Care Partner PPE (Prepared, Proactive and Energized): Strategies to Boost Care Partner Coping

In December 2022 the World Parkinson Coalition held the fourth and final session of the year in its Care Partner Virtual Talk Series. Elaine Book, MSW, RSW, from the Pacific Parkinson’s Research Center at the University of British Columbia moderated the webinar. The panel shared tools and tips related to coping and self-care along your journey as a care partner of a Person with Parkinson’s (PwP).

Kate Lorig, Dr.P.H. – Professor Emerita, Stanford University School of Medicine

It’s important to recognize that while as care partners you didn’t choose for your PwP to have Parkinson’s, you did choose to accept the role and should be commended for this. With this choice comes a lot of uncertainty, including questions about how your PwP’s disease will progress, how this will affect your daily lives moving forward, and how you will be able to cope with the challenging emotions, like anger, that inevitably come up. There are tools that can help you improve your life and the life of your PwP:

Effective self-management occurs when you cultivate coping tools and you have the skills and confidence to use them. These tools can give you a few seconds of time to break the cycle of whatever may be going on and regroup. One useful mindfulness tool is sometimes called Thoughtful Breathing:

1. Breathe in through your nose.
2. Breathe out slowly — at least 3x as long as your breath in.
3. Repeat two more times.

Action planning is making a plan for what can be done realistically in a certain period of time. The simpler and easier the better, including breaking down larger projects into baby steps.

Problem solving comes into play when your PwP becomes resistant to the current action plan and/or displays challenging behaviors. It’s helpful to identify the behavior trigger, how it typically plays out, and then explore ways to change the cycle. This process takes practice.

Karen Chinca, LICSW – Care Partner to her late mother

Cognitive Behavioral Therapy (CBT) is a technique that can help care partners along their journey. It’s based on the belief that people’s feelings of distress may in part be based on faulty or unhelpful ways of thinking. It offers techniques to examine and change our thinking patterns, face our fears, and recognize the connection between our mind and our emotions.

Different types of faulty or dysfunctional thinking patterns include:

• **Catastrophizing** — “Everything is going to be terrible during the holidays because my PwP’s condition is getting worse.”

• **Making predictions/jumping to conclusions without any evidence** — “Something bad is going to happen to my PwP if I do/don’t ______.”

• **Personalizing** — “It’s all my fault that ______.” or “I should be ______.”

• **Black/white thinking** — “I’m a bad daughter because I don’t go see my mother every day.”

In response, CBT encourages us to change our thinking pattern by weighing the evidence and asking:

1. Is this thought really true?
2. What’s the evidence for/against this thought?
3. How does this thought make me feel?
4. Is this thought useful?
5. What would a friend say?
6. What is a more accurate thought?
7. Does this new thought make me feel better?

Using these tools requires practice, which builds good habits and neuroplasticity — like building a muscle in your brain. It allows us to lean into our emotions rather than pushing them down or reasoning them away.

It’s important to use the self-care tools that help and speak to you. These can include movement, nutrition, sleep, social connections, family support, having fun, maintaining a spiritual practice, creative expression, hobbies, therapy and mindfulness/meditation.
**Ujjayi Breathing** soothes your nervous system, calms your mind, slows your heart rate, and lowers your blood pressure:

1. Breathe in slowly through the nose, expanding your diaphragm (abdomen).
2. Breathe out through the mouth, engaging your throat (like you’re trying to fog up glass).

*(See Links and Resources for apps that can help with meditation and mindful breathing.)*

**Rebecca Gifford – Writer and workshop facilitator, Care Partner to husband diagnosed in 2017**

Writing and journaling can be powerful tools in your care partner coping and self-care tool box. It can help you:

- Express and release emotions
- Break the stress cycle or feelings that overwhelm you
- Reflect on your experiences and clarify your feelings
- Deepen your relationship with yourself and your inner world
- Have fun exploring your creativity
- Build in time that is just for you

The idea of journaling can be intimidating, but it’s important to keep in mind that it can be a lot easier to add to your tool box than you may think. It’s your time and your space to express and be creative. Use it in whatever way is helpful for you.

Some tips for demystifying journaling and adding it to your tool box include:

- Use whatever tools you like — No need for a fancy journal or special pen.
- Forget the notion that you have to write “well.”
- Forget about any “shoulds” as far as length of time or frequency — Even five minutes (or less!) helps. The more you use it, the more available the tool will be. But even if you take a break for while, your journal will be there when you need it.
- Set up the support you need to give yourself this time.
- Use prompts if it helps — You don’t need to overthink it, but sometimes simple exercises can help. *(See Links and Resources for some prompt resources.)*
- Try writing with a buddy or take an online workshop if this helps you stay motivated and accountable for your journaling time.

**Links and Resources:**

- Headspace: [https://www.headspace.com/](https://www.headspace.com/)
- Calm: [https://www.calm.com/](https://www.calm.com/)
- Meditation Oasis: Simply Being: [https://www.meditationoasis.com/simply-being-app](https://www.meditationoasis.com/simply-being-app)
- The Breathing App: [https://apps.apple.com/ca/app/the-breathing-app/id1285982210](https://apps.apple.com/ca/app/the-breathing-app/id1285982210)
- Writing Down the Bones Deck: 60 Cards to Free the Writer Within: [https://nataliegoldberg.com/](https://nataliegoldberg.com/)
- Eckhart Tolle: [https://eckharttolle.com/](https://eckharttolle.com/)

---

**Watch the Webinar**

[https://www.worldpdcoalition.org/3rdcarepartner](https://www.worldpdcoalition.org/3rdcarepartner)

---

*This resource was made possible with support from Supernus Pharmaceuticals and Kyowa Kirin.*

“*My writing time is important to me because it is one way I stay in touch with myself, my needs, my joys, my grief. I dearly love my husband, but my most important relationship is with myself.*”

— Rebecca Gifford, writer and Care Partner