

Taking Care of the Parkinson's Caregiver

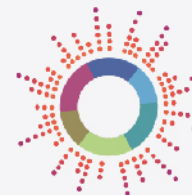
Tools, Strategies, & Resources
from Experts and Fellow Carers



CAREGIVER KIT

Dr. Sarah King, PT, DPT

invigorate
PHYSICAL THERAPY & WELLNESS



Why does this Caregiver Kit exist?

Being a spouse, life partner, or formal caregiver of someone who is walking a Parkinson's path can be confusing, challenging, frustrating, and anxiety-producing. It can also be overwhelmingly rewarding, full of love and gratitude.

Then, of course, there's everything in between.

The goal of this Caregiver Kit is to give you — as someone who is supporting a person with Parkinson's — some valuable tools, resources, and strategies you can use to make the years ahead less turbulent and stressful for you and your loved one.

We rounded up a handful of compassionate, down-to-earth, and well-versed Parkinson's advocates to share their wisdom, which you'll find in the following pages.

You can also find an entire community of supportive people inside our private Facebook group, ***The Invigorated Community.***

[Click here and request to join](#) — We'll get you right in.

Looking forward to having you in our tribe.

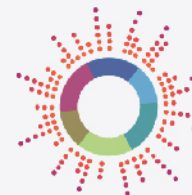
Big hugs,

Dr. Sarah King, PT, DPT



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What the Spouse or Close Partner of Someone Diagnosed with Parkinson's Should Know



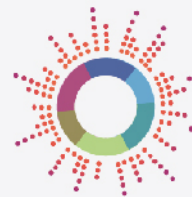
Fellow Caregiver: Nancy Hovey, Wife and Caregiver of 11 years

If your life partner gets diagnosed with Parkinson's, you're in for the ride, and if you don't learn how to best face this diagnosis head-on together, your days and years moving forward will be much more challenging than they need to be.

These 8 lessons come from Nancy Hovey, a wonderful woman whose husband, **Steve**, was diagnosed over 10 years ago with Parkinson's disease at age 50. Over the years they've both learned many lessons about how to live well with Parkinson's in their life.

#1. Take care of your *(whole)* self

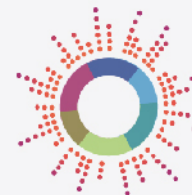
Feeling whole and healthy in order to be a helpful caregiver means taking care of mind, body, and soul. Feeling emotionally well, fulfilled in life, doing things that are physically active, remaining social and connected to loved ones, and leaning strongly on faith are all things that help me to be strong. And you've just got to stay strong. We already did those things, so there was a natural adjustment period.



#2. Give yourself time to adjust

When you go through those first early stages of diagnosis, take time to adjust. You don't have to jump into anything or hurry to join a support group. Let the diagnosis sink in and things will come around, a day at a time. Trying to read or trying too many things can be overwhelming, so don't try to put too much stress or pressure on yourself. You will feel better, you will come around, and you will find your stride.





#3: Gain knowledge from reliable sources

There are many resources out there; some are good and some are not as good. It's important to find the resources that are helpful to you and to know that what you're reading is the right thing for your situation. [Davis Phinney Foundation](#) and [Michael J. Fox Foundation](#) are both great, as is going to conferences, being in discussions, and being in support groups. Other people have new things to give you and they can help you stay on top of the research in the world of Parkinson's.

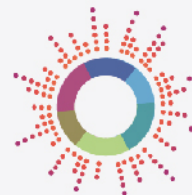
#4: Find support that's right for you

The support you gain from meeting other people who are experiencing the same is amazing. These are the people who know what you're talking about and who get it; they are living the same life that you are, so they understand things in a way that others do not. Family and friends are solid ground, but connection to the Parkinson's community is critical and empowers you to see that you are not facing things on your own.

Not every support group is right, and your family and friends may not be available to you the way that you need them to be. Don't be afraid to seek out a lot of different resources. You might need to try a few first.

#5: Don't be afraid of change

Don't be afraid to manage changes as you go along. Things will be less stressful if you don't feel stuck or trapped where you are. Move closer to family, if you need to, or make adjustments in your daily schedule. Talk about them with your partner and if a change is going to make your quality of life



better, do it! Parkinson's is progressive, but you can make your adjustments as you go along to make your life as enjoyable as possible.

#6: Communicate, communicate, communicate!

In any relationship, but a partnership especially, communication is so important. We are open with our emotions, and because we deal with a lot of unknowns, communication is critical for both of us. Being able to take a minute and say "Let's reset" when things aren't going well is a really good idea. Making time for each other to come together is important. Take time to be alone and not be surrounded by chaos to stay connected and bonded.

#7: Keep a sense of humor

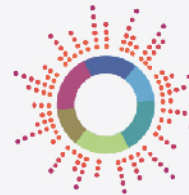
Maintain your sense of humor, whether you have one or not! Things happen with Parkinson's that might not be so much fun, but if you can keep your sense of humor and laugh, it feels good.

#8: Celebrate the small victories and give back when you're ready!

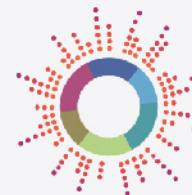
There are so many awesome things that will continue to happen in life! It's easy to get frustrated and down about the things that are tough, but there are so many things to take delight in. Be conscious about the things that you are doing that you enjoy so you can say "This is really great; we can be happy about this." Celebrate the victories, because there will be more than you realize.

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Once you feel healthy enough to help others, it is so healing and satisfying to be able to reach out to other people. It doesn't mean necessarily being a counselor; you could lead a support group or participate in a study. Meeting other caregivers is really rewarding, too, and so is advocacy for nonprofits.



Laying the Groundwork for Caregiving Early After a Parkinson's Diagnosis



Expert: Annie Wallis, MSW, Associate Director of Education at the Parkinson's Foundation

Are you wondering how you — as a spouse, partner, or family member — can step into the caregiver role and what you should expect in the days, months, and years ahead?

What kinds of things should you consider, as a caregiver, to make sure you and your loved one are set up for success in the future?

Are you worried about how this new dynamic will affect your relationship?

We interviewed Annie Wallis, Associate Director of Education at the Parkinson's Foundation, about how to lay the groundwork early after a Parkinson's diagnosis to ensure you, as a caregiver, and your loved one can move forward together in an effective and powerful way.

#1: What does it mean to be a Parkinson's Caregiver?

There's obviously a huge difference between the caregiver who has a person with Parkinson's who was diagnosed yesterday, and the person with Parkinson's who was diagnosed 30 or 40 years ago.



Parkinson's looks so different from person to person, especially from the beginning to later on in the disease, so the caregiver of a person with Parkinson's really doesn't look like one thing.

In a perfect world, a Parkinson's caregiver is the person who is:

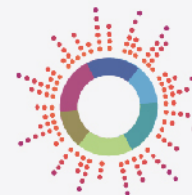
- Giving care to their loved one with Parkinson's,
- Flexible and ready to handle the disease as it comes (because it's not going to come the same way that you've seen it with other people with Parkinson's),
- Able to fluidly adjust as things change and face whatever challenge arises with an open mind, and
- Making sure they're also taking care of themselves as the disease progresses.

#2: What are the seven things you'll need as a Parkinson's caregiver*?

- 1) Learn about Parkinson's (without getting overwhelmed)
- 2) Time management
- 3) Self-care, health and respite
- 4) A support team
- 5) Your relationship with the person with Parkinson's
- 6) Medical, financial and care decisions
- 7) Community resources

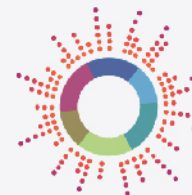
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*To learn about the 7 needs in-depth, head over to the Parkinson's Foundation website to download or order their book, [Caring and Coping](#).





#3: What are special considerations for Young Onset Parkinson's Disease (YOPD)?

This is not an easy hand you've been dealt. It can seem like an impossible feat to fit in everything you need to do for your loved one with Parkinson's, and also work and/or parent full-time. There are so many other people in a similar boat, trying to figure it out as well. You are not alone, and remember that it's okay to be scared and overwhelmed. Here are some things to consider.

- Set small goals for yourself
- Prioritize talking about the big stuff
- Prepare to apply for disability
- Get started on financial and estate planning

Resources from the Parkinson's Foundation:

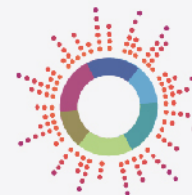
The Parkinson's Foundation offers a wealth of [resources for caregivers](#) on their website that are easy to navigate and incredibly comprehensive.

There's a **helpline (1-800-4PD-INFO)** that can connect you to support groups, expert care, specialists, or answer any question you may have.

You can also see if there's a **Parkinson's Foundation Center of Excellence** near you. There are 45 locations, mostly in North America, and are a great resource if there's one within driving distance. If not, there's still probably a local support group near you.

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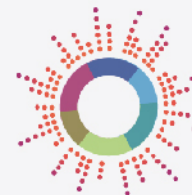
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To protect, prepare and empower people with Parkinson's before, during and after a hospital visit, the Parkinson's Foundation developed the free **Aware in Care** kit with tools and information to share with hospital staff during a planned or emergency hospital visit.



[REQUEST YOUR AWARE IN CARE PATIENT SAFETY KIT HERE](#)



Parkinson's Caregiver Burnout: Handling Grief, Anxiety, & Depression

Expert: Debbie Heidrich, from Companions on a Journey



One of the biggest myths about grief is that it only follows a death. The truth is that **grief can show up long before death arrives** and can often be triggered the moment a Parkinson's diagnosis is delivered.

This concept, called anticipatory grief, can affect everyone — the person diagnosed, their spouse, their children, their close friends — yet often goes unrecognized and rarely discussed.

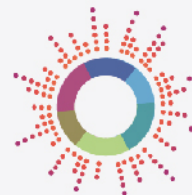
Feelings of sadness, anger, forgetfulness, isolation, and depression are just a few of the indicators that you may be experiencing grief. **While these feelings are a normal reaction** to such a significant life event, it doesn't mean you have to "just get over it" or suffer in silence.

We spoke with **Debbie Heidrich**, who serves on the Board of Directors at [Companions on a Journey](#), about how these feelings may impact Caregiver burnout and how to recover.



Companions on a Journey

GRIEF SUPPORT



#1: What are the symptoms of grief?

Grief will manifest itself in many different ways:

We have the **physical side**, where we can feel that stress inside. We can have an upset stomach, get headaches or muscle tension, or it can stress our bodies to the point of illness.

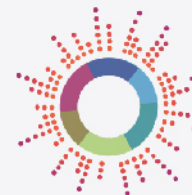
Then there is the **emotional side** of that where we can't concentrate, want to cry, get angry, or get very sad.

Then there's a **social side** of grief where we can isolate ourselves, feel distracted easily or like we can't accomplish things that we normally do.

Grief isn't just a feeling of sadness. Feelings of overwhelm, being really tired, or wanting to bust out and cry or explode at any moment may get misconstrued as "caregiver burnout", while in reality, you may be grieving.

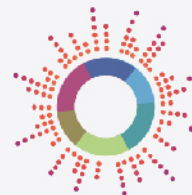
#2: Why does grief happen after a Parkinson's diagnosis?

Dr. Eric Casell explained this as that as humans, we are made up of many different aspects. If something happens to the body, there is a loss and we suffer. We have relationships and if someone is ill, it changes how we interact and can cause feelings of loss. If there are progressive losses in a disease, our relationships suffer. All the roles in our lives suffer when there is a progressive loss because of illness.



#3: How does grief contribute to caregiver burnout?

Grief contributes to caregiver burnout when we do not acknowledge the grief or the loss. It's when we shove the feelings down all the way like "I'm not going to feel that right now."



The first stage of grief is acknowledging that a loss has happened, and with death it's a pretty clear loss. With slowly losing function or needing more and more assistance, we have to acknowledge the losses happening there and allow ourselves to experience the pain of that loss.

We're not really good at allowing ourselves to experience the pain of loss, and that's where caregiver burnout can happen.

#4: What are healthy ways to approach sadness, grief, and anxiety?

Even if you're on both sides of the equation (patient or caregiver), there are activities or processes that you can go through. It seems like journaling might be a good way to move through the acknowledgment.

What works well for one person may not work well for another, but being part of a support group is really helpful for a multitude of reasons. One is that you are able to connect with somebody who is going through similar kinds of things and that they understand you in a way that other people don't.

If a group setting isn't for you, try and identify and confide in a nonjudgmental person. It can be a family member or clergy, or some other resource in your community, or your best friend from college, but just try to identify that person who is able to just listen to you.

The other thing that is certainly helpful is to get physical. So if it's just getting outside and walking for 10 minutes it can just help clear your mind or help you be able to process things.

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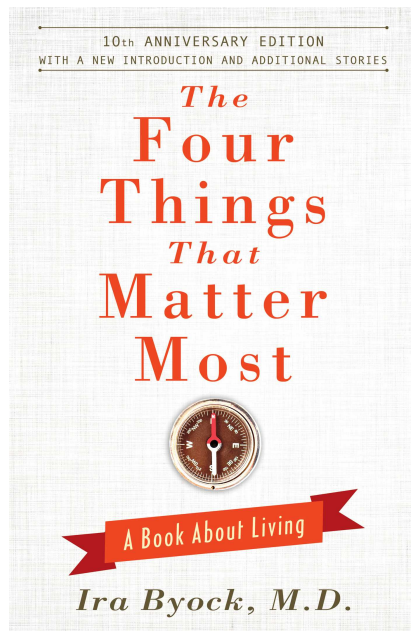
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Nobody can be a good caretaker without taking care of themselves, so you need to eat well and get adequate sleep. Take time to take care of yourself as a caregiver. Make a list of the things you need.

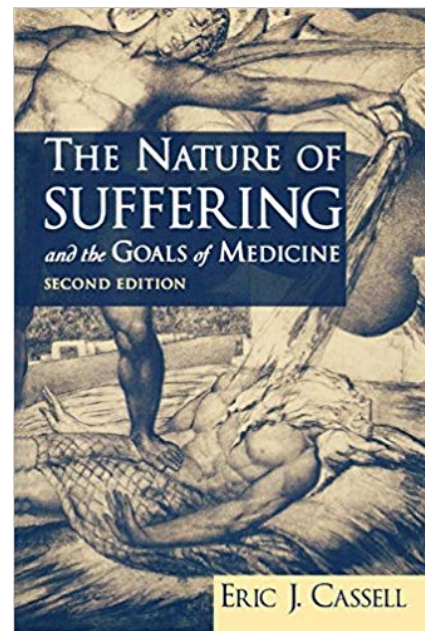
If you experience serious episodes of sadness or anger that last more than two weeks, see your care provider to talk about the possibility of clinical depression.

Debbie's Recommended Reading:



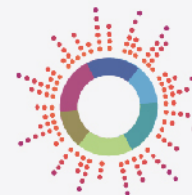
The Four Things That Matter Most

Ira Byock, M.D.



The Nature of Suffering and the Goals of Medicine

Eric Cassel



Caring For Someone With Advanced Parkinson's Disease

Expert: Anne Wallis, MSW, Associate Director of Education at the Parkinson's Foundation



For caregivers and their loved ones in the later stages of Parkinson's, **this time can be incredibly challenging emotionally, physically, and financially.** However, **there are simple ways to make this chapter of Parkinson's easier on you,** as a caregiver, and on your loved one.

#1: What are simple ways family and friends can help?

Think about who in your life may be available to help in some way, but don't try to narrow it down to exact skills and availability. Think about people like your neighbors, your kids, people at your house of worship, and then ask them to do a specific thing on a specific day. When your request is specific and reasonable, and people are able to help, they typically will.

Start small to get a few hours to yourself. Those small breaks can make a huge difference.



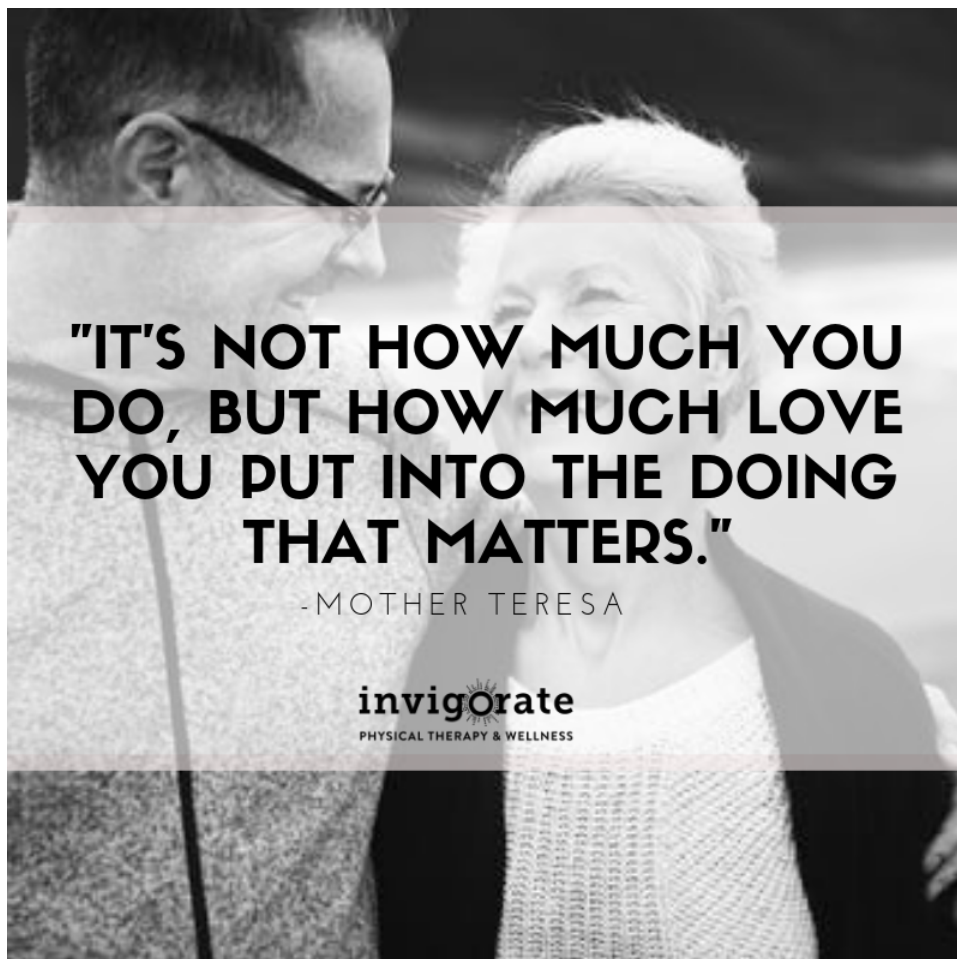
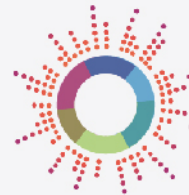
Inviting family and friends to websites like [Lotsa Helping Hands](#) can help herd your personal community into the specific logistics (times, places, and ways) of working together. Creating a private group of Facebook friends who are local to you is another way of contacting those who may be able to step up and help as situations arise.

#2: What if we don't have ANY support?

I would recommend finding a local Parkinson's support group because even if the people in those groups aren't people who are able to drop in and help on a tough day, they are people with whom you can commiserate. They may even have family and friends willing to help you, too.

I challenge the idea that there's really "no one" to help. Often our pride and anxiety keep us from saying "We need help." There are a lot of people who really do want to help you. Get into the habit of saying "Yes" when people offer to help, even to small tasks. If you get in the habit of saying yes when offered help, you can go to them with requests later because you know you can rely on them.

[Invigorate PT](#) and [Invigorated Community on Facebook](#) are virtual resources where you can find support, too. You never have to do it alone, and the community there will help as much as they can.



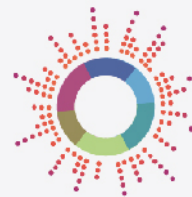
#3: How do I lasso the power of my healthcare team for better care?

Think about who has the tips and tricks of the trade to help you.

Occupational therapists are often the first step. They are pros at finding simple tools, techniques, and assistive/adaptive devices to make it easier to

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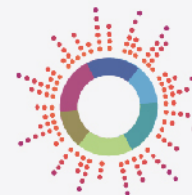
solve problems, especially in the home. **Physical therapists** can teach you how to prevent injury to yourself, especially with healthy practices for safely lifting or transferring your loved one.

It is critical to **understand the difference between palliative care and hospice**. Palliative care is not as common in the United States, and it is related to but different from hospice. It's working with a team of experts to provide symptom and pain management along with spiritual care and medical support to people with serious illnesses. It's a great fit with a chronic and incurable disease like Parkinson's. You may be able to find these resources under "supportive care," so people don't confuse it with hospice.

Spiritual care can also mean a lot of things, and it will be tailored to what is relevant to you and your needs and beliefs. If your movement disorder specialists aren't sure about how to access this care, ask if there is a social worker on staff to help you find local resources for this kind of care.

One of the valuable tools the Parkinson's Foundation provides is called [CareMap](#). Think of it as a how-to guide to coping with problems that may arise as a result of advanced Parkinson's.

There are videos to help with dressing, eating, using the restroom, and a ton more, as well as caregiver stories and tips.



What NOT To Do When Caregiving



By: Lianna Marie, author of “Everything You Need to Know about Caregiving for Parkinson’s Disease”

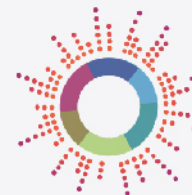
Here are a few of the ‘**don’ts**’ in caregiving:

#1: Don’t try to ‘fix’ everything all at once

You’ve probably been told this before, but it’s worth repeating: **pick your battles**. Your loved one may need help with many tasks and you may discover that they want things done in a way that is different from the way you’d do them. Remember that your goal should be to help them, not “fix” them. Prioritize their needs and work with them to tackle one task at a time.

#2: Don’t patronize

Sometimes, as an aging loved one becomes more fragile, we start treating them more like children than adults. Don’t do this. Even if you’re caring for someone with dementia, be careful not to talk down to them. Treat your loved one the way you’d want to be treated.



#3: Don't interrupt

Make sure you're really listening to what your loved one is saying. Try not to interrupt or fill the silence during a conversation. When it's your turn to speak, summarize what you think your loved one just said and then ask them if you have correctly interpreted their sentiments.

#4: Don't give advice unless it's asked for

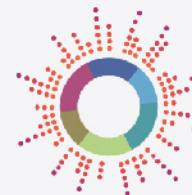
This is an especially important tip for adult children who are looking after aging parents. Your mother and father are used to providing you with advice and guidance. When this dynamic begins to shift, it may start to lower their self-esteem and make them feel out of control. Getting an outside expert — such as a financial advisor or an elder law attorney — to provide professional guidance can make an elder more receptive to new information.

#5: Don't forget about how they feel

Put yourself in their shoes. Remember, your loved one is probably feeling as though they are losing control over their own life. In their mind, their freedom and independence are being threatened. Always show empathy and sensitivity towards them.

#6: Don't be argumentative

One thing I learned very early in my caregiving journey is that I am not my mother. She has different ways of seeing things and wanting to do things, and because of this we didn't always see eye to eye. Remember to acknowledge

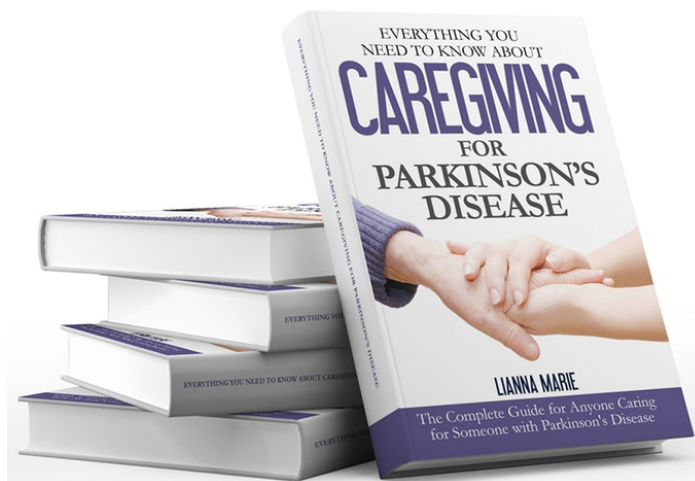


your loved one's questions, concerns, and viewpoints. Compromising was something I learned to do to reduce the number of our disagreements.

#7: Don't forget your TONE

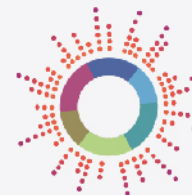
Though your patience will be tested throughout your caregiving journey, it's important to **pay attention to your tone when you're talking with your loved one**. Speak calmly and avoid raising your voice or being condescending. Doing so can quickly turn a conversation into an argument, which can then escalate into something even bigger. Also, if your loved one has difficulty hearing, keep your voice low and make sure to enunciate your words so that they can really hear what you're saying. Nothing's worse than an argument starting over something you didn't even say!

Excerpt from the book, "Everything You Need to Know About Caregiving for Parkinson's Disease", with permission from the author.



Everything You Need to Know About Caregiving for Parkinson's Disease

By Lianna Marie



Helpful Financial Resources

Tips for Paying for Treatment with Parkinson's

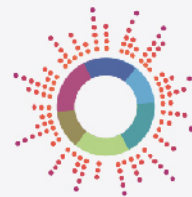
<https://parkinsonsdisease.net/basics/treatment-cost-tips/>

Dealing with a chronic illness like Parkinson's disease can be expensive, and many people with PD find they need help paying for treatment, as well as the other services and equipment that they need. There are several different avenues, listed here, for getting help with healthcare costs, as well as other financial needs.

Financial Assistance for Non-Medical Parkinson's Care, Assistive Technology, and Home Modifications

www.payingforseniorcare.com/parkinsons/financial-assistance.html

This article covers various ways and programs to help families pay for the non-medical care required by individuals with Parkinson's Disease. Often overlooked when considering financial assistance for Parkinson's care are the products that can help an individual maintain their independence, reduce their need for care, and therefore reduce their care costs. This article also explores how to pay for these items, what common insurance programs such as Medicare cover, and what other financial options are available.



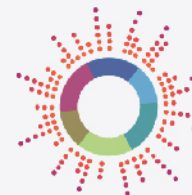
Government Benefits and Insurance

www.michaeljfox.org/understanding-parkinsons/living-with-pd/topic.php?government-benefits

The U.S. Government provides benefits and care coverage to those in need. On this page from the Michael J Fox Foundation, they outline some programs that may help people living with Parkinson's disease.

Can I get paid to care for a family member?

www.caregiver.org/frequently-asked-questions#faq2



Moving Forward Together

Positive Resources to Share with Your Partner

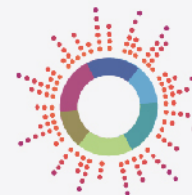
It can be hard to find information about Parkinson's online that doesn't leave you and your partner feeling full of dread and fear. I see it all the time in our community, and it doesn't have to be that way!

Will adjusting to a Parkinson's diagnosis be a challenge? **You bet.**

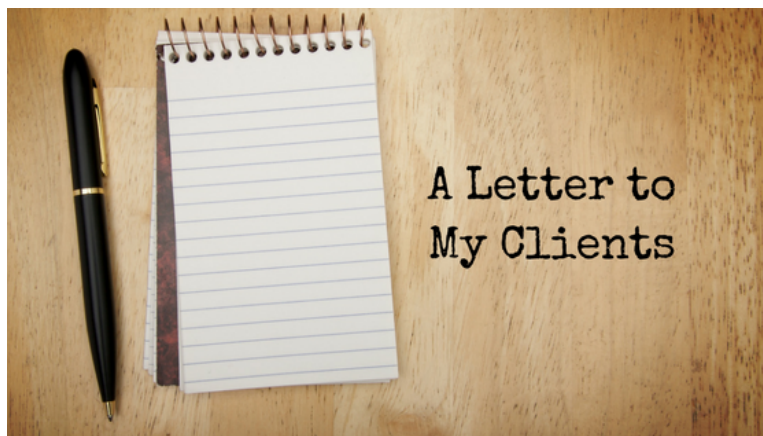
Will there be really tough days in the future? **There will.**

Does this mean you both have to give up on the life you live or the future you've planned together? **Absolutely not.**

These final resources are ones intended to be shared and explored with your partner by your side so you both can formulate your plan of attack moving forward.



A Letter to My Clients: Things I wish I could have told you the day you were diagnosed with Parkinson's

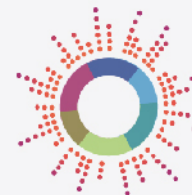


<http://www.invigoratept.com/blog//a-letter-to-my-clients>

What to Expect When You've Been Diagnosed with Parkinson's Disease (No Doomsday!)



<http://www.invigoratept.com/blog/what-should-you-expect-after-being-diagnosed-with-parkinsons-disease>



Parkinson's & Exercise: A Physical Therapist's Guide to Getting Started



<http://www.invigoratept.com/blog/exercise-and-parkinsons-disease-getting-started-guide>

You can do this.

As always, please let me know how I can help you two along your journey.

My best,

Sarah