

## How To Be A Parkinson's Caregiver

by Jennifer Bradley

As any caregiver knows, Parkinson's disease is both chronic and progressive. It persists over a long period of time and the symptoms worsen. Often the disease has been present for many years before active care even is necessary. This fact alone can bring many challenges along the way. A loved one secretly may have adapted their life to this condition, hiding any symptoms.

When the time for care arises, a caregiver first must take inventory of what is working and what isn't. A caregiver may have believed their loved one was perfectly fine and come to realize the truth is far from that. A caregiver for someone with Parkinson's must be very organized, informed, patient, and able to modify daily life to any situation that may arise.

In the latter stages, it's important for a caregiver to take a step back and not become totally entrenched in the caregiving and uninvolved in their own life. Since Parkinson's can persist for many years, by the time the latter stage arrives, a seasoned caregiver will be an "old pro."

### Managing Symptoms

There is no "across-the-board" standard for how Parkinson's affects any given patient. Just as everyone is different, every person's reaction will be unique. The most common symptoms are tremors, muscle stiffness and slow movement. These symptoms intensify as the disease progresses and alone can cause problems in daily living activities. A caregiver must be constantly evaluating what condition their loved one is in. Parkinson's is unpredictable and a loved one may be resistant to take assistance for as long as they can hold out. This makes caregiving more complicated. However, it is their caregiver's responsibility to help keep them, above all, safe in any environment. One important tip is to initially ask a loved one what they need, and not assume. During the latter stages, a caregiver should be familiar enough to anticipate and prepare for a loved one's needs.

In the latter stage of the disease, movement itself becomes nearly impossible. A simple task as dressing could take a person with Parkinson's disease literally all day to accomplish.



Walking is very slow, if at all. A lack of balance causes frequent falls and automatic movements, like the swinging of arms when walking, disappear. A caregiver should try to not be frustrated, but instead, be patient, and respond with love and humor.

As the disease progresses, communication difficulties and heightened anxiety become more prevalent. In the early stages, a loved one can hide symptoms easily, but as the tremors and stiffness worsen, a joke about getting older may be a good cover-up for the fact that daily duties are becoming harder and harder to handle.

With a loved one in the advanced stages of Parkinson's disease, it is nearly impossible to handle it alone. Whether in-home care or out-of-home, help is necessary. Whether in-home or a permanent move, options are available for caregivers to find some relief. There are many kinds of caregivers, from live-in spouses to long-distance children. No matter the caregiver, a support system is mandatory!

The National Parkinson Foundation's publication "Caring and Coping" divides caregivers into these categories:

- Stage One: The Expectant Caregiver
- Stage Two: The Freshman Caregiver
- Stage Three: The Entrenched Caregiver
- Stage Four: The Pragmatic Caregiver

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## Mission

To provide a comprehensive and coordinated system of services designed to promote the independence and dignity of older persons and their families in Muskegon, Oceana, and Ottawa – a mission compelling us to target older persons in greatest need but to advocate for all.



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## Go Green or Stop Receiving Newsletter

If you would like your copy of the *Caregiver Link* emailed or would like to discontinue receiving our newsletter, simply send your request to:

kport@seniorresourceswmi.org.

The first two stages are filled with learning. Once a caregiver is entrenched, they are knowledgeable, prepared and “in the trenches.” A caregiver in Stage Three “gets it.” The final stage, the pragmatic caregiver, has been in the thick of it for more than five years and through it all. They know what works and what doesn't. They see Parkinson's disease as what it was and what it has become. They laugh at things other family members may find sensitive and painful. They have become practical, realistic and are also experiencing much personal growth.

In the latter stages of Parkinson's, it may be hard for a caregiver to find happiness in the simple moments. The major joy-killers are the everyday tasks like bathing, dressing and toileting. It's hard to remember who a loved one was as a person pre-advanced Parkinson's. Sometimes taking a minute to tell jokes, share stories and enjoy a fun activity will bring back the feelings of father/son, mother/daughter, or husband/wife, whatever the situation.

The National Parkinson's Foundation tells caregivers to “hang onto your sense of self.” Regular activities and routines are also important to keep, as much as possible. Emotional and physical exhaustion will only lead to more exhaustion. Finally, a caregiver needs to see themselves beyond the caregiving role. It's essential to remember individual life goals, independent of the caregiving demands. A caregiver must take time to maintain social contacts and schedule respite time.

The unknowns of the day-to-day caregiving are probably the most stressful for caregivers. Having systems in place of organization and support will make these situations seem less overwhelming.

Adapting the home environment is one of the major tasks any caregiver must take on. Whether at a senior residence or the person's personal home, small changes can be made to avoid big disasters. Living areas, kitchens and bathrooms can be adapted to help the decreasing cognitive and physical abilities of a loved one with Parkinson's. Make sure there are open pathways around the home and remove obstacles and unsteady rugs, decorations, etc. that may cause an accident. Put grab bars in bathrooms and even along hallways. Designate hot or cold on faucets with labels and colored tape. Leave items at chest or waist height so reaching won't cause falls.

In addition to changing the environment, a caregiver must be able to help with adjustments on daily tasks such as dressing, teeth brushing, showering, etc. Confusion and unsteadiness make these seemingly standard tasks challenging. Help a loved one understand what is going on and proceed slowly, with care and compassion.

A very common symptom of Parkinson's is “freezing.” Help a loved one move around easier by pretending they are walking over something, or rock very slowly back and forth to get moving again. Exercise, to any degree possible, is very important to a loved one's health and well-being. Sitting around will only make their mind-set diminish, as well as the physical aspects.

Encourage activity, communication, and involvement socially as much as possible. As the disease progresses, these things will become more and more challenging to do. It's important a caregiver encourage it when a loved one still can be involved.

For caregiving in the latter stages of Parkinson's disease, challenges will arise. A caregiver should plan and anticipate problems. Have paperwork done and organized. Separate tasks into smaller, manageable parts to encourage independence. The trenches won't seem so deep then! ❖

# Best Medicine

by Carol Nelson, RN, BSN, MBA

It's no secret that caring for a loved one is a very stressful role, and the medical issues that your senior faces are certainly no laughing matter. But that doesn't mean that caregivers – and their loved ones – can't spend a few moments of the day finding the humor in life.

According to research by the Mayo Clinic, data suggests that laughter really is some of the best medicine out there.

In the short term, laughter:

- Enhances your oxygen intake, which stimulates the heart, lungs, and muscles.
- Increases the production of endorphins, which help relieve stress.
- Soothes tensions by stimulating circulation and muscle relaxation, which reduces the physical symptoms of stress.

In the long term, laughing:

- Improves your immune system. Both positive and negative thoughts produce chemical reactions in the body. Replace that negative energy with the release of neuropeptides that fight stress and are released when the brain experiences positive energy, such as laughter.
- Relieves pain. As mentioned above, laughter releases endorphins. These hormones work as a natural pain reliever because they produce dopamine that helps us feel happy and stimulated.
- Improves your mood. Let's face it – when you're laughing, bad thoughts get pushed out of your mind. Not only does it help you cope with the situation at hand, but laughter also improves your self-esteem.

Medical research asides, anyone who has experienced a prolonged fit of laughter knows that it just feels good to giggle and joke with loved ones.

To help you and your senior cope with some of the more mundane and serious daily activities involved in caregiving, here are some ways to introduce humor into your daily routine:

1. **Search for the funny.** Whether you find funny anecdotes in articles to relate to your loved one or watch comedies on television with them, set aside some time during the day to simply enjoy one another's company. You don't need to put on a comedy routine but telling a joke or two during the daily routine can help alleviate tension.
2. **Get online.** There are endless videos of funny events on YouTube and other video streaming services that you and your senior can enjoy. Obviously, you will need to make sure that the comedy is appropriate for your loved one's tastes but harmless videos that could make an appearance on "America's Funniest Home Videos" are a good option to start with.
3. **Ask your loved one to tell you some funny stories.** Your senior probably has some funny stories from their youth they would be happy to tell. Most people don't get through life without something hilarious happening along the way and reliving them can often be just as funny as the event when it happened.

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Wishing you nothing more than happiness on this great day!!!  
HAPPY 4th of July!!

## July's Website

[seniorresources.trualta.com](http://seniorresources.trualta.com)

## Remember...

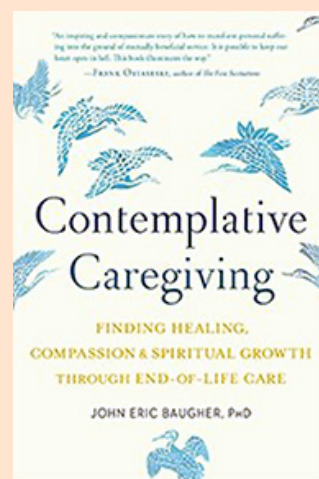
The number one thing caregivers can do for another caregiver is to say "you are not alone."

## This Month's Book

### Contemplative Caregiving

by John Eric Baugher, PhD

Contemplative Caregiving is an indispensable guide for end-of-life caregivers and for anyone seeking to transform experiences of caregiving and grief.



## Caregiving in Hot Weather

When we hear weather described as “treacherous,” images of blizzards or hurricanes usually come to mind. But sunny summertime can also bring hazards. According to the Centers for Disease Control and Prevention, more people die from extreme heat than from other weather conditions.

Extreme heat can be especially dangerous for older people, who are more susceptible to heat stroke, dehydration, and sunburn. Caregivers should have a plan ready for their loved one if a heat wave strikes this summer and to take a few steps to prevent negative sun-related incidents.

Heat stroke occurs when a person’s temperature control system stops working and the body can no longer cool itself down. As the temperatures climb to 90 degrees and above, be sure to have your loved one stay inside, preferably in air-conditioning. If your loved one’s home is not air-conditioned, make sure they have adequate fans operating. Better yet, at the hottest points of the day, take them to an air-conditioned environment such as a shopping mall, senior center, or church. Many urban areas will have cooling centers for older people to gather in if their dwelling doesn’t have air conditioning.

However, some older adults will not leave their apartments or homes. Be sure to check on your loved one. Go to their house, or if you are a long-distance caregiver, be sure to have someone visit them.

The effects of dehydration can happen quickly and can be quite harmful for older people. Dehydration can cause headaches, muscle cramps, dizziness, confusion, and fainting.

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4. **Consider laughter yoga.** Laughter yoga is a real practice where people laugh as a group. The laughter is forced, at first, but soon turns spontaneous. If you’ve heard the saying, “Laugh and the world laughs with you ...” then you can understand the motivations behind laughter yoga.
5. **Laugh at daily life.** Don’t be afraid to laugh when something funny happens during your daily routine. Caregiving can provide rich opportunities for the funny to simply happen and it’s not irreverent to laugh when it does.
6. **Invite friends over.** If you or your senior has some entertaining friends or acquaintances, feel free to have them over for lunch or dinner. Not only does having a new face break up the routine for a much-needed change but having a funny or entertaining exchange makes the visit that much more enjoyable.
7. **Get silly.** Don’t be afraid to mix it up. Try on funny wigs and outfits, dance when no one else is dancing and laugh out loud in public places. Acting silly - within reason - can often break up the monotony of daily life. And if it gets the people around you to laugh, as well, then the more the merrier.
8. **Remember that humor isn’t mean or disrespectful.** While laughing at one another’s actions during a particular situation can mostly be harmless, laughing at someone’s shortcomings is not funny. If your senior is laughing at their own antics, join in, but be careful to laugh with them and not at them.

For most caregivers, this chapter in their lives and in the lives of their senior is often the last moments in time they will be spending together. Joy can be found in the simple things: a joke, a shared funny moment or time spent watching hilarious videos.

The act of caregiving can often make you feel overwhelmed, anxious, or even depressed. Instead of focusing on the negative aspects that are too often a part of caregiving, a good laugh can push those negative thoughts out of your mind and help you find the simple joy in caregiving. ❖

# Taking Care of Yourself After Being A Caregiver

## 1. Give yourself permission and time to grieve

After any loss, you will need time to grieve.

The commonly held stages of grief include:

- Denial, disbelief, confusion, shock, and/or isolation
- Anger
- Bargaining
- Despair and/or depression
- Acceptance

Instead of hiding or feeling ashamed or guilty, give yourself permission to experience the grieving process. Realize that everyone grieves differently, and you may progress through the grief stages methodically or swing back and forth.

Likewise, you may experience intense emotions or a quiet sadness. No matter what you feel, understand that your grief is normal and that you have the right and need to experience grief in your way.

## 2. Use healthy and appropriate coping mechanisms

Grief can last months or even years, and you may wonder if you'll ever return to normal. To cope, you may turn to drugs, alcohol, food, or other unhealthy coping mechanisms.

While you will never forget your loved one, we promise that the pain will eventually subside. Stuffing your emotions or drowning your feelings will only hurt you now and into the future. In fact, unhealthy and inappropriate coping can cause physical pain, emotional illnesses, or long-term negative reactions.

Choose to exercise, talk, journal, or embrace other positive and healthy coping mechanisms as you grieve and protect yourself.

## 3. Ask for and accept help

In your caregiver role, you were the one who gave all the help. Caregiving depletes physical, emotional, mental, and spiritual resources, and now you're the one in need of assistance.

Allow yourself to be vulnerable and ask for help as needed. Consider writing a list of tasks others can do for you or call friends who will listen and offer support.

By asking for and accepting help, you receive support and allow others to show you love.

## 4. Take care of your health

Visiting a doctor may be the last thing on your mind, especially if you spent a lot of time in a hospital with your loved one. You deserve to care for yourself, though, as you respect and energize your body during the grieving process.

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Encourage your loved one to drink plenty of fluids. Do not offer beverages containing caffeine or alcohol, since those may exacerbate the problem. Do offer fresh fruit as a tasty snack and also a good source of liquid.

Your loved one may not have sunscreen on their shopping list, so it would be a good idea to buy a fresh supply to bring to their house. An older person may not feel that it is necessary to protect their skin from the sun, but older people's skin is more delicate and prone to dryness, which can be made worse by sun damage. In addition, some medications common among older adults increase sensitivity to the sun. As a caregiver, you need to be sure your loved one is following the sun safety rules, such as using sunscreen, wearing a large brim hat and light, loose fitting clothing, and staying out of the sun between 10 am – 2 pm.



Enjoy the warm weather with your loved one. Take advantage of the opportunities to go outside, breathe in some fresh summer air, watch the children play, take a walk, and enjoy an ice cream cone.

Just be sure to do it safely by taking sun and heat precautions seriously. ❖

# The Value of Friendship

by Marlene Pyle

I've learned many things since I began taking care of my 85-year-old grandmother. I know which supermarkets offer senior citizens' discounts on which days of the week. I know which drugstore has the most helpful pharmacist, and which beautician will fix my grandmother's hair just the way she likes it. But one of the most important things I've learned isn't about caring for my grandmother; it's about caring for myself. I've learned the value of true friendship.

When my grandmother moved here to Georgia from her home state of Michigan in order to be nearer to me, I knew my busy life was about to get busier and more chaotic. I have a full-time job, two teenagers and (thankfully) a very supportive husband. My plate was already pretty full.

I had long since given up on finding the time to do volunteer work, appeasing my pangs of guilt by donating clothing to my local battered women's shelter and writing a yearly check to the American Cancer Society. I quit making excuses for not getting to the gym, and finally let my membership lapse. I made peace with the fact that my house may not be immaculate at all times but is pretty clean most of the time. But one thing I always made time for was my girlfriends.

Going out to lunch with the girls was something I looked forward to. Our shopping trips and movie nights kept me sane. Even if we just met at the park for a quick walk, I

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*Taking Care of Yourself After Being A Caregiver, continued from page 5*

Apply your caregiving duties to yourself and insist on a healthy daily regimen. Eat a balanced diet, get plenty of rest, exercise regularly, and visit your doctor for scheduled checkups.

Prioritizing your health equips and strengthens you for your grief journey.

## 5. Join a support group

Talking about your caregiving and grief experiences may scare you. It's also hard to be vulnerable and continue to rehash the events surrounding your loved one's passing.

Other caregivers and professional therapists or grief counselors understand what you've gone through. You can share your experiences and discuss your feelings and concerns in a support group. Here, you'll gain practical advice and emotional support that sustains you as you adjust to life after caregiving.

Talking and sharing can also help others find healing, too.

## 6. Delay major decisions

The act of caregiving and managing grief takes a toll on your body, mind, and emotions. You need time to find a new normal.

Give yourself at least a year or as much time as you need before you make any major decisions, such as moving, growing your family, changing jobs, or entering a romantic relationship.

This cushion of time prevents you from making an emotional decision you later regret and helps you rediscover yourself.

## 7. Embrace new routines

Much of your daily routine used to revolve around caring for your loved one. Now, you may miss your caregiving responsibilities and struggle with the significant changes in your daily routine.

Rest assured that in time you can and will develop a new routine that becomes familiar, comfortable, and fulfilling. Start by deciding what will fulfill you each day. Remember to eat, exercise, and spend time doing things that fulfill you, too.



These steps lead you to embrace a new and positive routine.

## 8. Reevaluate your relationships

Loss affects everyone differently. Some people in your life may step up and offer additional support while others step away and distance themselves.

This relationship ebb and flow after a loss is normal, and you will eventually rediscover a strong and healthy support system.

For now, try to accept inevitable relationship changes. You can reduce stress when you bless and release people who withdraw and show gratitude for people who choose to stay.

## 9. Carefully choose new responsibilities

Without your caregiving duties, you may have fewer or even no responsibilities. You may find yourself bored, frustrated, or angry and be tempted to over-function and jump right into another caregiving relationship.

Consider giving yourself an extended time off from helping others. Work instead on the hard job of grieving.

You will also benefit from rediscovering the activities, interests, and duties that are important and fulfilling for you. Then carefully choose the new responsibilities you want to embrace as you fill your time.

## 10. Find fulfilling activities and interests

Caregiving takes time and energy. Instead of enjoying activities and investing in interests that used to be important, you may have put yourself on the back burner.

Now's a great time to return to the activities and interests that mattered before you took on your caregiving role. You may even develop new hobbies.

Whichever experiences you choose to embrace, know that it's healthy to fill some of your time with activities and interests that fulfill you and make you happy and content.

## 11. Discover new priorities and goals

Your role as a caregiver revolved around meeting your loved one's needs and putting their priorities and goals above your own. Through that process, you may have given up your dreams.

Take time now to think about your future and what you want your life to look like. Then decide your priorities and set goals that propel you to make your dreams come true.

## 12. Help others

As an experienced caregiver, you have developed dozens of skills. You also understand the hard work caregiving takes, and you know about the grieving process firsthand.

Consider using your experience to help others. You could offer encouraging and beneficial support to other caregivers and make a difference in their lives.

By giving back, you gain an outlet for your energy and may even ease some of your grief symptoms. ❖



always felt better and more relaxed after I'd spent time with them.

My grandmother's arrival changed things. It was difficult for me to make last-minute plans with my friends, and I often had to cancel even long-standing dates if my grandmother was ill or had an appointment that couldn't be rescheduled. I couldn't linger on the phone with my pals as often and leaving town for more than a day or two required elaborate arrangements and planning. For the first time in my life, I found myself buying greeting cards that read "Happy Belated Birthday." Weeks or even months would go by when the only contact I had with some of my friends was a hurried email.

But there was also Paula, who sat me with me in the dingy hospital waiting room while my grandmother had surgery, and who spent an entire Saturday helping me paint my grandmother's bedroom the perfect shade of yellow.

There is Pam, who leaves funny messages on my voice mail, even though she knows I may not get to call her back for a while, and who volunteered to take my grandmother to an appointment when I had a meeting I absolutely couldn't miss.

What would I do without them? I don't even want to know. As the song goes, I get by with a little help from my friends. My grandmother's taught me a lot over the years. My friends have taught me even more. ❖

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Every Thursday – 1-2:30 p.m.  
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Tanglewood Park • 560 Seminole Rd., Muskegon

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The Book Nook • 8744 Ferry St., Montague

### ZOOM VIRTUAL GROUP

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