual level, once you connect with your inner self, you can direct your intention to bring this sense of peace and healing to yourself or others in your life.

In Your Journal

Write about a moment when you felt a particular emotion and how you felt it physically. Were your palms sweating? Was your heart racing or head throbbing? How did you sense your environment through sight, touch, hearing or smell? Was it dark, sunny, stuffy or breezy around you? What did you hear and smell? By expressing your emotional state through your physical experience, you can fully understand it. You can also write about your current state. What emotions are you feeling right now, and how is your body responding?

In Your Journal

Who am I? Part 1—
List 5 qualities of your personality or outlook on life that you think define you. Write just one word, a phrase, or a sentence for each—not a summary of your whole life. Don't think too much! What seems most important now? You can do this exercise every now and then to see how the list changes. Then write about each of those qualities.

Reflection

The story you tell yourself about your life is powerful. It can help you understand the central themes of your life and find meaning in them. When your sense of meaning in life changes, it can lead to feelings of distress. Getting that sense of purpose back is important for feeling healthy in your body and mind.

Meaning and purpose help you deal with emotions such as loss and grief, hope and despair and joy and sadness. They allow you and your loved one to accept the new normal, find a sense of feeling as well as possible within it and control your outlook on life.

Writing in your journal, writing stories or poetry, doing art, working with someone who has been a caregiver or talking to a hospital chaplain might help you consider questions of who you are as a person and a caregiver.

Chaplaincy Services

A hospital chaplain, or a military chaplain if your loved one is a veteran, can help you find meaning and purpose in yourself, your situation, other people and a higher power or God. Some chaplains are also specially trained to support families in health care settings. They can counsel your loved one and help you speak up for them. They provide a safe place to grieve and can help you find ways to cope.

Mindfulness

“It’s not that mindfulness is the ‘answer’ to all of life’s problems. Rather, it is that life’s problems can be seen more clearly through the lens of a clear mind.”

—Jon Kabat-Zinn, founder of the Mindfulness-Based Stress Reduction (MBSR) Program, in “Full Catastrophe Living”

You might think of “mindfulness” as being in a calm, Zen state. And it can be. To be realistic, you can also think of it as being aware of what your mind is doing in each moment, but not letting those thoughts control you. It can even help to remind yourself: “My thoughts do not control me.” Research shows that being mindful helps with depression, post-traumatic stress and chronic pain. Mindfulness can improve the quality of your life.

Some specific skills to cope with stress and anxiety are positive thinking, a learning mindset and living in the moment.

Positive Thinking

Positive thinking helps you see opportunities where you felt anxious before. It can help build up your sense of self-esteem and value. This can keep you from doubting your decisions and being down on yourself during the ups and downs of caregiving. Tips for positive thinking:

- Start each day with the goal of learning something new.
- Give yourself permission to be wrong.
- Start a gratitude practice. Just get a journal and write down three things that you are grateful for each day.

Gratitude

“It is not happiness that makes us grateful. It is gratefulness that makes us happy.”

— **Brother David Steindl-Rast, monk and scholar**

Gratitude turns what we have into enough. Even the smallest things, such as taking a bite of a beautiful strawberry or being welcomed home by the family pet, can make you smile. With practice, gratitude will come easier than grumbling. Some people take a moment each day to write down 3 things they are grateful for. Others like to think about what they are grateful for throughout the day. Do what feels right for you.

Living in the Moment

As you start being aware of your thoughts and feelings, notice how much of your day is spent thinking about the past or the future. Thoughts of the past can keep you from being present and making the most of your day.

You might feel extreme worry and fear when looking too far ahead. Knowing that you are not alone in these feelings can help. Other caregivers also have this experience. When it happens, spend a few moments in a mindfulness practice of your choice, such as meditating or taking a walk. Or connect with other caregivers in an online support group.

Trust Your Inner Guidance

How often do you ignore what your gut is telling you? You may think, “I should call a friend for support,” but decide not to because it’s late. Or think, “I wish I could reschedule those plans,” but do them anyway and regret it later.

Over time, as you become mindful of your thoughts and feelings, you will begin to trust your inner guidance. You may notice that when you follow your instinct, you feel better. On the other hand, when you fall back into old patterns of holding back and doing what you think you should, you feel worse.

Repeating a Calming Word

Silently repeating a specific word that helps you feel “centered” or calm, or repeating a prayer word, is like pressing a pause button for your mind. It is a way to calm down, focus your attention and think more clearly during times of stress or fear. Some people call this practice mantra repetition. It’s as simple as pushing negative or “noisy” thoughts out of your mind by using a word or phrase you connect with. You don’t need to sit quietly or close your eyes. You can do it anywhere and anytime. Use a phrase or word that feels right for your religious or spiritual beliefs.

In Your Journal

Think of a real or imaginary place where you feel safe and at peace. Create that place in your mind and write a detailed description of it using all your senses—what you see in this place but also what you hear, smell, taste and touch. Then close your eyes and imagine you are in this place. See, hear, smell, taste and touch everything you wrote about.

Being mindful of your emotions is an important part of self-care. What you feel affects your ability to make healthy choices.

Set a Self-Care Goal

What is one realistic goal that you can set today to improve your relationship with yourself?



Part 2: CHOOSING HEALTH

“ Self-care is survival. It’s not thinking about yourself more.
It’s thinking more of yourself.
—Gail Sheehy, Caregiver and author

As a caregiver, you spend most of your time thinking of and acting for others. This makes it hard to shift the focus back onto yourself. It can even feel selfish. Yet self-care is critical to *surviving*—making it from day to day. It is even more important to *thriving*—doing well in life. Each time you fly on an airplane, you are told to put on your own oxygen mask before you help others with theirs. When you are your best self, you can share your best with your family.

“Seven of 10 deaths are from preventable chronic diseases.”

—Health Affairs, Nolte and Mckee, 2008

Living a healthy life is one of the main things you can do to feel and be as well as possible. How you eat, move, relax and connect to others are all important to caring for your body, mind and spirit.

If making healthy choices was tough for you before your loved one’s illness or injury, it may seem nearly impossible now when you have so much more to do. But it is possible.

Making Healthy Changes

You probably know what you “should” do. But the problem is actually doing it, whether you want to stop smoking, lose weight or take time for yourself.

Finding a way to enjoy a new healthy habit can help. Try giving yourself a reward for drinking water instead of a sugary soda or finding a buddy to walk with once or twice a week.

“Just for today, do the next right thing and good things happen.”

—Dr. George Ceremuga

Eating, Drinking and Cooking

Water, Water Everywhere

Your body is made up of 60-70 percent water, so you are what you drink. Even if you don’t sweat, your body still loses water every day that must be replaced.

Getting enough water is important for keeping a healthy weight, keeping your muscles working and your skin and kidneys working correctly, and keeping your digestive system regular. Carrying a bottle of water with you everywhere you go may help you remember to drink more often. Also, try to drink a glass of water with every snack and meal instead of another type of beverage. Flavored sweet drinks rarely contribute to better health.

Food is Fuel

The physical burden of caregiving can take a toll on your body. Eating good whole foods can help you stay at your best. A healthful anti-inflammatory diet like the Mediterranean diet, with a focus on vegetables and fruits with few whole grains and an occasional small portion of animal protein will keep your body powered up.

It can help to focus on adding good whole foods rather than depriving yourself of things that don't contribute to better health. An added bonus: Since vegetables and fruits contain mostly water, they will increase your hydration levels.

Consider the following when focusing on food:

- Instead of thinking about what you shouldn't eat, start with what you can **add** to your diet. A low-fat diet with moderate protein, high fiber, whole grains and at least five servings of vegetables and fruits a day is best for your health.
- Try keeping a food journal on your phone or on paper to track what you eat throughout the day. We are often not aware of what and how much we eat. Some mobile apps help with this. They can help motivate you to choose a healthier diet.
- Foods with sugar, corn syrup, artificial sweeteners and unhealthy fats have been linked to heart disease, cancer and diabetes. Ask your doctor how much of these foods you should eat, and read labels to choose healthier foods. Eating a lot of foods with fiber, such as vegetables and whole-grain bread or cereal, can help lower some of the harmful effects of other foods.
- Eating too much and not exercising are the usual causes of obesity, but not the only ones. You might not be eating enough healthy food or not eating during the day. This can starve the body and affect the body's metabolism—your body's ability to burn calories.

Your health care provider or a dietitian may be able to help you design a healthy eating plan and set realistic weight goals to keep you healthy.

Why We Eat

As important as knowing *what* to eat is knowing *why* you eat. For some, food can be loaded with meaning and emotion. Food is family, tradition, comfort and sometimes even used to self-medicate. When you use food or alcohol for emotional reasons, you might overeat or make unhealthy choices. It can be easy to overeat or drink too much alcohol out of stress, anger, depression, anxiety, frustration or loneliness.

In Your Journal

What role does food play in your life?

Are you filling an empty space with food or drink, or using it as a friend?

Build a Positive Relationship with Food

Being healthy is not just about making good food choices. It's about having a positive relationship with food. As with other relationships in your life, it's important for your relationship with food to be a healthy one.

Having a positive relationship with food involves changing some thoughts and behaviors. Here are some ways to do that:

- Become aware of why you are eating.
 - Ask yourself: Am I physically hungry or am I eating to comfort, de-stress, please myself or others or keep from feeling bored or lonely?
 - If you aren't hungry, try to recognize the triggers and temptations that prompt you to eat. (See Mindful Eating.)
 - Be hopeful and trust that you can overcome any challenges that you are facing. You may be going against years of unhealthy behaviors, so be patient with yourself. If you make an unhealthy choice, treat yourself with love and kindness.
- Accept that the food rules of your past may no longer be needed or helpful for you anymore. For example, we are often told as children to finish everything on our plates. Give yourself the OK to no longer be a member of the "clean plate club."
- Understand that you are a unique person with your own needs and challenges. Learn to trust your hunger and listen to your sense of fullness. (See Hungry? Scan for Signs.)
 - Comparing your habits and your body to others around you or in the media may be harmful.
 - What you see in magazines and on TV is not always true. For example, you might see extremely thin or

fit celebrities, but those pictures are often changed by computers to look “better” than reality. If you struggle with having a healthy body image, it may help to limit what you see in magazines, online and on TV.

- Set positive health goals. Big weight loss goals can seem too far away to reach, so you stop trying. Try setting small goals, like a pound each week.
- Be positive, even in how you talk about food. Thinking of your food as a diet or bad adds judgment. Changing your language can help. Instead of seeing sweets as bad, see them as a treat. Allowing yourself a treat from time to time may prevent you from feeling starved and ready to quit.

Hungry? Scan for Hunger Signs

Before you eat, stop and do a hunger scan.

1. Scan your body: Does your body need nutrition? When you need food, your stomach grumbles and feels empty. You may feel dizzy or unable to focus. Are you actually hungry, or are you thirsty and need to drink water?
2. Scan your mind: Did you just see or hear an advertisement that made you crave a certain food?
3. Scan your feelings: Is your hunger coming from emotion? Emotional cravings like loneliness, pain and pleasure-seeking can never be satisfied with food. Understanding if and why you are hungry helps you to react less to the urge to eat.

Mindful Eating

Too often, because of the stress of daily life, food is eaten without even a thought. It's easy to eat what's in front of you without attention to whether you are hungry or when you become full. This is especially true when you are a busy caregiver. Keep these tips in mind:

- Eat slowly. Most meals are eaten in an average of 7 to 11 minutes. Fast eating can lead to overeating. The body doesn't have time to tell your brain that you are full. Putting

In Your Journal

Describe a recent food craving. Were you really hungry? Scan your body for its food needs. What does it feel like right now to be hungry, full or in between?

your fork down between bites will help. If you tend to eat too fast, focus more on enjoying the meal rather than just slowing down.

- Eating includes all the senses—taste, touch, smell, sound and sight. Paying attention to the experience of eating is called eating mindfully. Mindful eating can help with a healthy lifestyle.
- Tune into when you are full. This is another part of mindful eating. Your body’s signals might be small. If something is so delicious that you want to keep eating, try saying, “I can have more later. I don’t have to eat it all now.”

Meal Planning and Mealtime

Planning what you will eat and when can be good for your budget, your stress level and your waistline. Knowing what you’re going to eat or having snacks on hand can also make preparing food less overwhelming. When you come home from work with a meal already planned, cooking won’t feel like one more thing at the end of an already long day.

Prepare Plan B

Be flexible. Have some ingredients in your pantry or freezer so you can make meals if you don’t have time to stop at the store. Know where you can stop for a healthier take-out option if an appointment or workday is long.

Recognize Your Patterns and Hurdles

Are you so hungry that you grab a snack on your way home before mealtime? Try having a piece of fruit, bag of healthy popcorn or handful of nuts on the way home so you aren’t starving when you walk in the door.

Are you too tired to make the healthy meal you planned, so you find yourself ordering pizza several times a week? Maybe having more easy meals like sandwiches or soup on the schedule would help.

It's important to have realistic expectations for yourself in meal planning.

Meal Planning Tips

- Try to shop only once a week. The time you take in planning your meals before you head to the grocery store may result in fewer trips to the grocery store and drive-through. Running into the store to pick up an item can lead to over-buying and more stress.
- Do the kind of cooking you like best. Do you like using the Crock-pot in the morning? Cooking a week's worth of meals on Sunday? Using the freezer? Cooking from what you have in the pantry? Don't fight your cooking style. Cook the way that works for you.
- Keep healthy food on hand. Having your pantry, fridge, freezer and cabinets stocked with healthy foods makes it easier to cook and eat healthy.
- Involve your children so they will be more likely to eat and help with meal prep. If they can see the meal plan, it will cut down on the questions of "What's for dinner?" or "What can I eat?"
- Don't start the plan from scratch. Begin with a two-week or one-month rotation of your favorite recipes and add a new recipe occasionally.
- Make sure your plan is realistic. Plan for occasional take-out.
- Look for meals that include similar ingredients to avoid waste and cut down on prep time.
- Consider starting a small, manageable garden. Use pots on the balcony for easy-to-grow herbs or vegetables. This provides a chance for children to learn and get involved.

Your healthy changes can help your family as well. Children see their parents as their biggest role models. Be what your children should be.

Meals planned, prepared and shared together at home tend to be healthier and more balanced than meals eaten at restaurants or on the go. Meals eaten out are often fried or highly salted. Plus, soda and other sweetened beverages are usually consumed more often when eating out. But there are more benefits to eating together than just health.

In Your Journal

What are some positive family traditions that you would like to go back to or start for your family? Are there any unhealthy traditions that you can change or let go of altogether?

Meals Bring Family Together

In a busy family, it isn't always possible to eat together every day. But when you can, making time for family dinner is good for the mind, body and spirit. Eating meals as a family several times a week can help children get better grades. Also, children who eat regular family meals tend to use less alcohol or illegal drugs.

Family meals help increase feelings of belonging, security and love. This is especially important during times of change, like when you are someone's caregiver. Eating together builds a sense of tradition that can last a lifetime.

Family Traditions and Health

Family traditions can affect your ability to make healthy choices. Becoming a caregiver might mean you need to change or develop some healthy new traditions like taking a walk after a shared meal.

Move More!

Being a caregiver can be very hard on your body. Caregiving can be physical, especially if you have to do a lot of cleaning or laundry, take over new chores or even lift the person you are taking care of. Stress and lack of sleep also affect your body. Exercise is a great way to refresh your body and help your mind work more smoothly.

At least 30 minutes a day of exercise is important.² Ask your doctor for advice on the best type of exercise and how much is right for you. It is important to ask especially if you are trying to lose weight or have certain physical conditions, such as a knee problem or diabetes

Movement in the Moment

Try fitting physical activity into your day, even when you can't go to the gym or an exercise class.

Your doctor or a physical therapist may be able to give you a list of exercises and stretches to do when you have a few minutes to spare. Can you do leg lifts or ankle circles while waiting in a doctor's office? Can you park farther from the store to get a few more steps in? Use the stairs instead of the elevator? These activities add up.

Just going on walks can be good for your health. Walking gives you many of the same health benefits as running. If you can do it with your loved one, family members or friends, then it can be a fun activity to share. Having a regular walking partner or group also helps get you out on your walks and gives you a way to have fun and be social.

Recharge at Night

You might know that 7 to 9 hours of sleep is the recommended amount for adults. But if you are someone's caregiver, it can be hard to get this much sleep. Or you might get up several times each night to help your loved one. Your sleep affects many areas of life, including your health, pain level, memory, weight and mood.

Can You "Catch" a Sleeping Problem?

Sleep can be especially challenging if you sleep with a partner who has sleep problems. These can include not sleeping much at night (insomnia, or being unable to sleep), restless leg syndrome, teeth grinding or clenching, sleep apnea and sleepwalking. Sleep disturbances are common in people who had a traumatic brain injury, or TBI.

Consider these tips for sleeping:

- Have a bedtime routine. In the hour before you go to bed, do quiet activities such as taking a bath or shower, reading a book or listening to music. Avoid exercising, playing video games, working or using your phone.
- Go to bed and wake up at the same time each day—even on weekends.
- Sleep in a dark room without a computer or other electronics, if possible.

- Avoid smoking, chewing tobacco or having foods and drinks with caffeine or a lot of sugar for several hours before you go to sleep.
- Exercise in the morning or early afternoon.

Ask your doctor for help if these tips are not enough. You could have a health condition that is causing your sleep problems. Many things can cause sleep problems, including physical changes, breathing problems, medication, pain and depression. Other causes include using too much alcohol, caffeine or nicotine; being stressed and not getting enough physical activity. You might also have sleep problems if you are a caregiver and worry or think a lot about your loved one. So, talking to your doctor or other health care provider is important. Let them know if you do have any sleep problems. They might be able to help you make the most of the sleep you get, even if it is not as much as before.

Making Time for Joy

Feeling grateful can help you deal with the challenges of being a caregiver, even in difficult times. It can keep you from feeling helpless and hopeless. Also, forgiving yourself, your family, or even God and the person you are taking care of can help you cope with feelings of blame or regret.

Instead of worrying about what you can't control, spend it finding moments of joy. Here are some ways to do this:

- Dream new dreams. You may have had to put past dreams aside, but that doesn't mean you can't come up with new ones. Focus on new goals and dreams that you can work toward.
- Find a creative way to let your emotions out. Doing a puzzle, finding a coloring book and some colored pencils or playing music are great ways to take care of yourself. Other ways to find joy and release emotions are crafting, sewing, drawing, writing in a journal, gardening and photography.
- Look forward to the future. Hope is important, even if the person you are taking care of feels hopeless. Have something to look forward to, such as meeting a friend for coffee, taking a vacation or taking a full day away from caregiving.
- Keep inspiration on hand. Call a friend, visit a place of worship or carry inspiring quotes or pictures with you. All these can help during rough times.

- Do things that make you happy. Join a walking club. Say yes to an invitation to do something with a friend. Spend time with people who give you energy and help you feel rested or hopeful. Go back to a hobby you used to enjoy, like reading, knitting or doing woodworking.
- Laugh and play. Try a game night at home, play fetch with your pet, do a crossword puzzle or listen to a comedian on TV. Laughter and play can lower your stress level, give you more energy and help you connect with other people.
- Don't compare your life to others. Allow your life to be unique.

Balance During a Crisis

In the first phases of caregiving, you may always feel rushed. Family caregivers of severely wounded loved ones may even feel guilty about leaving the room or taking 30 minutes to run to the grocery store.

If your loved one has an emergency, keep taking care of yourself. Let yourself leave the hospital or rehabilitation center for 15 minutes to get some fresh air. You can go home and take a shower and get something to eat without rushing back to the hospital. Taking care of yourself, even when things are very stressful, helps you stay healthy so you can keep taking care of your loved one.

In Your Journal

List 5 things that you're grateful for— people, positive experiences now or in the past, places and things. Then write a few sentences about each one. Describe what you are grateful for in detail, perhaps at a particular moment in time.

In Your Journal

List 3 activities that bring you joy. Write a few sentences about each one. When did you do it recently? Did you get totally involved in it?

If you have difficulty doing these activities as often as you want now, write down 1 or 2 ways you could do each of them more often.

Creating Balance for the Long Term

You need balance in your life to keep from getting depressed. Balance can be more important after you have been a caregiver for a while. Balance is also important to get out of “crisis mode.” This means dealing with one crisis or emergency after another and just waiting for the next one.

Adding personal time to your schedule of work and responsibilities is important for balance. Activities you enjoy can help create the balance you need. Find activities that are fun and rewarding so that you want to do them regularly. This can be anything from walking with friends and playing with your kids to taking your dog for a walk, playing a team sport or going on picnics. Try joining a club or faith-based organization, volunteering in your community or learning a new skill or craft. Living a balanced life can keep you from feeling “burned out.”

Nourish Your Spiritual Self

Focus on love and forgiveness—and start with yourself. If you do not love and forgive yourself, you probably cannot inspire, motivate and encourage anyone else.

A technique called loving-kindness meditation can help you cope with anger and emotional pain. If you struggle with shame, guilt, fear, chronic pain, problems with other people or feeling like you have no support, try a loving-kindness meditation.

Loving-kindness meditation

Loving-kindness meditation involves silently repeating phrases that help you heal. Close your eyes and repeat the following words to yourself:

May I be safe.

May I be happy.

May I be healthy.

May my life unfold with ease.

Then, think about helping the people around you heal by saying:

May you be safe.

May you be happy.

May you be healthy.

May your life unfold with ease.

In Your Journal

List 2 things you often say “yes” to or said “yes” to recently. Then, list 2 things you often say “no” to or said “no” to recently. By each “yes,” write whether you were taking good care of yourself when you said yes, or not. Do the same thing with each “no” answer. Think about whether you say “yes” when you don’t want to, or say “no” to things you would really enjoy. Write 2 ways you might change your answers next time to take good care of yourself, or write 2 reasons you made a choice that helped you.

Time Management

How can you finish your to-do list? The first piece of advice might surprise you. Take a nap, meditate, go for a walk. Taking 20 minutes to practice self-care makes you more productive and able to do everything else. When you feel good in mind, body and spirit, you are a better caregiver.

With this in mind, make your own physical and mental care a top priority. Get help with some of the other things on your list, or just decide not to do them—even if just for now.

Additional tips include

- Do what is most important, and let the rest go. Don't feel like you have to do everything at once. Divide large jobs into smaller parts you can do one at a time. For example, you might not have time to clean the whole kitchen. But having the counter cleaned off makes you feel better. So, clean off the counter, and leave sweeping the floor and other jobs for later.
- Think of a comforting saying, such as "Perfect isn't real," or "Good enough is great." This can put your mind at ease.
- Make things simple. Do errands and go to appointments all at once, if you can. Learn if you can get your loved one's regular appointments, such as blood draws, done close to home. Get prescriptions filled when they are ready so you do not need to rush and make extra trips at the last minute.
- Take a deep breath when your day is not going the way you planned. Getting upset won't help you or the person you take care of.

Breathe

Caregivers live high-stress lives. You can feel anxiety and fear with even everyday activities. For example, you might feel panic when you hear a ringing phone, or checking on the person you care for can make you start thinking "what if?"

Breathing techniques can help you calm down. This is because your breathing causes changes in your nervous system, and these changes help you manage stress better. Research shows that deep-breathing techniques can help service members with post-traumatic stress and help emergency workers do their jobs better.

Try this deep-breathing technique. Put one hand on your chest and another on your stomach. As you breathe in and out, your stomach should rise and fall. If not, you might not be breathing deeply enough to be calm.

Be Aware of "Catching" Behaviors

You might find yourself doing things that the person you take care of does. For example, if you have always been outgoing and social, but you take care of a veteran or law enforcement officer, you might start being extra alert, such as by checking the exits when

you go somewhere. You might do this even when they are not with you.

Senator Elizabeth Dole wrote, “Those caring for individuals suffering from [post-traumatic stress] and TBI become hyperalert for potential triggers. They must be sensitive to what may cause mood swings, anxiety attacks or angry outbursts. In many cases, the caregivers become more sensitive than the veterans themselves. Veterans may only occasionally react to triggers, while caregivers put up their guard with every potential risk factor. This is a real and debilitating phenomenon facing our caregivers—many for the rest of their lives.” The TBI that Senator Dole refers to is traumatic brain injury.

If her description sounds like you, remember that you aren’t alone in this— reach out for help.

It’s also OK to feel joy during the difficult times. You may think, “How can I feel happy when my loved one is in pain?” It’s important to let this guilt go and focus on how you feel. Taking on someone else’s suffering doesn’t help you or them.

Dealing with Unhealthy Behaviors

Let’s face it, we all do things we know are not healthy. What is important is avoiding letting them become habits. Once they do, they are very hard to break and sometimes we need professional help.

Groups can help. You might find a group, though the important thing is to be aware of your behaviors and seek help. If you are a very private person who hesitates to share personal issues, taking that first step to look for help is the most difficult. Getting someone to go with you can make it easier.

In Your Journal

List 3 strengths that you value in yourself. Then list 3 strengths that you would like to have. Write 2 or 3 sentences about each strength. For the ones you already have, when did you use them recently?

For the ones you would like to have, how can you develop them?

Use people you have good relationships with to fix behaviors before they become habits. Break bad habits so they do not become addictions. Find healthy habits to fill the space the bad habit used to take up. For example, if you quit smoking, you might chew sunflower seeds when you crave a cigarette. You might take up walking to relieve stress, instead of smoking.

Practice a Healthy Lifestyle

Healthy behaviors can help you feel better overall. They can also help you avoid getting sick, or get better when you have a health condition. Making good food choices, exercising, coping with stress and avoiding unhealthy behaviors are important for your lifelong good health.¹

Set a Self-Care Goal

What is one healthy behavior you would like to add to your life?



Part 3: YOUR CIRCLE OF SUPPORT

“

Sometimes our light goes out, but is blown again into instant flame by an encounter with another human being.

—Albert Schweitzer, Nobel Peace Prize-winning Philosopher and Physician (1875-1965)

You are a social being. Your relationships with others and your role within your community provide a sense of belonging, care and support. Positive relationships can also be good for your health and the person you take care of. Love and support reduce stress, boost your immune system, help you enjoy and appreciate life more and help prevent loneliness and depression.

Positive relationships give you strength and energy. Counselors call these healing relationships. They usually include trust, honesty and compassion. If a relationship makes you feel exhausted, think about how to protect yourself. You might need to try some ways to take care of yourself and make the relationship better. Then this can be a healing relationship for you too.

Your Relationship with Your Loved One

Your relationship with the person you take care of is a large part of your life. It might even seem like everything

In Your Journal

Relationships,

Part 1—Think about a positive relationship in your life. Write about it. Describe what is positive about this relationship and how it nurtures you.

else depends on it. If possible, this should be a healing relationship. This involves acknowledging how the relationship has changed; moving beyond the past; shifting roles and responsibilities; reconnecting in love; looking forward to a different, joyful future and keeping your sense of self.

Acknowledge the Past

Whether you are taking care of your spouse, child, friend or neighbor, you had a relationship in the past. This can make it hard not to think too much about what things were like before they got sick or hurt.

To heal yourself, it is important to acknowledge that what things were like *before* may no longer apply. But the *after* can be a happy one.

Thinking of what life was before the injury or illness might make you sad. Grief does not only happen when someone dies. You might grieve as you struggle with and accept the changes in your life. You might grieve for memories, dreams or simply that the person you used to know is not the same person now. You might even grieve for your own old life and who you used to be.

Grieving can help you understand who you are now, and what your relationship is with the person you care for. Going through the grieving process might even help you heal.

“The five typical stages of grief are denial, anger, bargaining, depression and acceptance. However, this is not a linear process. Not everyone experiences all five of these feelings and they can occur in any order, in addition to other feelings. What’s important is to acknowledge the role of grief in healing, know that it is normal and that there are resources to help. Community resource centers, your health care providers and your chaplain can point you in the right direction.”

—David Kessler and Elisabeth Kubler-Ross

Your Changing Roles and Relationships

When you take care of your adult child, your parent or a partner who was an independent adult, the roles you play in your family and their lives change. Roles are the things you do and how you do them with one person in charge some or all of the time, one person acting like the strong protector or one person being the nurturing one. It can be very confusing and stressful when these roles change. You might have complicated emotions. Jobs and responsibilities change, and you and your loved one might not be sure what to do or who is responsible.

The person you take care of might be anxious, resentful or angry if they could take care of themselves before, but now cannot. These are natural reactions that you and your loved one can work through. You might need a professional helper such as a counselor, or personal help such as from friends or family. Eventually, with help, patience and work, these intense emotions can lead you and the person you care for to feel like yourselves again. You might not be the old self, but you can be a new person who has a sense of peace.

Talk with the person you are taking care of about how roles can or have changed. Talking about your new relationship can relieve your stress. It can also help the person you are taking care of. Being honest and understanding that you are still learning can help your relationship with that person. You might make mistakes along the way, and that's OK.

You might still need help even if you do everything "right." Ask people for help. You can ask doctors and other health care providers, counselors and spiritual leaders. You can also ask family members, friends and people in support groups or community groups, such as a neighborhood group or book club.

In Your Journal

Who am I? Part 2—List 5 roles you think define you. For example, you might be a mom, sister, daughter or wife. Write just a one-word phrase or sentence for each one. They do not need to be in order of importance, and you do not need to list every role in your life. Just notice which ones you write down. Which ones seem most important right now? Then write a couple of sentences about how each one is part of who you are. You can write down 5 roles every now and then to see how the list changes.

In Your Journal

Write a letter to the person you are taking care of. What is on your mind and in your heart that is hard to say in real life? Writing it down might help you actually tell the person you care for about it. Or writing might help you understand your thoughts and feelings. This can help you feel better around your loved one and be a better caregiver.

Redefining Intimacy

“Intimacy” is more than having sex. It is about being emotionally close to your loved one. When you are intimate, you can relax and let them know how you really feel. Intimacy is also about being able to accept and acknowledge their feelings.

After taking on the role of caregiver, you might need to rebuild intimacy with the person you take care of. The goal is for both of you to feel the other’s love and respect. Your loved one’s injury or illness might have physical, emotional or mental health effects that change how intimate you are right now. For example, changes in the interests, personality, mood, patience, self-control, self-worth or self-image may change how they relate to you and other people.

Consider these tips to develop intimacy:

- After an argument, talk about the deeper feelings behind the anger, hurt or anxiety.
- Improve your communication. (See page 46).
- Be positive about what you have. Tell the person what you love or like about them, even if they already know.
- Take some extra time to get to know the person you are taking care of, as if they are a new person to you.
- Talk to your doctor or another health care provider if you are concerned about your loved one’s injury affecting your relationship.
- Ask your doctor or other health care provider what is realistic. What should you expect with your loved one? You can also ask people who support you, such as a counselor, friend, family member or another caregiver.

- Learn how to express love and affection in ways other than sex. This is especially important if having sex is difficult right now.
- Think about taking a class on relationships or talking to a counselor.

Talk to the people who support you for other ideas. Your doctor, a medical social worker or your friends and family might have helpful tips or be able to tell you where to find help.

The Healing Power of Touch

Whether it's holding hands or resting your head on someone's shoulder, we have all experienced the healing power of touch. The healing practices called reiki, healing touch and therapeutic touch make the most of this power.

Short-Term Counseling

You might think that seeing a counselor goes on for a long time. If so, you might think, "I don't need that," or "My partner would never agree to go."

But if you have a specific problem, short-term counseling might help. Talking to a counselor for a few weeks or months, or going to a weekend workshop, might help you find answers. And going for a short time might be easier.

These techniques are similar to massage, but lighter. They are not sexual. Your reiki or touch therapist lightly puts their hands on you to help with healing. The benefits include

- Reduced stress
- Release of pain or discomfort
- Emotional calming
- Deep relaxation
- Greater feeling of wellness

Some hospitals and clinics have volunteers or nurses who do these techniques. Ask your doctor or other health care provider about them.

In Your Journal

List 1 goal for today, 1 for this week, 1 for this month and 1 for this year. Then write a few sentences or a paragraph about each one. Write about the support you might need to reach those goals, ways to reach them, potential barriers and how to overcome the barriers.

Goals for Success

Define your own success. Don't let others define success for you. Paying attention to your goals, and celebrating your achievements, might help you as a caregiver. It is powerful to say, "We reached our goal today!" Goals might be small or step by step, but they give you pride and motivation for the next step.

Your medical team may provide advice about what is practical to make sure your expectations are realistic. A caregiver support group may also have ideas on what are appropriate milestones to work toward.

When Your Loved One Will Not Get Better

Some symptoms, conditions and circumstances lessen with time and treatment. Others do not. You might be taking care of someone whose condition will get worse, not better. Learning to cope with reality is helpful in this case. When **recovery** isn't possible, shift your focus to **discovery**. You and your loved one may discover steps, self-care strategies and behaviors that reduce daily challenges and improve the way your life feels to you.

As a caregiver, you learn to deal with someone else's moods and feelings of others. Taking good care of yourself is important because it can be easier to deal with other people's emotions when you are healthy and taking good care of yourself. Once you feel strong and healthy, you have a better chance of having a healthy relationship.

Coping with Anger

You might have to cope with two angry people if you are a caregiver. One might be you, and the other might be the person you are taking care of. Some people, such as armed services members and law enforcement or health care workers, might have learned some coping skills such as self-regulating or self-relaxation skills and communication and problem-solving skills. Those same skills can help you cope, too.

When dealing with your loved one's anger, see if these strategies help:

- When a discussion starts to become a fight, stop talking. Agree to come back to the topic when you are both calm. Make an appointment to talk. Say, "I'm getting upset. Can we talk about this in two hours when we have calmed down?"
- If your loved one starts getting louder, speak more quietly and slowly than usual. This allows you to hear and understand them better.
- Take 3 deep breaths. This will help you to calm down. It forces the other person to calm down because people copy each other's breathing unconsciously.
- Use non-threatening body language. Uncross your arms if you crossed them across your chest. Stand or sit at an angle so you are not directly confronting the other person.

You need outside help sometimes. That's when it's time to contact your support people. Also, professional counselors and many health care workers are well trained to help you deal with your anger and the anger of your loved one.

Keep Your Sense of Who You Are

Somewhere on the journey of caring for their loved ones, many caregivers find that they have lost themselves. *"Three years ago, I was someone else. Now I don't even know who I am."* When so much of your time is focused on your loved one, it can be easy to forget who you are and what you enjoy.

When you are a caregiver, your own needs, wants and thoughts don't disappear, but they can get lost. Being a caregiver is a role that you didn't plan for, have little or no training in and that seems to change everything. But you are still a person, not just a caregiver. It's important to be aware of yourself, your interests and your needs.

In Your Journal

Your thoughts, emotions and behaviors are all related. Write down 2 examples of thoughts, 2 of emotions and 2 of your behaviors in the past month. What effect did they have on each other? How do you think your changes in each category affect the other two? For example, if your thoughts changed, how did that affect your feelings and emotions?

Keeping a journal is one way to get back to your sense of self by exploring your thoughts and feelings.

Explore Your Joy

Keep from feeling lost by exploring your own interests when you have a moment. If you liked crafting before you became a caregiver, can you pick up a simple crochet or knitting project while in the doctor's waiting room? If you liked reading fiction, such as novels, before you were a caregiver, try reading again.

You may find that taking a moment each day to think about what makes you happy helps you remember who you really are. You might feel guilty if you think, "How can I feel happy when my loved one is in pain?" But it's OK to still feel happy during this time. Your happiness may also help your loved one feel better. Even wearing a top in your favorite color or taking time for a massage can brighten your spirits.

Moods and attitudes spread from person to person easily. So, it's important to acknowledge how you feel versus how the person you care for is feeling.

How Your Loved One's Feelings Affect You

Other people's moods spread as easily as the flu. You might hear that it is important to share someone else's feelings, but that is not always healthy. Sharing another person's pain or bad moods can leave you feeling tired. As a caregiver, it's important for you to be at your best, and that includes being aware of your mood and how other people's moods affect yours.

Here are some ways to protect yourself from someone else's negative feelings³:

- Imagine a protective barrier around yourself. It could be a light or a warrior's shield that blocks negative emotions.
- Try to react positively instead of becoming negative when others are.
- Take a moment to pause, breathe or walk away if a negative mood starts to affect you.
- Manage your stress level. This helps you react less and get less stressed when other people are negative.
- Spend time with a positive person to balance things out. Let their happiness spread to you and give you energy.
- Find a good place to let out your thoughts and feelings, or "vent."

Venting

Letting your thoughts and emotions out is sometimes helpful and appropriate. It can help you release tension instead of keeping it inside. However, some ways and places to vent are more helpful than others. See if any of these work for you.

- Get out a piece of paper and write for 10 minutes without stopping. You can even pretend that you are talking with a person.
- When venting to a person, be sure to do so with someone you trust, are on good terms with and are not upset with. Choose someone who is supportive and helpful, but not someone who encourages you to have negative thoughts and feelings. Tell them you just need to vent and ask them to listen.
- Exercise. Physical activity can release certain chemicals in the brain. These chemicals relieve stress and tension. You can go for a walk or run, go to the gym or do an exercise video at home. Consider yoga, qi gong and tai chi because these can be calming.
- Breathe. It is impossible to be stressed and relaxed at the same time, so use breathing techniques to calm down. Taking 3 deep breaths in a row is one example of a breathing technique.

Setting Boundaries

A boundary is how much you let other people affect your time, energy, feelings and personal space. It is like an invisible fence you build around yourself, and it helps you control how much other people affect you.

Having clear boundaries is an important part of taking care of yourself. If you do not have that “fence” to protect you, other people’s comments, moods and opinions can leave you feeling bruised and battered. On the other hand, staying closed up can leave you feeling alone and locked up inside yourself. Setting your boundaries where you need them is a process that happens with time. Counselors can help you set boundaries at your own pace. They can help you protect your feelings, stop needing to please other people all the time and say “No” when you really do not want to do something.

Learning to establish healthy boundaries can help you in all your relationships, including with the person you care for and your family, friends, neighbors or coworkers.

Widen Your Circle of Support

Developing a healing relationship with the person you take care of is important, but don’t ignore the rest of the world. What is important to you may change with time, but it is important to build and maintain relationships that will support you over the years to come.

It is easy to feel alone with all your new responsibilities. Instead, think about bringing people who support you together. You can imagine a circle of people around you, holding hands around you and your loved one. Then, consider making that circle wider by adding new people.

Look at your community and think about who might join your circle. Consider family, friends, co-workers, neighbors and people from community groups such as a volunteer groups or places of worship.

Who is in the Circle?

It might help to create a written directory of your circle of support, including contact information and notes. You can put this on paper, on your phone or on the computer. Looking at it can make you feel better, and you can call these people for support if you need it. It can also help people who want to contact your other friends and family so they can support you.

Create a team of caregivers who can work together. Here are some tips:

- Develop a shared family calendar. You can use an app on your phone, an online calendar or a paper calendar.
- Introduce people in your circle to the person you are caring for. That way, they know them when you need someone to help instead of you.
- Recognize who can give help and who cannot. Set limits on or let go of those who are not helpful. Some people might say they want to help, but their “help” causes problems or they bother you with constant questions. Those people do not need to stay in your circle, at least not to help.

Ask for Help in Your Own Way

Being independent is important, but being too independent can lead to burnout. Asking for help is a sign of strength, not weakness. Being a super hero can be isolating and lead to exhaustion.

There are things that people can do for you to lighten the load, such as getting the oil changed in your vehicle, doing laundry or helping you with errands. When you see how wide your circle of support really is, it is easier to give people different jobs to do. That means no one is overwhelmed.

The following tips might also help:

- When asking for help from others, use “I” statements. Rather than saying, “You never help!” try saying, “I feel burned out. I need help with the chores.” (See Communication is Key.)
- Don’t let small things become overwhelming. You might find yourself doing things that you have never done before now that you are a caregiver. Jobs like taking out the trash, maintaining the car, sorting the

In Your Journal

Think of one thing you need right now. Write out how you can tell a specific person about that need. Then write out what you think that person’s response will be.

mail, mowing the lawn and changing the light bulbs can all add up. Consider asking someone in your circle to help. Although you *can* do these things, *not* doing them lets you spend more time doing what you value, such as spending time with family and taking care of yourself.

- Arrange regular breaks for yourself. This helps avoid “caregiver burnout.” A break might be meeting a friend, taking a walk or taking half a day, a weekend or several days off while someone else takes care of your loved one.
- Say yes when people offer to do things for you. Give them the gift of accepting their help, even if you think you should do the job yourself.
- Ask your doctor about respite care programs. These are programs where someone else takes care of your loved one while you take a break.

When to Ask for Help

How do you take care of someone while keeping your own life together? How do you keep your spirits up for a long time without becoming emotionally, physically and spiritually exhausted? At times, you need to ask other people for help. Here are some signs it’s time to do this:

- You begin feeling a lot of anger, fear, resentment, guilt, helplessness and grief. Talking about these difficult feelings can help you to deal with them.
- You show signs of depression or anxiety. These can include crying spells, loss of sleep and appetite, losing or gaining weight, irritability, restlessness, difficulty concentrating and making decisions, feeling sad much of the time, feeling anxious or empty and thinking about suicide.
- You show signs of burnout. These can include feeling tired even after resting, increased feelings of resentment, new health problems or problems getting worse, difficulty concentrating, neglecting your responsibilities and withdrawing from activities or people.
- You have difficulty maintaining balance in your life. You feel overwhelmed by caregiving and no longer do other activities that are important to you.
- You have difficulty sleeping.
- It seems difficult to take care of your own health care needs. For example, you put off regular checkups or visits to the dentist.

- You use alcohol and drugs to escape.
- You think about dying or hurting yourself.

Get Help If You Are Dealing with Abuse

If you often feel frightened or threatened, don't feel like you have to stick it out. Learn the signs of abuse and get help.

Caregiver Support

If you are like most family caregivers, you are not trained for the challenges you are facing now. You probably never thought you would be in this situation. But there are places you can turn to for support, including

- Family members or friends who will listen without judging you.
- Your church, temple or other place of worship.
- Caregiver support groups at a local hospital or online.
- A therapist, social worker or counselor.
- National caregiver organizations.
- Organizations for your loved one's illness or disability. For example, if they have Alzheimer disease, an organization for this illness probably has help and information for caregivers.

"The capacity to care is the thing that gives life its deepest significance and meaning."

—Pablo Casals

In order for you to maintain your capacity to care, it is essential for you to receive the support you need. If you do not take care of your own needs, you may begin to feel

In Your Journal

Think of a recent conversation with your loved one. First, write out the words that were said, as much as you remember them. Then describe what was communicated by facial expressions, body language, posture and other non-verbal messages. What did you both “say” this way? Did your words and non-verbal messages match? Or were they different? Which was the true message?

distracted, burned out or overwhelmed by the daily routine of caregiving. Learning to manage your stress and responsibilities as a caregiver is the first step to taking care of you.

Communication is Key

Being aware of your communication style can lead to fewer misunderstandings among family members, health care providers, employers, friends and the person you take care of. Also, honest and open communication is important to the healing relationships you are building. Although we all communicate daily, we rarely see that *what we say* and *how we say* it affects what people hear.

You probably already know that most communication has little to do with what you say. Your posture, breathing and even your muscle tightness all send a message—as does the tone, speed and volume of your voice.

Focus on Listening

When you listen, focus on both verbal and nonverbal messages. Here are some tips for active listening:

- Maintain appropriate eye contact for your culture.
- Paraphrase to confirm you understand what the other person is saying. Don't jump to conclusions.
- Ask questions to clarify.
- Try not to think about what you are going to say next; it's more important to be attentive, even if it means there is a thoughtful pause before you talk.
- Affirm their comments and offer encouragement by nodding, saying yes or saying things such as “tell me more” or “I understand.”

- Listen to disclaimers (maybe, but, mostly, usually, probably), as they are typically followed by new information.
- Give your care recipient time to form a response; try not to interrupt.
- Avoid distractions such as TV or pets so you don't have to compete for attention.

Especially in high-stress situations, the more you can encourage the other person to talk, the more you can understand what they are trying to share with you. Encourage conversation to continue through active listening.

Speaking Your Mind Mindfully

Honest communication is vital. It can be important to talk about feelings or fears that may seem unthinkable. Keeping them inside can lead to angry outbursts, withdrawal or resentment and guilt. These things can cause problems in your relationship.

Here are some tips for open communication:

- Relax and breathe.
- Go into difficult conversations with a goal. Example goals include: Be honest and direct, express feelings and thoughts and find things in common. Do you need to ask for help? Address the way they have been treating you or the person you provide care for. Raise a concern.
- Treat the person with dignity, respect and courtesy.
- When helping, do not insist or be offended if your offer is not accepted.
- Ask if it's a good time to talk. This can start the conversation off better.
- Make appointments to talk.

In Your Journal

Think of two recent conversations—one that went well and one that didn't. In each one, explore the positive and negative aspects. What led to the outcome?

In Your Journal

Think about 2 group experiences—one that helped you and one that didn't. Write a few sentences about each one. Why was it helpful, or not? Was there a specific incident that was especially helpful in the positive group? Did something specific happen in the group that did not help you?

- Don't be afraid to say, "I don't know," or "Let me check." You can be clear about how much you can respond to a person's needs or requests.
- Be mindful that symptoms of traumatic brain injury, or TBI, and post-traumatic stress may go up and down. Many things influence these symptoms. Your loved one might have times of ease and comfort as well as more challenging times.
- Support, patience and understanding go a long way. Be generous with these.⁴

Focus on "I" Communication

Use sentences that start with "I," instead of "you." These types of sentences are called "I" messages.

"I" messages:

- Help you take charge of your own thoughts and feelings.
- Make you explore what you really think and feel.
- Increase your chances of being heard.
- Help keep conversations positive.

"You" messages may make a person feel uncomfortable and attacked. They may make a person stop listening, withdraw or fight back. None of those answer your question or solve your concern.

Examples of "I" and "you" messages:

"I" message: I can take John to his appointment on Wednesday. Can we talk about Friday? I need help then.

"You" message: You need to take John to his appointment on Friday since you can't take him on Wednesday.

Do you notice the difference? How do you think the person you are talking to might respond to each type of message?

Good communication skills build strong relationships.

Creating Healing Groups

Whether it's a school, workplace, church or community organization, you are part of many groups that impact your ability to care for yourself and others. Seeking out and being involved in groups that are healthy and have positive healing qualities supports your health and wellbeing.

Healing groups:

- Promote open and honest communication.
- Create a climate of trust and personal responsibility.
- Inspire a sense of belonging.
- Allow you to make decisions that affect you in a positive way.
- Focus on learning rather than blame.

Support Groups

The best emotional and practical support and advice often comes from others who have experienced something similar. That's why caregiver support groups provide such great help. They can speak to your fears, know what you need even before you do, help you find resources and begin to see hope, joy and potential in the new path.

You might also find comfort in giving advice that helps another person or family in a similar situation. Being able to help someone else can give your caregiving

In Your Journal

Relationships, Part 2—

Think about a negative relationship that drains you. Write a few sentences about the reasons it makes you feel tired or discouraged.

Next, answer these questions. Are these things that

- 1. You can accept?*
 - 2. You can work on?*
 - 3. Mean you should let this person or relationship go from your life?*
-

experiences a sense of meaning and purpose. It also reminds you that you are not alone in this journey.

You can find support online, in person and even on Pinterest. Visit drwaynejonas.com/caregiver for a list of resources.

Some Advice isn't Helpful

Family and friends want to provide comfort, but most people don't know what to say. During stressful times, you may be more vulnerable and sensitive to comments. Comments made with good intentions can hurt, minimize feelings or underestimate the problem. Whether it's "I know how you feel," or "Everything happens for a reason," all caregivers have heard phrases that irritate or upset them.

Dealing with insensitive people or comments in a productive way is part of caring for yourself because it helps you manage your stress.

Here are 3 ways to handle insensitive comments:

- Remind yourself that people often mean well, but make such comments from ignorance and fear. When people can't relate, they may say things they have heard before. Or they might make comments that make your situation or feelings seem less serious.
- Tell them where to find information on your loved one's condition so they can learn about it. Tell them in a kind way why their comments hurt or bother you.
- Keep taking good care of yourself. When you feel well, rested and calm, it's easier to handle insensitive comments.

A Changing Process

Becoming a caregiver means experiencing surprise and shock. It is not a life you expected. Many days it can feel like there is no plan or roadmap. Rather, it's a series of changes that can be painful and scary. You and your family would rather have a stable, predictable life again, but the healing process changes constantly. This can make you feel uncertain almost all the time.

You can compare caregiving to riding a roller coaster. One doctor's appointment may have you plunging into sadness. Two days later, better news may boost you to a false

high. Your loved one may go to the hospital for a simple procedure and be back in the hospital for weeks. You may become depressed as your life is turned upside down once again.

Set a Self-Care Goal

What is one realistic goal that you can set today to improve your social connections?



Part 4: **SURROUND YOURSELF WITH CARE**

“

Each day is different, and you get up, put one foot in front of the other, and go—and love; just love.

—First Lady Nancy Reagan

When your focus is on caring for your loved one, the places where you live, care, work and play may fade into the background. But what is around you affects your ability to find peace, rest and strength. Your home and workplace, as well as the time spent at the doctor, in the car, outside and in the community can add or subtract from your stress levels.

Have you ever been somewhere that just makes you feel good? You might consider this a space where you can heal and feel better. These “healing spaces” minimize stress. They let you bring your family and friends together and feel your best. Many things are outside of your control, but your physical space is one thing you can control. You can try to create spaces at work or at home that add to your joy instead of your stress.

Making Your Home a Healing Place

When you walk in the door after a stressful day at work or a medical appointment with your loved one, it can help if home is a place of peace. Your home’s colors, organization, smell and decorations all affect you. Here are some tips to make your home a place of healing and peace:

- Surround yourself with nature. This can include
 - Natural light

In Your Journal

Write down the places you spend most of your time. In your car? At home, work or school? Compare those places to the place that makes you feel good. This is the “healing space” you thought about earlier. What are some specific things about your healing place that make you feel better?

Now, write a few notes about each of the places you spend most of your time. What can you change in those places to make them more nurturing, safe and peaceful? For example, if you spend a lot of time in the car, you might decide to add a soft seat cover or listen to podcasts while you drive. If you spend a lot of time at work, adding a green plant and some photos to your work area might make the space more pleasant.

- A view of nature through the window, or art that shows nature scenes
- Nature sounds from an open window or recording
- Flowers
- Decorate with things that mean a lot to you. These can include
 - Photographs of family and friends
 - Religious symbols
 - Objects that reflect your interests. For example, if you love traveling, a globe might make you feel happy.
 - Furniture arranged to encourage people to enjoy being together. For example, a coffee table you and your family can enjoy snacks and board games on.
- Simplify your life. This can include
 - Getting rid of clutter. This means things you no longer use, don't plan to use, don't like or don't need. It also means garbage, such as wrappers, papers, boxes and packages.
 - Clean the space. Dust, vacuum, wash windows, clean furniture and wash soft items such as throw rugs and cushions. This is healthier for you and your family and makes you feel better.
 - Create quiet spaces where you can sit, think and rest. For example, you might put one chair in a quiet area.

Each change, like becoming a caregiver, is a chance to think about your own life. The need to be calm and have times of rest can encourage you to throw away old items and make your schedule simpler. Having an orderly, peaceful home helps you feel calmer.

You might want to ask for help doing things in your home. You can ask a friend, family member or someone

from one of your community groups, such as your church, temple or book club. The people in your circle of support might be able to help you make small changes in your home that make a big difference in how you feel.

As Life Changes, So Does Your Home

When your loved one returns home from a hospital stay, they might have physical challenges that require changes to your home. Their health care team can help you get your home ready. For example, you might need a hospital bed, a walker or wheelchair, a ramp instead of stairs or a shower stool in the bathroom. You might also need to remove items that are easy to trip on, such as clutter, area rugs and cords.

You might also want to replace some items because they bring up emotions. You and your loved one are both going through emotional changes that can affect how your home feels to you. Items that once brought you joy may now make you sad or angry. Recognize those items and consider replacing them with things that make you feel good. This will be different for each person.

A Restful Bedroom

Having a dark, clutter-free bedroom at night is a great way to sleep better. You can buy inexpensive blackout shades or curtains if streetlights keep your room too bright. Find comfortable bedding that feels good against your skin.

Colors Matter

Choose colors to suit your mood. Reds, oranges and yellows can stimulate you and give you energy. Blue, green and purple can make you feel rested and at peace. Think about how you want to feel in each room of your home.

Experiment with Scents

Your sense of smell has a powerful connection to your brain. What you smell can give you a sense of feeling well, improve your mood, relieve stress and clear your mind. Experiment with different scents in your home, whether from candles, natural herbs or air fresheners. Only burn candles when someone is in the same room with them, and look for non-toxic or natural air fresheners. When you choose a scent, ask yourself what makes you and your loved one enter a room and breathe more deeply? That scent could be a good choice for you.

In Your Journal

Describe your home before and after your loved one required care, identifying the changes you made. Determine whether those changes are truly serving you both and explore what further adjustments you might make to render the home environment more nurturing, safe and peaceful.

Talk to your care provider about using aromatherapy. If you or someone in your home is pregnant or has asthma or a chronic lung disease, your doctor might want you to avoid certain essential oils. You should also check with your doctor about air fresheners and sprays to make sure they are OK.

Control the Sounds You Hear

Sounds can be stressful or soothing. Experiment with playing music to set a mood or block out disturbing noises like street traffic. Carpets, curtains and soft fabrics absorb sound, so you might want to add more of these if your home has a lot of noise from outside. Hard surfaces, such as hard floors and furniture, make sounds seem louder. This might be fine if your home is in a quiet area or you do not mind noise.

Light Your Day and Night

Warm, natural light is soothing. At night or when you don't have much natural light, try light bulbs that are marked "neutral" or "warm." Some LED light bulbs and most fluorescent bulbs give a harsh, bright light that is not relaxing.

Using bulbs that give a warmer, less bright light can make you feel warm and cozy. Use a dimmer switch for overhead lights, especially over a table where you eat. You can also use lamps on side tables or have some lamps attached to the wall.

Get Help to Get Rid of Clutter

Taking care of a loved one can prevent you from keeping your home clean and clutter-free. Not being able to clean regularly can allow clutter to build up. This might make you anxious. Clutter around the house can also trip

people who have difficulty walking or keeping their balance, so it is a good idea to get rid of it for their safety. You might feel ashamed of not being able to clean or stay organized, but you are a busy caregiver. Talk to your doctor, nurse, social worker, friend or family member about getting help to clean and get rid of clutter.

Making Your Car Comfortable

If you feel like you live in your car, make it a positive place. Small changes like keeping the inside of your car clean and throwing trash away every night might make the traffic jam less stressful. Here are a few more ideas for making car rides more pleasant:

- Consider adding an air freshener or car diffuser. Smelling lavender or vanilla can relax you, while orange or eucalyptus can give you energy.
- Turn “wasted” car time into a time to learn or relax. Play an interesting podcast or listen to an inspiring radio show.
- Take a few minutes to repeat a positive or motivating thought. This helps you focus your attention on something positive, interrupting your stress response. Your thought can be a religious or spiritual prayer or an affirmation. Affirmations are positive thoughts you can repeat every day, such as, “I’m doing the very best I can,” or “We are creating a new life together.” Affirmations help you change your mindset and stay positive during challenging times, even when things seem impossible.
- Play music to set your mood.

Your Work

You might be a full-time caregiver or go back to work after taking time off to care for your loved one. You might be part time, or be retired when you take care of someone. But if you work at least part time, you have unique challenges. You play two roles in life: worker and caregiver.

Changing your workplace to be a positive place might take more than creating a pleasant, clutter-free area. Life as a caregiver can be unpredictable. You might have emergencies or other demands on your time, and these might take you away from the office more than your boss and coworkers would like. Even if they try to be sensitive, their sensitivity may run out over time.

In Your Journal

List 3 changes in your work situation since you started being a caregiver. Then write a few sentences about how they affected you and how you handled them.

You might wonder how to manage the demands of work with the growing needs at home.⁵ A support group can help you answer the following questions:

- How can I talk about my caregiver experiences at work without seeming weak and vulnerable?
- How can I talk about the challenges of being a caregiver when I don't want them to think my productivity and performance will suffer?
- How much of what I'm going through should I tell people at work?
- How can I be a good worker and focus on my job while fulfilling my duties as a caregiver?
- How can I be a good caregiver and keep my business running, if I work for myself or own a company?

Communicating with Your Boss

You might need to ask for more time off, a more flexible schedule or different work responsibilities when you are a caregiver. Asking for these things can be challenging. But you might be able to use some of the communication skills you have gained in communicating with the person you take care of.

Here are some tips for communicating in the workplace:

- Think about the message you want your boss to get. Write down what you want them to know before you talk, so you feel ready for the conversation.
- Be clear about what you want or need from your boss. Be pleasant, but firm. Avoid sounding demanding, angry or upset.
- Practice what you want to say. You can do this alone or in front of a mirror if you want. Or you can practice with someone in your circle of support.
- Use "I" statements such as, "I need to leave at 5 o'clock to pick my child up," instead of "you" statements such as, "You always make me stay late."

- Communicate regularly with your boss to develop and maintain a comfortable relationship.

Work-Related Stress

Being a caregiver might make you set work-related goals and dreams aside. You might also miss the sense of identity, purpose or self-esteem you got from work. Now, you might feel a loss of meaning. Stress can build if you have to change or leave a job, face a loss of income or have a tighter budget.

But the changes are not all bad. Recognize the new skills you have learned as a caregiver. The challenges you have overcome as a caregiver might make you more flexible at work. Little things might bother you less, and you might feel stronger or better able to set priorities. You might be proud of all you can get done during the day.

If you need to change jobs, give yourself credit for all the new skills you have gained as a caregiver and mention them in your job search. For example, if you have learned better communication skills, you can add “excellent communication skills” to your resume. If you have learned to read complicated records or use new apps or software, you might share that in an interview.

Connecting with Nature

When dealing with the stresses of a busy life, it’s easy to tune out the natural world of plants and animals around you. But spending time in nature can be good for your mind, body and spirit. Take time to watch a sunset or find a green space to eat lunch on a workday. Working in a garden can help you connect to the earth. If gardening is not an option for you, try walking in a local park or

In Your Journal

What new skills have you learned as a caregiver that you can bring into your current workplace or a new career?

In Your Journal

Who am I? Part 3— *List 5 important experiences in your life that you think define you. Write just one word, a phrase, or a sentence for each one. They do not have to be in order, and you do not need to write a summary of your whole life. Don't over think. What is important now? You can even do this exercise again from time to time to see how the list changes. Then write a few more sentences about these experiences, exploring the effect they had on who you are.*

green space. Listen to the sounds of a fountain, watch birds in the trees or visit some other natural setting.

Whether you live in the city, country or somewhere in between, be aware of the life around you. You can do this through artwork that shows nature scenes, a view of green grass and sky through a window or an online video of waves crashing along the shore.

In your own life, find places that involve all of your senses and help you feel peaceful, safe and connected to other people. You can also keep track of how changes in nature affect you, your mood, your weight and your energy level.

Being aware of these things can help you to make the best decisions. You can even try to change the way you think about a situation. For example, if you find yourself becoming depressed or sad during rainy weekends, try to see the beauty in the raindrops or make something you love a rainy-day-only activity. You might even begin to look forward to rainy days!

Although bad weather can make you feel down, nature can also give you positive images for meditation. Just as winter turns to spring, your ability to heal yourself can come to life and grow. The way nature and your body both recover is an important image to hold onto throughout your journey.

Mindful Meditation in Nature

Put on some comfortable shoes and go for a walk. Slow down from your normal pace and focus on each of your senses. Notice the colors of nature, hear how each bird's song or city noise is different, feel the air on your skin and smell a flower or the other scents around you. As your mind begins to wander, gently but firmly return to experiencing the moment so that you can make the most of this healing time. As you start to look outside yourself and take in more and more, you become more aware of the life around you. By being aware, you might appreciate your surroundings more. You might feel more like a part of things than an outsider looking in.

In Your Community

Whether it's a school, workplace, place of worship or community organization, you are part of many groups that affect your life. Being involved in groups that are healthy and have healing qualities supports your health and general feeling of wellness.

What makes a healthy group?

A healthy group allows you to participate in making decisions that affect you. It promotes open and honest communication, creates a feeling of trust and personal responsibility and makes you feel that you belong.

Take part in groups that are specific to you or your loved one's experience. Some of these include

- Veterans' communities. Be aware that groups for Vietnam-era veterans might have a different culture than groups of veterans who served in Iraq and Afghanistan.
- Groups of people with your condition. There are groups for people with traumatic brain injuries, post-traumatic stress, heart failure and more.
- Caregiver groups. You can find groups for spouses and partners, parents, friends and other caregivers of people with your loved one's condition. Connecting with people who share your experience can provide practical tips and a lot of emotional support.

In Your Journal

Describe your current medical care. When was the last time you got a checkup? Do you have any long-term health problems that need care? List the things you think are keeping you from getting regular checkups. For each one, write down the support you need or the changes you could make to overcome these barriers.

- **Survivors.** If you lost a loved one, you might find comfort with other spouses of people who had cancer or Alzheimer disease, or with Gold Star Wives, mothers and fathers. Survivors of suicide might find help in connecting with others who lost a loved one this way.
- **Volunteer groups.** Joining a group that helps others can be rewarding. You will expand your social circle and enjoy a sense of being useful.

At the Hospital or Care Facility

Making the most of your experience with the medical system is important. This includes taking care of your own health, communicating with your loved one about appointments, feeling less anxious during appointments and finding integrative care.

Taking care of your own health

Without proper care, a cough can become pneumonia and a strain can become a broken bone. Keeping up your own medical care is important to prevent long-term problems and keep your body, mind and spirit as healthy as possible.

Regular dental and medical care are more important now that you're a caregiver. Finding out what is keeping you from getting any needed care can be helpful. Certain beliefs can get in the way of taking care of yourself.

For example, it might seem easier to care for someone else than for yourself. You might have a lifelong habit of not taking care of your health. Or you feel guilty going to a doctor or dentist appointment when you feel your loved one needs you. Finding the thoughts that keep you from getting the care you need can help you decide to get it.

You might also want to learn certain caregiving skills. For example, learning how to lift your loved one or move them on a bed or chair can protect you from getting hurt when you do it. Ask your loved one's doctor or nurse where you can learn this or other skills.

Coping with Your Loved One's Health Care Visits

Depending on your loved one's healing process, you might spend a lot of time in the hospital or doctor's office. Talking with your loved one before, during and after a health care appointment can help decrease tension and conflict. This is especially true when you and your loved one have different ideas about what you want to discuss. Consider the following:

- **Prepare for the visit**—Write down what you need to talk about during the appointment to make sure you don't forget something important. Bring a list of their medicines and the doses they are taking. You can find forms online to write this information down. Also, bring notes about symptoms or problems your loved one has had.

Consider talking with the doctor separately sometimes. This can help with sensitive topics such as sexual problems, memory loss or anger. Ask your loved one ahead of time how they want to handle sensitive topics, or if they want you to leave the room at any time. Would they like you to sit in the waiting room or go get coffee during their appointment? Would they like you to go into the exam room, but stay silent? Or would they like you to ask questions or lead the conversation?

Talking about this with your loved one makes it easier for you to talk with health care providers in an appropriate way. If you bring up a problem your loved one was not ready to talk about, they might feel betrayed. You might benefit from having your loved one sign a form that says you may talk about health concerns with health care providers.

- **During the visit**—You might want to record the appointment on your phone or computer. Ask the doctor or other health care provider first, because not every hospital or clinic allows this. You can also take notes on paper to remember what the doctor or other health care provider said. If you are confused, ask them to repeat or explain. Make another appointment if you need more time or want to talk more about the problem.

Speak up for your loved one and yourself when you think you need to. Tell the doctor or other health care provider what you need. If they do not seem to understand, it is OK to ask more questions or explain your need in a different way.

- **After the Visit**—Ask your loved one how they think the appointment was. Do they wish anything had been different?

How to Cope with Anxiety

You might not be able to control the things that stress you, but you can learn to keep the stress from controlling you. First, check your breathing. Are you taking short, shallow breaths that only reach as far as your upper chest? This is a sign of stress. Take 30 seconds to do a deep breathing exercise. This will cause your body to relax naturally.

Take a "4 X 4"

Pause and breathe in for a count of 4. Count slowly, "One, two, three, four." Then, let the breath out, counting slowly to 4 as you do. Exhale.

You can also try doing things to distract yourself from what stresses you. For example, if the sounds of medical equipment make you anxious, try listening to music or a book or podcast.

Take a moment to be mindful of how these things make you feel. How does listening to music, a book or a podcast change the way you react to your environment?

Finding Integrative Care

You might have heard the term "integrative care" before. Other names are "alternative medicine," and "complementary medicine." This type of care combines conventional medicine and other treatments such as acupuncture, massage, chiropractic care and more. You might hear that you should use these treatments instead of regular medical care, along with other treatments such as energy medicine, homeopathy or mind and body medicine. But integrative treatments work best when you use them with conventional care. When

you do this, you get the best of modern medicine and science, plus care that helps your mind, body and spirit heal naturally.

If you are confused by all the terms for types of health care, keep reading to learn more. You can also decide which term describes this type of health care best for you.

About the terms

According to the National Center for Complementary and Alternative Medicine at the National Institutes of Health

- “Complementary” generally refers to using a non-mainstream approach together with conventional medicine. This means using regular medical treatment, plus other treatments such as massage or acupuncture.
- “Alternative” refers to using a non-mainstream approach in place of conventional medicine. This means not using regular medical treatments, but only using other treatments.
- “Integrative” means using both. You receive mainstream medical therapies and complementary and alternative therapies for which there is high-quality scientific evidence of safety and effectiveness. These are the other treatments that researchers have studied and found to be effective for certain conditions.

Integrative care is important for you and the person you care for because it acknowledges the whole person in mind, body and spirit. You can do some types of integrative care by yourself, so it can be useful for taking care of yourself. You can learn some things from a health care provider and then do them at home without more help.

In Your Journal

When your loved one is receiving care, ask yourself, “What is it about this place that bothers me? What sights, sounds, smells and touch sensations do I have control over? How could this be a better experience for me and my loved one?”

What makes your care integrative?

1. **You matter.** *You* play a major role in your own care, especially treatment decisions. This is commonly called “patient-centered care” or “person-centered care.”
2. **It is care of the whole person.** By exploring more than just one part of a person or one issue, it works to solve issues at the core and acknowledges the effect of many factors, including your mind, spirit and environment on your body. It also acknowledges how your body can affect your mind and spirit.
3. **Your doctor is your partner.** The doctor-patient relationship is important, and you and your doctor develop it in a way that helps you receive all the care you need for as long as you need it.
4. **The body is a self-healing machine.** Integrative care recognizes that the body heals itself, so helping you make the most of this ability is a top priority.
5. **You get the best of both worlds.** Integrative care includes the best of conventional and complementary medicine.

Learn more about the evidence behind integrative care, including fact sheets on acupuncture, yoga and art therapy at drwaynejonas.com/caregiver.

What to Expect from Your Health Care Team

Proper health care requires teamwork, with the patient in the center. You, the caregiver, are in the center too. The health care providers for your loved one should communicate with each other. Ask if they are doing this, and if they are not, ask them to start. They should have your loved one’s best interest and your best interest as the top priority. Your health care providers should work together to set goals and expectations for your loved one’s care.

Set A Self-Care Goal

Spending time in places you enjoy is one way of taking care of yourself. A comfortable couch, clean bedroom or colorful towels in the bathroom can comfort you and cheer you up.

Wherever you spend your time, make sure that the spaces around you don't add unnecessary stress to your days and nights. Ask a friend or neighbor to help you clean up, or take a break to go shopping for new sheets, towels or something else to freshen your space. Start with the spaces where you spend the most time first, and then move on to make the others more pleasant.

Set a Self-Care Goal

What is one improvement that you can make at home, work or at the doctor?



Take Your Next Step Forward

Take a moment to reflect on these 3 pieces of advice for being a healthy caregiver:

1. Being a caregiver is like running a marathon, not a sprint. This means taking care of yourself is extremely important for your mind, body and spirit.
2. Focus on your breathing at different times during the day. Taking just 5 seconds to feel thankful for something or to focus your mind on what you are doing right now helps lower your stress back to normal levels.
3. Ask for help. Accept it when you get it. You do not have to be alone. Friends, family, respite care, nonprofit groups, your doctor or hospital, your church or temple and your military organizations if your loved one is a service member can all help. You can also look at the resources on drwaynejonas.com/caregiver.

You have seen that self-care means the following:

- Getting back a sense of who you are
- Building strong social connections
- Making healthy life choices
- Surrounding yourself with healing where you live, care, work and play

You are on your own unique place on your journey. To make progress, you might need to take some steps that feel like you are going sideways before you go forward. When you are ready, take your next step to improve your own situation.

In Your Journal

Write a letter to yourself. What advice would you give yourself if you were just starting out as a caregiver? What would you say to reassure yourself, that you did not know when you started?





Too often, we tell ourselves and others that we aren't caregivers because we feel caregivers have special training and fancy titles after their names. In reality, few people choose to be an informal caregiver—it's simply what happens when you are drafted to care for those you love while also trying to negotiate the countless other responsibilities in your life.

—Zachary White, PhD, Author Of The Unprepared Caregiver Blog

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