

Caring for the Caregiver Notes

Becoming a caregiver is usually not something we plan in advance. It can be compared to being lost in a dark wood. We have no idea what to do. We are in crisis mode. If we were a Boy or Girl Scout, we would have some tools like a compass, a map, and a flashlight with us. Caring for the person who requires our care can become our sole focus and our own needs are forgotten. The purpose of our time together today is *not* to learn how to give care, but to discover some tools—many of them powerful tools—to care for ourselves while caring for another. It is to help us find a caregiver’s version of a compass, map and flashlight to navigate the difficult task of self-care.

The term “caregiving” sounds so soft and sweet and helpful, warm and fuzzy, friendly, humane. But the reality can be anything but these descriptions. It is a physically, emotionally, and spiritually exhausting journey, sometimes the most difficult and painful of our lives. The caregiving journey can be similar to grief—the loss of what was. We often follow the same stages as Dr Kubler-Ross famously describes about grief: Denial, Anger, Bargaining, Depression, Acceptance. And we can go back and forth between these stages during our journey as a caregiver. The feeling of guilt—failure as a caregiver if we have to ask for help. Deep, chronic loneliness often accompanies caregiving.

VOLUNTEER CAREGIVER DICTIONARY DEFINITION: “A caregiver is an unpaid member of a person’s family or social network who helps them with activities of daily living. Since they have no specific professional training, they are often described as informal caregivers. Caregivers most commonly assist with impairments related to old age, disability, a disease, or a mental disorder. Typical duties of a caregiver might include taking care of someone who has a chronic illness or disease; managing medications or talking to doctors and nurses on someone’s behalf; helping or bathe or dress someone who is frail or disabled; or taking care of household chores, meals, or processes both formal and informal documentation related to health for someone who cannot do these things alone”

Caregiving Myths: (Frances Lewis TED talk) (1) Feelings are contained within the individual. *Reality:* Feelings affect others. (2) All you need is a happy

relationship. *Reality*: Studies have shown that just because someone has a happy relationship does not ensure that they will succeed in caregiving or self-care (3). The caregiver must forget about themselves. *Reality*: This is one of the biggest myths of caregiving. Without self-care the caregiver's health, mental and physical, will decline. Taking care of yourself first is not selfish.

Ways in Which Caregiver's Condition Affects Caregiver: (1) Depressed Mood/Anxiety (According to the National Association of Family Caregivers and AARP half of caregivers become clinically depressed). (2) Our assumptions and expectations are challenged. (3) Communication and ways of being fail. (4) We experience negative effects on the caregiver/care receiver relationship.

Are you a caregiver for a spouse, a child, a parent, a friend? Many of us are, but few of us are masters at performing the delicate balancing act of helping others while also getting our own needs met. Attending to the needs of someone else does not mean that we neglect our own needs. In fact, not paying attention to our own needs inevitably leads to exhaustion, depression, and health problems. To care well for others we need to take care of our own needs first. While this may seem counterintuitive at first, practicing good self-care helps to sustain us physically, emotionally, and spiritually while we help another. Here are some tips that caregivers can use for taking good care of ourselves.

Take Responsibility: The first requirement for a caregiver is to accept the responsibility. And what is acceptance? Acceptance means that we acknowledge the facts of reality. We do not fight with reality. Sometimes it takes multiple efforts over time to accept a reality that seems unacceptable. We have to choose to accept reality as it is. We become willing to accept what is, not what we want it to be. It also includes letting go of expectations and assumptions is essential. Expecting the person we are caring for to meet or our expectations or assumptions for them—the way they SHOULD BE—is unrealistic. The word SHOULD is not your friend!

Sleep: Good sleep—quality and quantity are critical for self-care. Sleep is foundational to self-care. Sleep restores our bodies and minds. Knowledge about

the importance of sleep has exploded in recent years. We know that there are various sleep stages (light sleep, deep sleep, and REM sleep), each of which refreshes and revitalizes us. Scientists have discovered that the brain actually does a power wash each night through the glymphatic system, that removes cellular debris, including amyloid proteins that are associated with Alzheimer's Disease.

Exercise: Our bodies are made for movement. Exercise is a pillar of self-care. Like sleep, exercise has countless benefits to keep us healthy and able to cope with the challenges of caregiving. Exercise should include at least 150 minutes weekly of moderate aerobic exercise, where we get our heart rate up to a level where we can talk but can't sing. In addition to aerobic exercise, it is important to include flexibility exercise. This can be done by stretching, yoga, Pilates, tai chi or other methods. This helps keep our joints and muscles supple and increases range of motion. A third exercise anchor is strength training. This can be performed using weights or body weight. For those just beginning, it is helpful to begin easy, with the help of an instructor or coach and go slowly to avoid injury. Lastly, balance exercises help ensure our ability to avoid falls and stabilize our equilibrium. All four types of exercise together—aerobic, flexibility, strength, balance—create a stronger more resilient body that is better able to withstand the physical demands and to mitigate the changes that come with aging.

Nutrition: Sleep and exercise by themselves are critical to good health, but without the basis of good nutrition, they are less effective. Healthy eating secures the benefits of the other two, and the three together—sleep, exercise, and healthy eating—form a formidable trio in maintaining good health. Researchers at Tufts University School of Nutrition found that poor dietary choices were associated with half the deaths related to heart disease, stroke, and diabetes.

Breaks: “Two people were talking on the phone and one said, “My favorite thing to do on my days off is to sit in a cozy chair on the deck with a cup of coffee and read a book.” The other replied “I'm a caregiver and I don't get any days off.” That is the reality for many people. To avoid caregiver burnout breaks are needed. There can be shorter breaks and longer breaks. They have a role in refreshing you from the constant burden of caregiving. If you are not taking breaks, find a way to incorporate breaks into your life. Make sure that your break is to do something

nourishing and refreshing for yourself, not just another task that needs to be accomplished. If you don't take breaks, caregiving can break you.

Practice Self-Compassion: Be patient with yourself. Keep a sense of humor. Afford the same compassion for yourself that you would for a friend or loved one who is doing the same thing you are. Be gentle with yourself. Be kind to yourself and treat yourself with gentle care to prevent burnout. Allow yourself to make mistakes. Don't expect yourself to be the perfect caregiver. Whether you start a self-care routine or begin incorporating small self-care practices into your day-to-day life, the most important part is that you start. Period!

Maintain Your Spiritual Life: Neglecting our spiritual well-being has negative consequences. We need to remember that God loves us no matter what (and loves the person we are caring for no matter what) Practicing spiritual disciplines like prayer, participation in spiritual community, and reading scripture and devotional literature can help us weather storms and the inevitable challenges we face as a caregiver. Say to ourselves "God is with me, GOD is with me, God IS with me, God is with ME"

Emotions: Emotions are normal. Caring for someone you love is involves feelings and emotions. Learn to accept your feelings, including negative ones of frustration, guilt, and anger. Don't confuse self-care with self-indulgence. It may be helpful to get professional help when you are feeling emotionally overwhelmed. Three emotions are commonly associated with caregiving: **Guilt:** "I promised I would always care for dad at home. I should be doing a better job. I shouldn't be feeling angry or resentful. "**Sadness and Depression:** "I've lost so much. I just can't cope. I can't stand for things to be this way. It's hopeless; there's nothing I can change."**Loneliness:** "I feel abandoned. Friends and family have dropped away. I have nobody to talk to anymore. My social life is nonexistent. When would I have time for outside relationships? I can't socialize. I have to stay home all the time to watch mom. I feel so alone."

Stress Management: A 2020 report by the National Alliance for Caregiving and the AARP found that 21 percent of the millions of Americans providing informal care report their own health as fair to poor. Studies have also found that 30% of caregivers die before their care receiver does. Many more will become sicker than their loved one and need a caregiver of their own. People in caregiving roles are often so focused on giving and providing support to others that they may put their own needs on the back burner. This can lead to caregiver stress and burnout.

Signs of caregiver stress, burnout or distress:

- Anxiety, or feeling constantly worried.
- Loneliness
- Depression
- Difficulty sleeping
- Exhaustion
- Hopelessness
- Irritability
- Withdrawing from people and activities you once loved.
- Physical symptoms like headaches, upset stomach, racing heart (Broken Heart Syndrome), weakened immune system, high blood pressure, bodily aches and pains

Relaxation: Breathing: Sometimes when you don't know what else to do, it can help to just stop and breathe—deep, cleansing belly breaths. Breathing can calm us and switch our nervous system from a fight-or-flight mode to rest-and-digest mode. Deep breaths increase the amount of oxygen in your blood, which helps you relax instantly. Shallow breathing makes your heart beat faster and your muscles tense – intensifying your stress. When you feel stressed, put your hand near your belly button. Inhale slowly through your nose and watch your hand move out as your belly expands. Hold the breath for a few seconds, then exhale slowly.

There are many apps on the internet for relaxing breathing practices. Do something that you enjoy, something that relaxes you. Some examples: **Get out in nature**, which can refresh and invigorate your mind, body, and spirit. An NPR report once described those who don't go out in nature enough as having NDD: Nature Deficiency Disorder. **Music and other arts:** Music and art are therapeutic and can lift one's spirits. There are professional music and art therapists, who use these arts

to help a person reduce anxiety, pain, and other stressors. **Go Out to Lunch with a friend:** Food and good conversation are always good stress relievers. These are a few of the ways to practice relaxation.

Get Support: Learn to ask for help. Let other people help you. It can be hard to accept help, even when you know you need it. But just as you're caring for someone you love, don't underestimate how willing other people are to help you when you need it. Sometime they just need you to ask. When you're overwhelmed you may assume that other people will know and recognize what you need in terms of help and support, but it's not realistic to expect others to know what we need and how to help us. Don't be afraid to ask for the help you need. Think of tasks that you can outsource. It is important to share with others what you're feeling and to be specific about the ways you need help.

Community Support: Caregiving can feel isolating and be a lonely place when it falls on one person. Consider what community resources might be available, especially if your support system is limited. Examples of community resources include Adult Daycare Programs, Community meal programs, Community mental health programs, respite care, and senior centers. Local care management services can often help you find and connect with professionals in fields like transportation, counseling, meals and more.

Support Groups Join a support group. In person and virtual support groups connect you with other people who are facing similar challenges in caregiving. They can help you feel less alone and more understood—and that's just for starters. Support groups can provide education on specific topics relevant to caregiving and offer you the opportunity to learn from other caregivers to help you cope.

Boundaries: Practice Self-Awareness: Setting boundaries to ensure that you get what is essential for your own well-being. Know what makes you feel safe and comfortable. **Name Your Limits:** Create boundaries that you are free of things that cause annoyance, discomfort or pain, create guilt, push you to your limits, or make you feel vulnerable. **Set boundaries early in the caregiving relationship** so that your care receiver knows your limits and expectations, and you know theirs. This avoids frustrations, confusion and hurt along the way. **Express Your Boundaries**

Clearly: Be assertive, yet respectful when stating and implementing them. Use “I” statements to communicate feelings and opinions, what you need to feel safe and secure, and what makes you uncomfortable. **Learn to say no:** Be comfortable saying no without having to explain one’s decision. **Be consistent with your boundaries:** Communicating boundaries and reminding others about these can help reinforce them and develop respect and trust in the caregiving relationship.

Communication Issues: Be honest and open with your care receiver about how care giving can be challenging. It is easy to feel resentment when one family member feels that he/she is doing it all and other family members are absent or don’t pitch in, or experiencing family estrangement.

Embrace Hope: Hope is central to life. When you lose hope, you can choose hope again for the things you can control and the things you can’t. Sometimes caregivers discover how their new situation brings new meaning to their lives, for example, patience, resilience, even humor during challenging times. The keys to renewing hope are in nourishing relationships that support and energize you. It lies in self-care practices, in living each day believing that acceptance is not about giving up or liking the circumstances you are in, but in making peace with them. Hope is a spiritual resource that offers the possibility of a positive future alongside the difficult transitions and challenges caregivers face. It is an inner source of strength. Be willing to say yes to life in all its mysterious twists and turns. God is with us.

I hope this talk has given you some food for thought and new tools to use in caring for yourself while you are caring for a loved one.

Serenity Prayer: God, grant me the serenity to accept the things I cannot change, courage to change the things I can, and wisdom to know the difference. Living one day at a time; enjoying one moment at a time; accepting hardships as the pathway to peace; Taking as He did, this sinful world as it is, not as I would have it: Trusting that He will make all things right if I surrender to His will: That I may be reasonably happy in this life and supremely happy with Him Forever in the next. Amen.

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