

Burden and Benefit

Embracing the duality of the
Parkinson's caregiving experience

November 2022





Thank you

As a company committed to Parkinson's disease, we have come to appreciate the importance of care partners in the patient journey. Whether living with a patient or caring from afar, you often dedicate yourself to providing around-the-clock support, helping your loved one navigate the physical, emotional and cognitive effects of Parkinson's disease. As the disease impacts a growing number of people — with 10 million living with the disease worldwide and nearly one million in the U.S. aloneⁱ — more people find themselves in your position, prompting us to ask: How can we better support a growing care partner community?

In a quest to further understand the unique challenges faced by those in your role, Kyowa Kirin partnered with the Davis Phinney Foundation for Parkinson's (DPF) and the Parkinson's and Movement Disorder (PMD) Alliance in April 2022 to conduct a survey of more than 750 care partners from across the U.S. This survey, consistent with earlier research done in 2020, revealed unique insights about the care partner experience and their support needs. In June 2022, leaders from each organization, along with a person with Parkinson's disease and a care partner, joined us for a roundtable discussion that explored how these findings translate into real-life experiences and what you can do to plan for and navigate the road ahead.

Our research and discussion revealed a unique duality in the care partner journey: it is both a challenging burden and, for many, an extremely rewarding experience. This whitepaper explores this duality further, sharing insights from the survey and our conversation with roundtable participants to provide a deeper look at the Parkinson's caregiving experience.

At Kyowa Kirin, we are committed to supporting care partners as you navigate the complex and ever-changing challenges of Parkinson's disease together with your loved one. Whether you're new to the care partner role or have supported a loved one for years, we hope this is a helpful resource.

Best regards,



Susan Thiele

Senior Director, Communications & Advocacy
Kyowa Kirin North America

We are immensely grateful for our partners in this project — **DPF and PMD Alliance**. We also want to extend a special thanks to representatives from those groups, along with **Allan Cole, Ph.D.**, a person with Parkinson's disease and founder of PD Wise, and **Bernadette Baumann**, a care partner for her husband with Parkinson's disease, for coming together and sharing their personal and professional experiences in our roundtable discussion.



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Introduction

To put it simply, a care partner provides support to someone living with Parkinson's disease. In reality, the role is far more complex and wide-reaching, with support ranging from logistical assistance to medical coordination to emotional strength, and much more.

In early 2022, Kyowa Kirin and its partners conducted a survey that found care partners spent an average of ~46.7 hours/week assisting their loved one with Parkinson's disease — more than a standard work week. When you consider that they also may be dealing with their own health issues, demanding careers, young children or aging parents, a greater understanding of the challenge they face emerges.

Interestingly, even in the face of these challenges, many care partners have shared that it is an incredibly meaningful role — one that often results in closer, more fulfilling bonds with their loved ones and others in the community.

Related Survey Question:

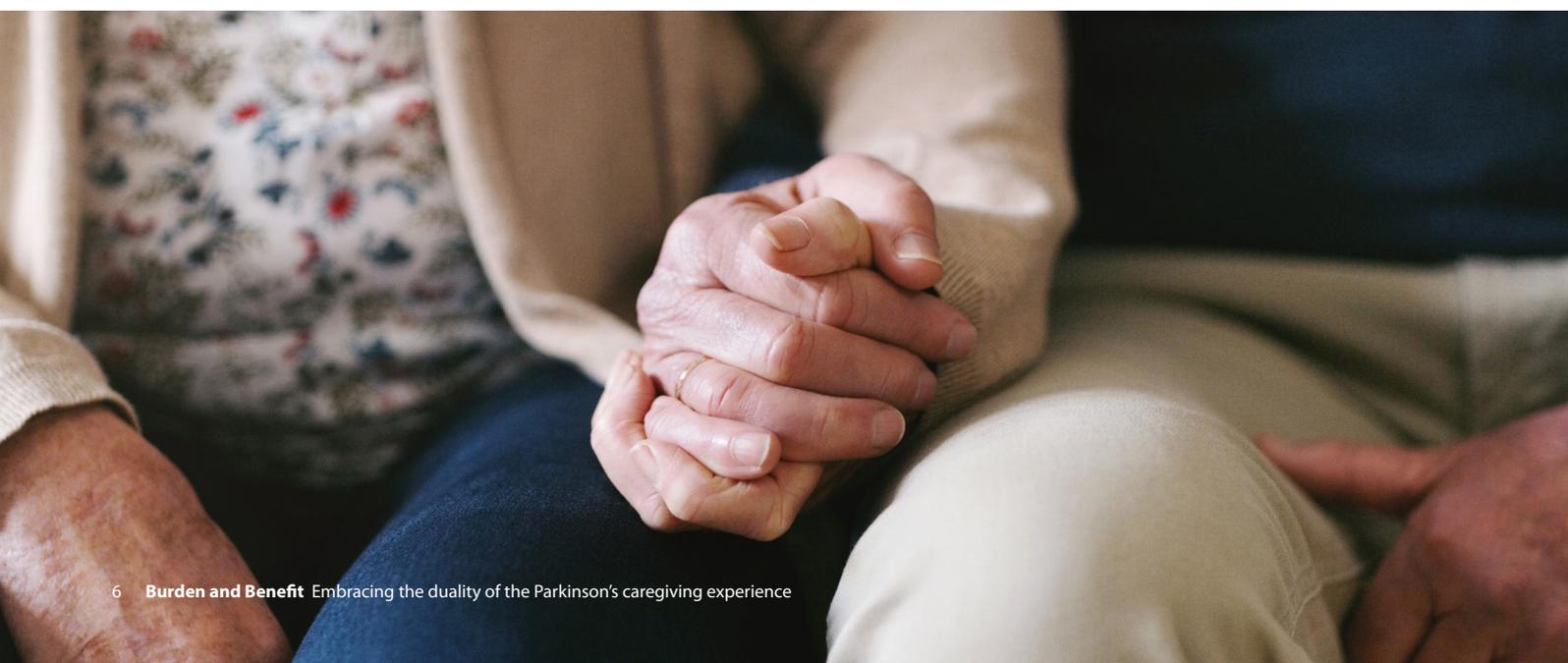
S5. In an average week, how many total hours do you spend doing specific tasks related to caring for someone with Parkinson's Disease?

This document summarizes key insights and advice from the survey and roundtable participants. It explores the difficult moments that you may face as your loved one grapples with Parkinson's disease, along with the bright spots that may be found throughout the journey, often by having a sense of humor, forging deeper connections with loved ones and discovering a greater sense of self. It is important to note that the suggestions in this whitepaper were provided by survey respondents and roundtable participants for Parkinson's care partners and are not meant to replace medical care or advice, but rather to provide additional insight to the support received from qualified healthcare professionals.



Love is at the center of the care partner-patient relationship."

**Parkinson's disease advocate,
roundtable participant**



Parkinson's Disease Care Partner Profile

Data cited throughout this document are from the 2022 Care Partner Survey



82% were spouses or significant others



Spent an average of **~46.7 hours/week** on caregiving

65

~65 years of age on average



Had been a care partner for **~7 years**

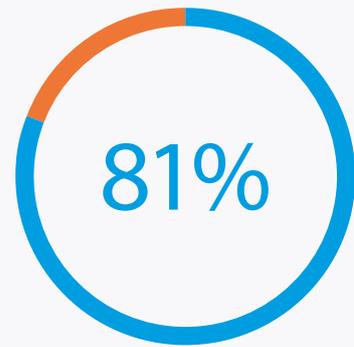


Main responsibilities included providing emotional support, participating in healthcare discussions and managing healthcare/logistics

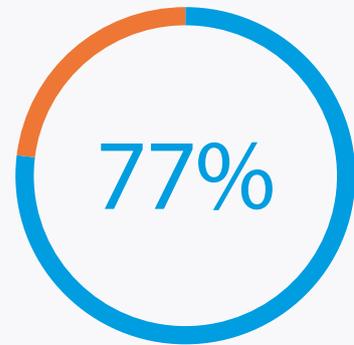
Survey fielded from February 28 to March 22, 2022 and included 752 Parkinson's disease care partner respondents.

Demographic Data and Related Survey Question:

Q16. What are your primary responsibilities as a care partner for someone with Parkinson's Disease?



of survey respondents said caring for someone with Parkinson's was the **hardest thing they'd ever done**



of survey respondents said caregiving had **strengthened their relationship** with the person with Parkinson's

The impact of caregiving in Parkinson's disease

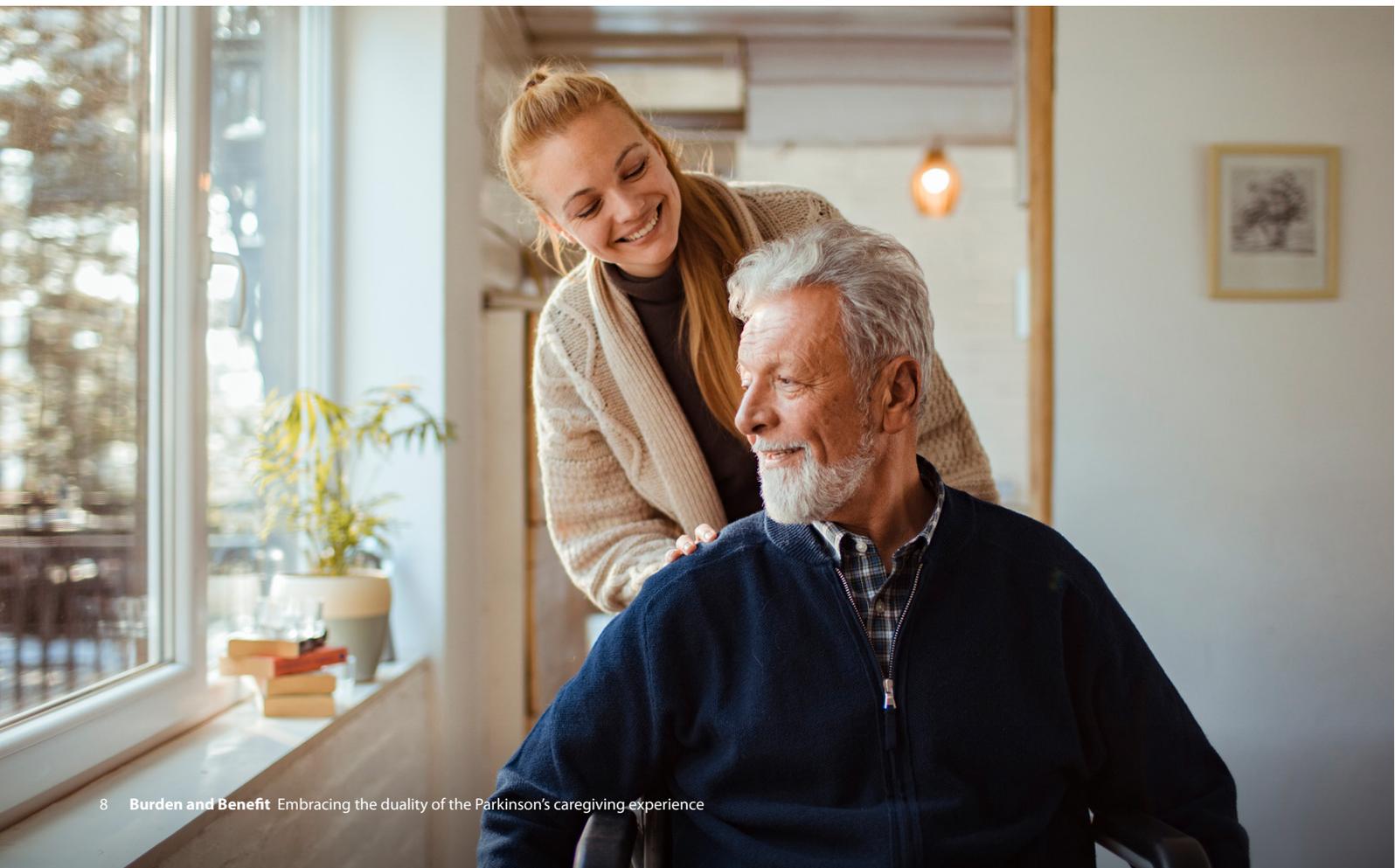
While a new diagnosis of Parkinson's disease is usually communicated plainly to a patient, less attention may be focused on the experiences you may face as a care partner. Ideally, roundtable participants said conversations about patient care and care partner education should begin the moment a loved one is diagnosed.

Every care partner in Parkinson's disease has a unique experience, just as every patient has a distinct journey. Your personal experience may be influenced by many factors, including the stage of your loved one's disease (early versus late), age, health literacy and mindset, as well as other personal daily responsibilities. What defines your role may also evolve over time.

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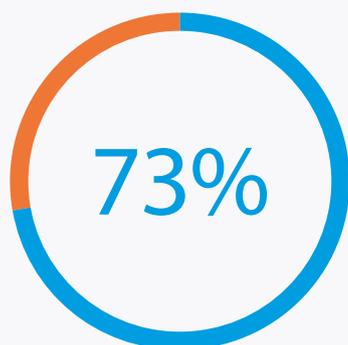
I think caring for a loved one with Parkinson's disease, in many ways, can push you to become a better version of yourself.”

**Parkinson's disease care partner,
roundtable participant**



Despite the vast differences which may exist between any two caregiving experiences, there was a recurring theme of a burden/benefit duality that emerged from the 2022 survey results and roundtable discussion: the idea that despite the immense challenges care partners face, there were also positive aspects gleaned from this role. How care partners described their experience in the survey ranged from “isolating” and “overwhelming” to “loving” and “rewarding.”

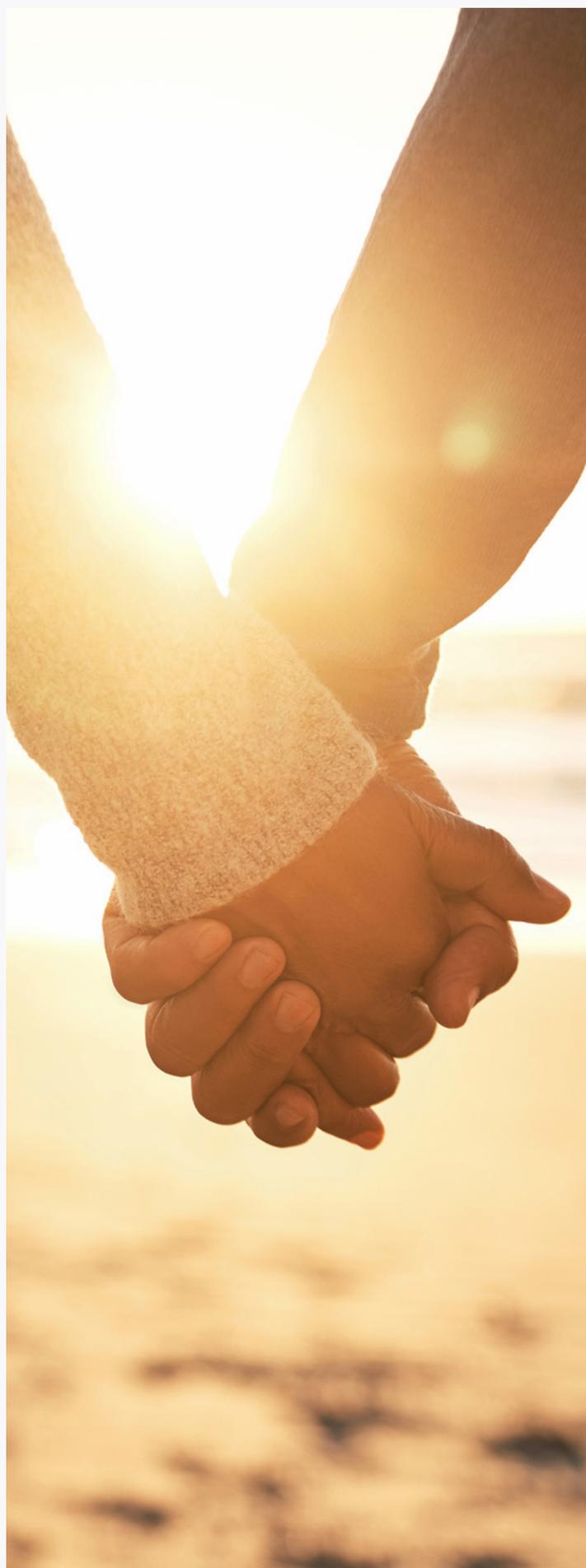
The following section explores aspects of this duality further, delving into the burdens and benefits that you may face at some point in your journey. Finding the positive points and celebrating the small victories or shared experiences along the way may help fuel you and your loved one through the more challenging periods.



of survey respondents said **the top challenge of being a Parkinson's disease care partner** was watching the patient's symptoms worsen*

* Related Survey Question:

Q18. Which, if any, of the following are the MAIN challenges you face as a Care Partner for someone with Parkinson's Disease? Additional challenges survey respondents could choose which weren't noted above include: communication, disease understanding, financial barriers, new treatment/therapies and access to resources.



THE CONNECTION/DIVISION DUALITY: RELATIONSHIP DYNAMICS

The relationship between a care partner and his or her loved one can change over time: sometimes you may feel more **connected**, while at other times, you may feel more distant or **divided**. One person living with Parkinson's disease described it as a dance – sometimes you lead, other times your partner does, and as the dance continues, you may move from being closer together to farther apart and need to learn new steps in between.

Based on learnings from our survey and roundtable discussion, it is clear that the changing dynamics of a relationship can be difficult to accept and manage. If the person with Parkinson's is your mother or father, you may struggle with seeing your once strong and independent parent become increasingly more dependent for basic tasks. If you are a spouse who long awaited the "golden years," you may be resentful at how the burden of caregiving has changed your retirement plans. If you are a friend, you may have a hard time connecting with someone whose personality appears to change as the disease progresses.

At the same time, there can be positive aspects associated with this changing dynamic. During the roundtable discussion, a participant spoke about the renewed inner strength and empowerment she found in her role as care partner, while another shared how living with Parkinson's helped him become more emotionally available and grateful for those around him and the time they have together, leading to a new level of closeness and mutual appreciation.

Related Survey Question:

Q17. What has been the most challenging responsibility or activity for you as a care partner of someone with Parkinson's Disease?

To help set the foundation for a positive and supportive relationship as a care partner, roundtable participants stressed the importance of tackling sensitive and difficult topics early in your loved one's journey. The reality is that different abilities may be compromised as the condition progresses, such as driving, time management, keeping track of important information and more. Parkinson's can also affect intimacy due to the nature of the disease, medication or the associated stress. It is better to discuss any concerns, associated feelings and needs early on, in a calm and loving way, so that a plan for handling them can be developed together.



A key challenge is keeping my relationship as spouse from being lost in caregiving."

**Parkinson's disease care partner,
survey respondent**



My relationship with my wife has always been good but after my diagnosis, I was finally able to give her the emotional access she had craved for years. This was an unexpected gift that Parkinson's disease gave me."

**Person living with Parkinson's disease,
roundtable participant**

THE NEED/SUPPORT DUALITY: EMOTIONAL HEALTH

An unfortunate irony is that as care partners provide emotional **support** to their loved one, often their own emotional health **needs** go unrecognized. The vast majority (93%) of survey respondents said that their primary responsibility as a care partner was to provide emotional support, yet more than 70% also noted that caregiving had the largest negative impact on their own emotional and mental health.

Loneliness was common — 82% of survey respondents agreed that caregiving made them feel lonely at times. To combat the isolation, survey and roundtable participants shared that connecting with other care partners, through Parkinson's disease support groups, online forums or otherwise, can be a great source of support. Building a support system early on may help you cope with the challenges, both mentally and physically, associated with later stages of the disease.

By being aware of the emotional toll associated with caregiving, you can try to manage or limit the contributing factors that lead to burnout and, at the same time, focus on your own health. For instance, sleep problems may exacerbate mental health conditions such as depression and anxiety — 54% of the survey respondents noted they were unable to sleep or had their sleep interrupted due to their loved one experiencing an "off" episode. Establishing a healthy sleep routine can be a useful step towards protecting your own emotional health.ⁱⁱ

With all of this said, given the multifaceted and evolving nature of Parkinson's, individual experiences can vastly differ from one another, making it essential that you weigh your own circumstances against any recommendations you're given by others or read online.



My emotional as well my mental health was negatively impacted due to high stress of caregiving responsibilities which resulted in depression, fatigue and social isolation."

**Parkinson's disease care partner,
survey respondent**

Related Survey Questions:

Q16. What are your primary responsibilities as a care partner for someone with Parkinson's Disease?

Q17. What has been the most challenging responsibility or activity for you as a care partner of someone with Parkinson's Disease?

Q19. What impact has caring for someone with Parkinson's Disease had on each of the following aspects of your life?

Q20. How much do you agree with each of the following statements?

Q22. Which, if any, of the following scenarios have you experienced because of an "OFF" episode?

Q25. What, if any, of the following are your top three preferred activities/resources for helping you manage being a care partner to someone with Parkinson's Disease?

THE STRAIN/REWARD DUALITY: LIFE LOGISTICS

The everyday tasks of managing a typical household are often shared between family members, with each person taking on roles that naturally fit their strengths, abilities or interests. As Parkinson's disease progresses, your loved one may need more assistance and many or all of their daily household tasks may become your responsibility. This can become a **strain** — adding to an already heavy load. Others in your position have described this feeling as “juggling many balls in the air,” causing them to feel exhausted by daily responsibilities.

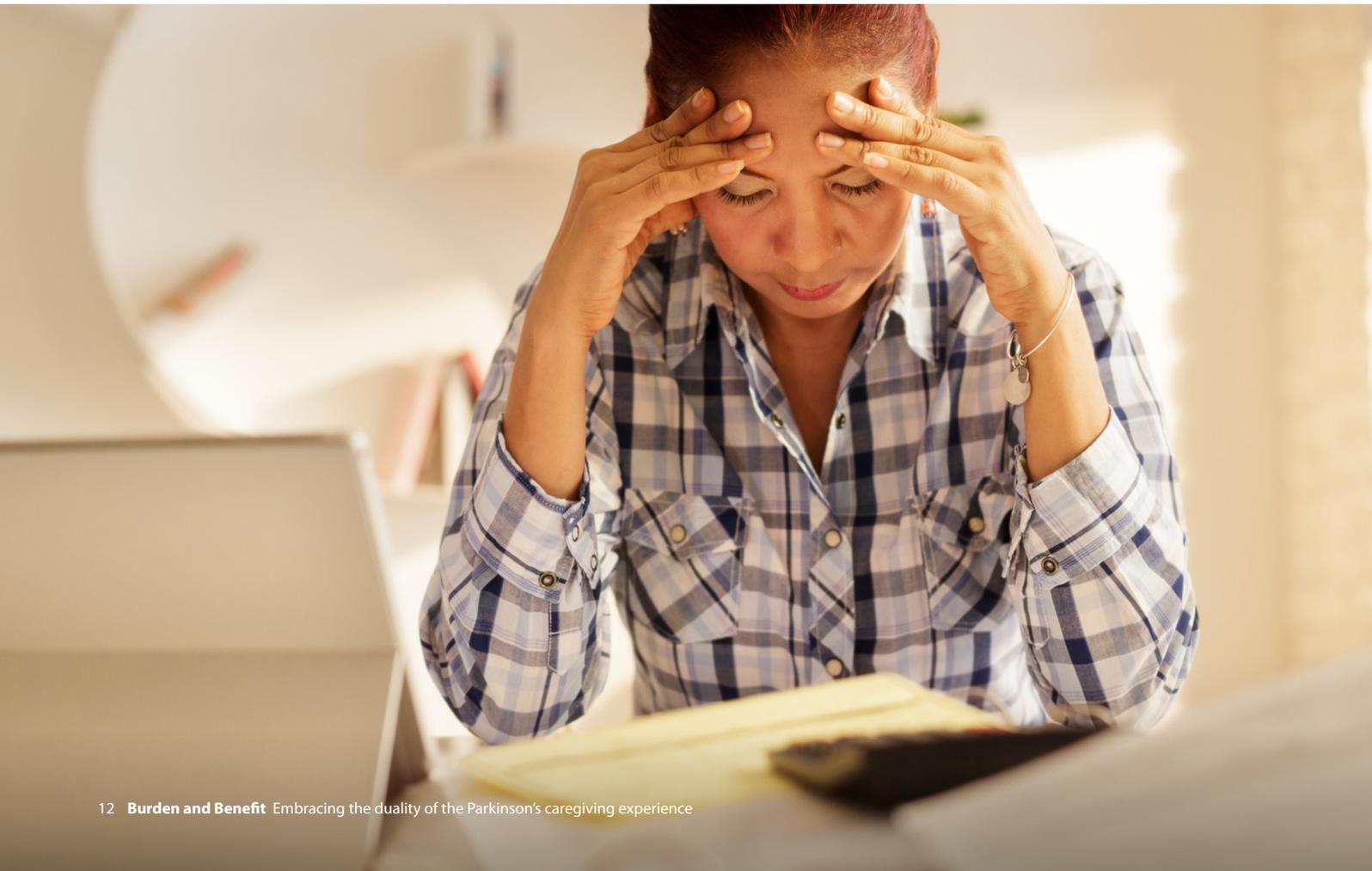
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It's a challenge to learn how to deal with the cascade of loss, while simultaneously trying to stay on top of the growing list of responsibilities and needs for the person with Parkinson's disease and our household.”

**Parkinson's disease care partner,
survey respondent**

Related Survey Question:

Q17. What has been the most challenging responsibility or activity for you as a care partner of someone with Parkinson's Disease?



Survey and roundtable participants suggested taking the time to consider who has the best skills (or interests) to take on certain logistics and activities. For instance, if you find driving stressful, then it may be best to ask another family member or friend for help with transportation or consider using a car service. If household cleaning is a task that is more easily outsourced, then consider bringing in outside help. If family and friends are offering to help, find specific tasks where they can step in. Remember that no one can do everything alone and it's okay to find help for activities you find particularly burdensome.

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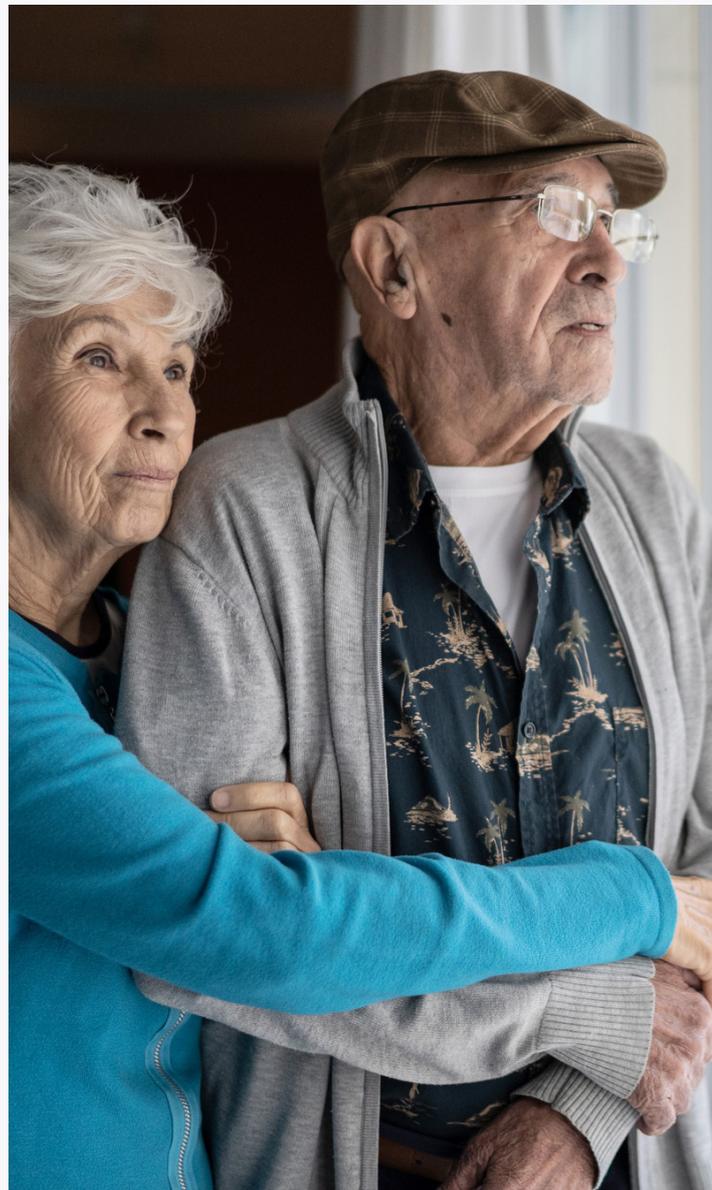
I find it fulfilling when I can solve a problem for my husband — like buying a chair that helps him stand on his own. He was so grateful to be more independent and it made me feel so good to do this for him.”

**Parkinson's disease care partner,
roundtable participant**

Related Survey Question:

Q23. What advice would you give someone who is just starting to care for someone with Parkinson's Disease?

The roundtable discussion also identified some hidden **rewards** that can come from daily logistics. Working through a checklist and helping to keep your household on track can be surprisingly fulfilling. Taking the time for self-reflection about your own strengths and allowing others to fill in the gaps can be empowering. Finding solutions to help your loved one maintain independence or preserve their quality of life can also be immensely gratifying.



THE INSIDER/OUTSIDER DUALITY: MEDICAL INFORMATION AND CARE

According to survey respondents, carrying the weight of responsibility for a loved one's health and treatment can be both satisfying and overwhelming. Care partners play a pivotal **insider** role as part of the medical care team, often handling responsibilities for medical appointments, medications and follow-ups. Yet many expressed feeling like an **outsider** when it came to fully grasping complicated medical information and patient care needs.

As the eyes and ears of the medical team outside of routine appointments, care partners are in a unique position. Survey respondents reported that they are often the first to notice changes in Parkinson's symptoms, have witnessed "off" episodes — when symptoms return as the full effects of medication wears off — or have observed subtle differences in their loved one's personality or behavior. They saw tracking and communicating these updates to the medical team as an important task.

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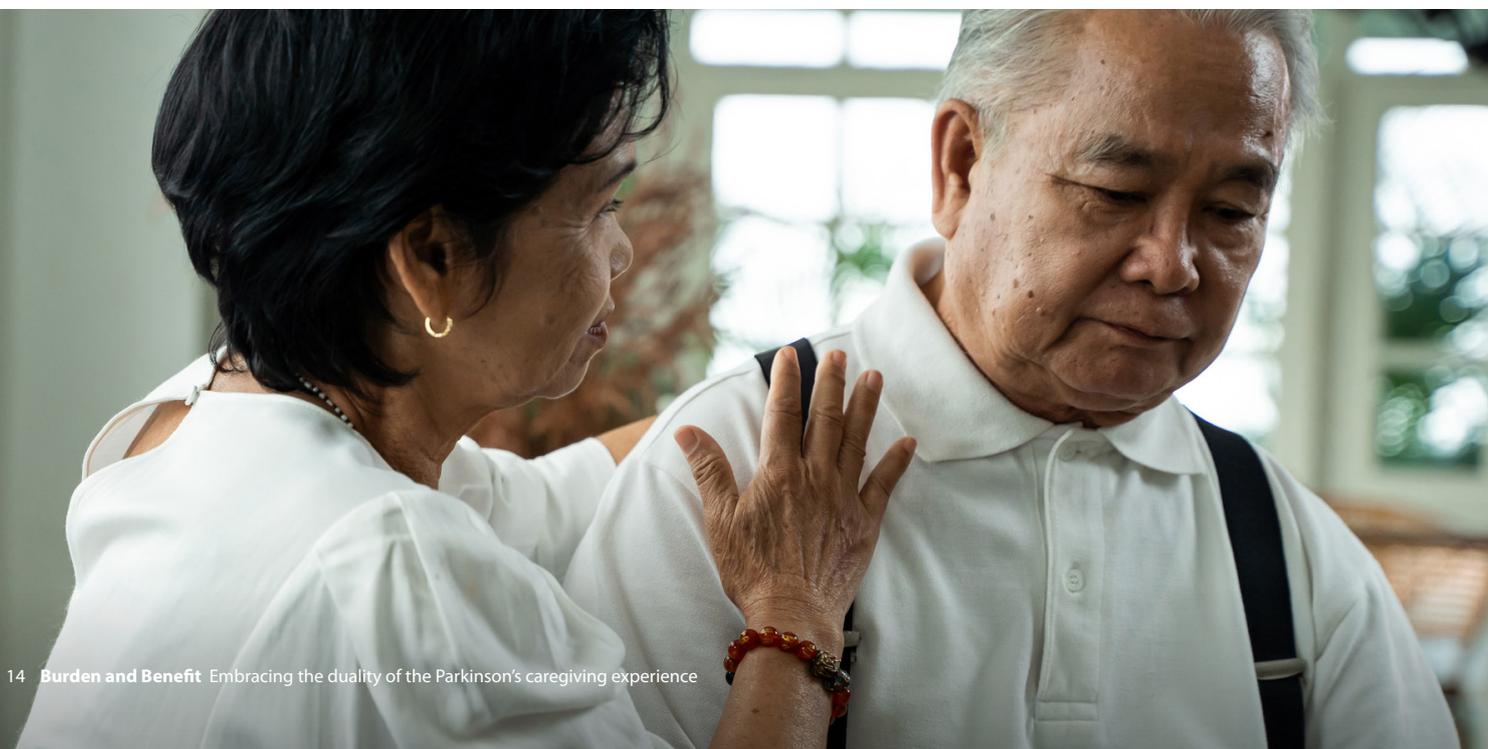
Despite the fact that I engage in all meetings with the healthcare team, I often find myself unable to comprehend the majority of what is said when physicians discuss topics such as Parkinson's disease progression or new symptoms that may develop in the future.”

**Parkinson's disease care partner,
survey respondent**

Related Survey Questions:

Q16. What are your primary responsibilities as a care partner for someone with Parkinson's Disease?

Q17. What has been the most challenging responsibility or activity for you as a care partner of someone with Parkinson's Disease?





Guiding principles

When people are first diagnosed with Parkinson's disease, they often receive brochures and pamphlets filled with information about the condition. Care partners, on the other hand, said they are often left in the dark about their new role and are expected to do their own research, often making it all the more confusing and overwhelming.

During the roundtable discussion, advice for care partners was discussed at length. A common theme emerged around accepting and (ideally) embracing the role of care partner from the start. Doing so early, collecting useful information and starting to plan for the future may allow you to move forward with confidence and may be key to reducing anxiety as changes eventually occur.

With this in mind, following is a suggested list of actions from survey and roundtable participants. While every point will not be relevant for everyone, it summarizes things to consider as you plan for the road ahead.

ENGAGE THE PATIENT AS A PARTNER

A perhaps unexpected point was made that the person with Parkinson's disease also has a responsibility to the partnership, to be accountable for striving to be the best partner and patient possible. To forge a successful collaboration, both sides of the partnership need to be "all in" and work together to tackle the challenges Parkinson's may present along the way.



The burden of care shouldn't be 100% on the care partner. The patient can and should strive to be the best patient and partner possible. Finding and managing that equilibrium is important."

**Person living with Parkinson's,
roundtable participant**

ADOPT A LEARNING MINDSET

Just as your loved one's needs may differ at each stage of the disease, the skills and knowledge that you need may also evolve. Being informed and prepared, from early on, can arm you with the tools to confidently manage decisions and potentially lessen the anxiety and stress that can accompany this role. Staying flexible and open to new solutions may help you to manage the challenges of day-to-day life for you and your loved one — from learning about household tips to gathering advice from a support group to understanding treatment options. Embracing tools and technologies can also be an asset for caregiving, such as keeping a journal of symptoms or updating medical portals.



My advice is to gain knowledge, learning and awareness upfront to prepare for what is to come — while building resiliency and staying flexible in the event of unexpected changes.”

**Person living with Parkinson's,
roundtable participant**

BE PROACTIVE

Good preparation may help reduce your anxiety and stress. Setting expectations, making plans for the future, tackling issues proactively and reevaluating them routinely may help you build a solid foundation and potentially curb problems down the road. Being proactive is not limited to making plans for your loved one. In fact, you are encouraged to discuss your own needs with the patient and make it clear that certain activities will be prioritized, such as taking care of your own health, maintaining a social circle or exercising every day.



Learn as much as you can about Parkinson's disease. Set realistic goals for yourself and your loved one.”

**Parkinson's disease care partner,
survey respondent**

Related Survey Question:

Q23. What advice would you give someone who is just starting to care for someone with Parkinson's Disease?



PRIORITIZE HEALTH AND WELL-BEING

As a care partner, you may find yourself putting your personal health and priorities on the back burner to support your loved one. In fact, more than half of survey respondents said one of their biggest challenges was finding time to take care of themselves. The findings drive home the importance of taking care of yourself so that you are better able to take care of your loved one. From the outset of the treatment journey, mutual health and well-being should be a regular topic of conversation with your loved one. Develop a plan and check in regularly. Identify what will keep you healthy and strong — physically and mentally. By prioritizing what fills your own “bucket” — whether it be exercise, meditation, regular breaks, lunch with a friend or going for a walk — you can become a stronger version of yourself and, consequently, provide better support to your loved one.

FIND MULTI-DISCIPLINARY CARE

Roundtable participants suggested visiting a Movement Disorder Specialist (MDS) center because they offer a high level of integrated care for people living with Parkinson’s disease and their care partners, including neurologists, nurses, speech, occupational, and physical therapists, mental health professionals, social workers and more. If it’s not possible to receive ongoing care from an MDS (due to geographic location or otherwise), visiting an MDS center once may provide a holistic view of the care required. The experience can then be replicated locally through a variety of care services. An important aspect of care, wherever it is received, is to communicate with the care team both at and between visits. Health portals can be good tools to facilitate connections with different specialists and to get questions addressed between visits. Understanding what ideal care looks like, early on, can serve as a north star as you and your loved one chart a path forward.



Going even one time to an MDS center can set a new bar in terms of the level of care and support provided. It allows you to see what’s possible and enables you to recreate it for yourself locally.”

**Parkinson’s disease advocate,
roundtable participant**

Related Survey Question:

Q17. Which, if any, of the following are the MAIN challenges you face as a Care Partner for someone with Parkinson’s Disease?



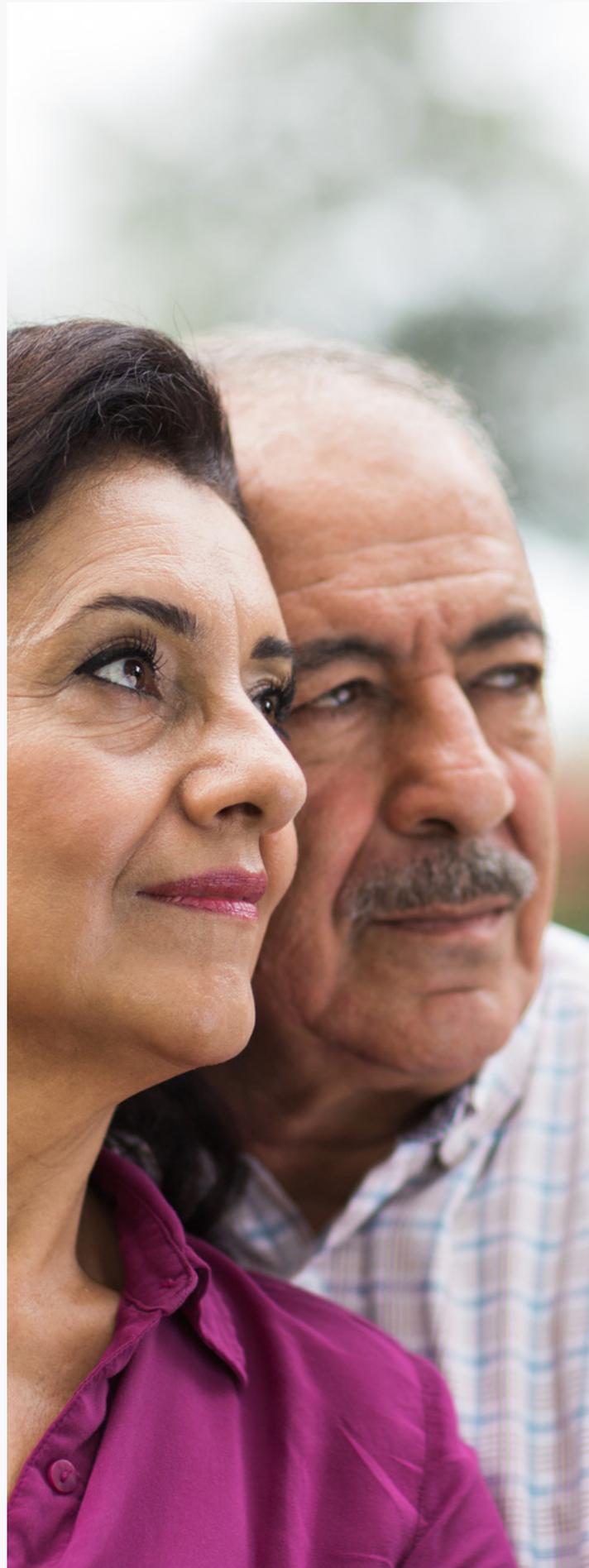
DON'T WAIT, COMMUNICATE

As Parkinson's disease progresses, your loved one may experience new or worsening symptoms or periods of "off" episodes. It's important that you communicate any changes to your medical team so that action can be taken as promptly as possible. Take note of the situation, record how often and when symptoms or "off" episodes occur, note when medications are taken and any additional information that may be relevant to the medical team. If you are between visits, use a health portal to update the team or ask to speak with your loved one's treating physician. Having an open and ongoing dialogue with the medical team, including discussing treatment changes or new ways to manage "off" episodes, may help you feel better supported and ensure your loved one is receiving the best care possible.



Once your loved one is diagnosed, you have suddenly become a care partner and you need to understand what that means. That does not change your relationship as spouse, partner or child, but now you are an important part of the overall healthcare team, along with the doctor, patient, nurses, social workers and others."

**Parkinson's disease advocate,
roundtable participant**



SEEK PROFESSIONAL COUNSELLING AND SUPPORT

Therapy can be an outlet for you and your loved one (if they are willing) and provides an opportunity to grieve the changes in the relationship, as well as learn how to adapt to your new normal. Counselling can help you process intense and complex emotions and help to evaluate and reinforce positive choices and routines. Many care partners will experience some level of trauma with the diagnosis or from the continued stress, which could lead to mental health issues such as depression or anxiety. Coping with trauma and restoring resilience is important to maintaining a healthy care partner-patient relationship. While depression and anxiety can be overwhelming, there are approaches to help you maintain a balanced life.ⁱⁱⁱ



Getting support can help you feel less alone and more confident in your capacity to care for others.”

**Parkinson’s disease care partner,
survey respondent**

OFFER AND ACCEPT HELP

It may seem counterintuitive to help others when you may be feeling stretched in this role, but even the simplest actions can provide affirmation and joy. Providing help and advice can also provide perspective in how far you have come as a care partner. Conversely, it can be beneficial to outline specific areas where you need assistance (e.g., picking up medication, needing help with financial planning, providing a ride to an appointment or cooking a meal). Begin by reflecting on your own strengths and limitations. This can help identify key places where others can step in. By defining these specific tasks, you can more easily see where help is needed and find assistance on a consistent basis.



No one should have the expectation that the care partner can fill every role. Play to your strengths and fill in the gaps. Take on the tasks that you can confidently handle and ask for help when you need it.”

**Parkinson’s disease advocate,
roundtable participant**

Related Survey Question:

Q23. What advice would you give someone who is just starting to care for someone with Parkinson’s Disease?

LOOK FOR THE BRIGHT SPOTS

Providing care for someone with Parkinson's disease is filled with challenges, but there will likely be bright spots along the way. Taking note and recording these in a journal or through photographs may be beneficial. It may take some time to spot the positive aspects of caregiving, but others have reported experiencing closer relationships, feeling more gratitude, spending more time together, having deeper connections and more. A positive mindset and sense of humor can help to create an uplifting atmosphere and reduce stress and tension.

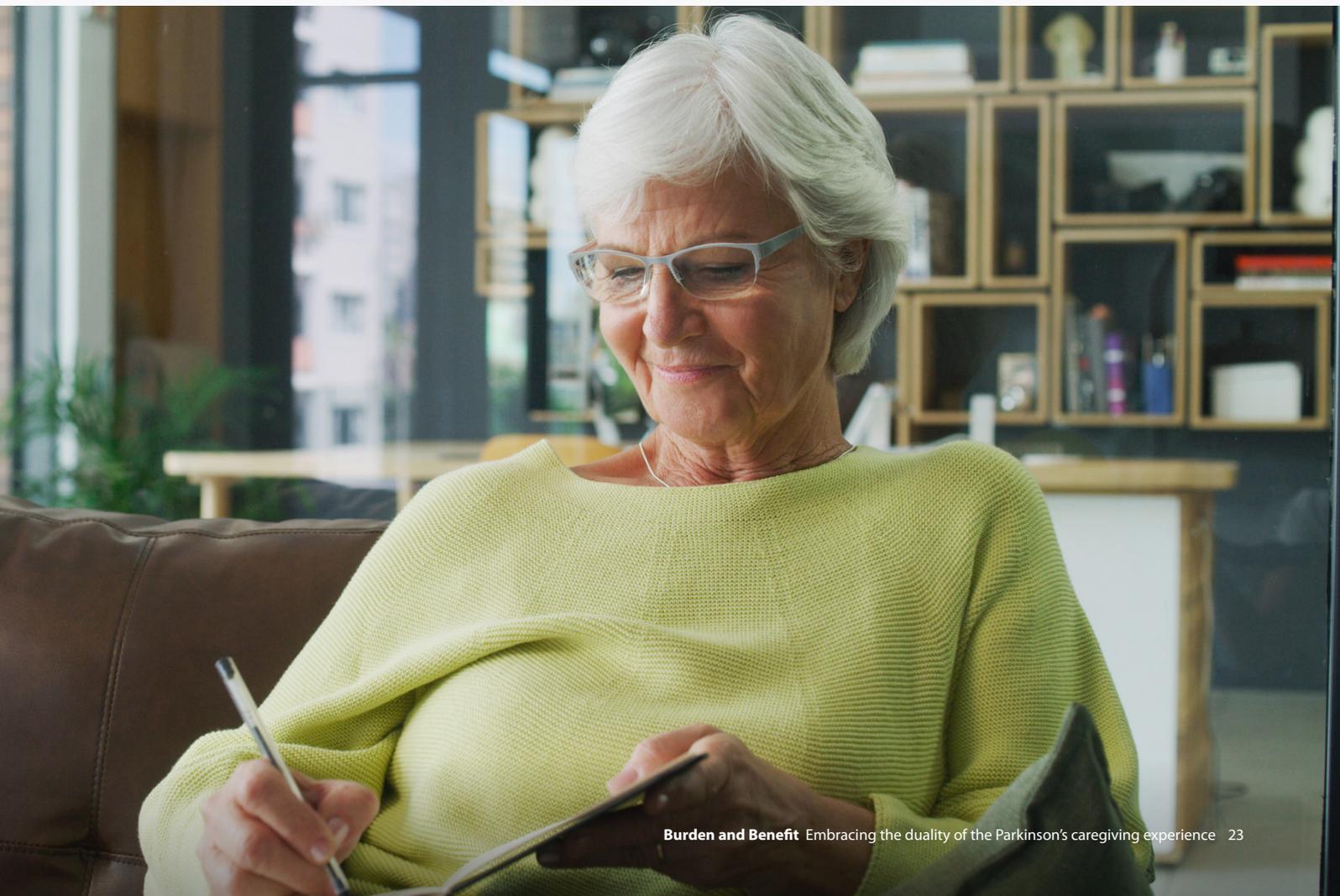
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Remember that they are still the same wonderful person they always were — continue to treat them with respect and love with a bit of humor thrown in.”

**Parkinson's disease care partner,
survey respondent**

Related Survey Question:

Q23. What advice would you give someone who is just starting to care for someone with Parkinson's Disease?





Resources

The patient's healthcare team can be one of your most important resources. This can be supplemented with additional sources of information and support such as connecting with other care partners.

The following resources were selected by our partners as some of the most relevant and helpful for those serving as a care partner. Even if some aspects aren't relevant immediately, compiling information and "filing it away" for later use as needed will ensure important information will be on-hand.



The Every Victory Counts® Manual for Care Partners

A manual that includes some of the most frequently asked questions received from Parkinson's care partners over the past 18 years, with responses from the Davis Phinney Foundation for Parkinson's, Parkinson's experts and Parkinson's care partners. It is designed to be accessible to all care partners, whether you care for someone young, newly diagnosed or in the advanced stages of Parkinson's.

Monthly Live Parkinson's Care Partners Virtual Meetup

One-hour sessions where Connie Carpenter Phinney, Davis Phinney Foundation Ambassadors and care partners, Pat Donahoo and Gail Gitin discuss the concerns, challenges and questions that many Parkinson's care partners face.

Parkinson's Care Partner Resources

A collection of the most popular and helpful Parkinson's care partner resources that can help you live well while also providing the best care possible for your loved one.

Getting Real!™ Online

A virtual community for care partners, adult children and family that includes an on-demand educational video library covering topics from symptoms, practical tips for management, to support in short, bite-sized videos you can access anytime day or night. Getting Real!™ Online also features a monthly social worker facilitated support group called Real Talk.

Neuro Life Online®

A program that puts you in touch — in real-time — with a community of experts and movement disorder allies. Wherever you live, through interactive access, the program addresses everyday strategies and the potential of the whole person to live, move and thrive. The online programs feature a variety of topics and experts that help arm you with the knowledge and tools to navigate your journey with Parkinson's.

emPowered!®

A tool to help families, loved ones and physicians communicate effectively with each other. The goal is to surface a handful of issues that present significant challenges, impacting your quality of life.



As overwhelming as it can be to take on the role of a care partner, it can be helpful to draw strength from the many people who have walked this path before.

By reaching out to the Parkinson's disease community for support and guidance, it is possible to find the inner strength to get through the tough times and discover the positive moments along the way.

i Parkinson's Foundation. Statistics. Accessed July 2022. <https://www.parkinson.org/understanding-parkinsons/statistics>.

ii Franzen PL, Buysse DJ. Sleep disturbances and depression: risk relationships for subsequent depression and therapeutic implications. *Dialogues Clin Neurosci*. 2008;10(4):473-481. doi:10.31887/DCNS.2008.10.4/plfranzen.

iii Anxiety and Depression Association of America. Treatment. Accessed July 2022. <https://adaa.org/understanding-anxiety/depression/treatment>.



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