

# Sleep Issues & Care Partners

Sleep Is Essential for  
Everyone, Including  
Care Partners

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Caring for another human being is one of the most incredible acts of love there is. As we get older and/or a loved one is diagnosed with Parkinson's the level of care required can change. With Parkinson's the need for care typically changes gradually, over time. Sleep (or lack thereof) is one of the ongoing changes that can wreak havoc on both the person with Parkinson's AND you as a loved one. Without adequate sleep, you may find yourself more irritable, physically weaker, less patient, lacking focus, and generally exhausted.

You may find yourself struggling to manage expectations (of yourself, your loved one, and others). You may find yourself "nagging" or snapping at your loved one or others more, leading to increased feelings of guilt. As a care partner you may find yourself often minimizing your own sleep issues and feeling that your sleep is less important than what is happening with your loved one. You may think that you can "get by" on limited sleep and "catch up" on that missing sleep later.

Research indicates that "up to 76% of caregivers report poor sleep quality, and the proportion is considerably higher for female caregivers compared to male caregivers."<sup>1</sup> This number increases exponentially (up to 92%) when the care partner is providing advanced care or the person, they are providing care for has significant cognitive issues. In general, poor sleep quality in care partners can be attributed to two causalities: 1) those associated directly with the act of providing care such as increased role overload, lack of support, stress, physical and mental challenges in



one's own day-to-day. And 2) those associated directly with the actions of their loved one such as a loved one's insomnia, REM Sleep Behavior disorder, nighttime wandering, frequent trips to the bathroom, etc.

Let's address those sleep issues associated directly with the act of providing care first. Sleep is essential for everyone, including care partners; but between regular life and caregiving responsibilities getting enough quality sleep can be a big challenge.

- » **Increased responsibilities** – You may find yourself taking on household responsibilities that were once your loved one's domain when they are no longer able to manage such tasks safely or effectively. Things like driving, cooking, yard work, banking, laundry, etc. may not seem like huge, earth-shattering tasks, but the little things add up and can make it difficult to feel like you can get it all done in a day. You may find yourself getting up earlier or staying up later to get your growing to do list completed.
- » **Change in routine/role** – As the need to provide care for your loved one increases; you may find your own health and self-care routine gets eroded – after all there are only so many hours in a day. You may put off your own medical appointments and have less time for fresh air, exercise, relaxation, social connections which can all reduce stress and promote sleep. You may also find yourself consuming more caffeine to help fight fatigue and feeling "run down" which will hinder sleep.
- » **Stress/Worry** – You may find it challenging to quiet your mind – especially at night. Thinking about concerns, challenges, to do lists, or even all the "what ifs" can make it difficult to relax and fall asleep or may even wake you up in the middle of the night leading to insufficient and poor-quality sleep.
- » **Lack of support** – You may not have family available to help you and/or programs and services that help provide respite might be limited (or non-existent). And, even if either is available to you, you may find it hard to ask for/accept help or trust someone else to provide care and support for your loved one. You may also experience frustration/guilt if your loved one is struggling/not willing to accept outside help.

As you have read (or will read) throughout this issue, there are a variety of sleep-related issues in Parkinson disease. These sleep-related issues are attributed to the second causality of poor sleep for you as a care partner wherein your loved one's actions (as a result of Parkinson's and/or Parkinson-related issues) directly impact your sleep quality.

- » **Needs of your loved one** – As Parkinson's progresses and new challenges appear you will likely find yourself needing to help your loved one more frequently during the nighttime. Medication management, help to the washroom or even with repositioning in bed. Additionally, symptoms like pain, restless legs, or even anxiety can keep your loved one from sleeping, which can impact your ability to sleep as well.
- » **Sleep-Issues in Parkinson's** – From insomnia to nighttime wandering to REM Sleep Behavior Disorder there are a host of sleep-issues in Parkinson's that result in your loved one doing things (consciously or unconsciously) that impact your ability to get a good night's sleep. It could be the sound of the tv turning on at 1:30AM, or the rattling of dishes in the kitchen at midnight by your loved one who either has insomnia or can't sleep because of the excessive daytime sleepiness they've been experiencing. Maybe you've been jolted awake by your loved one yelling or even kicking or hitting you – your heart and mind racing while you scramble to figure out what the hell is going on. Or you've woken up one too many times with that cold feeling knowing something is off and finding your loved one by the open front door putting their slippers on to go outside at 3AM.

Burnout, stress, exhaustion, frustration, guilt, fear for your loved one's safety, and fear for your own safety – none of these things are conducive to getting a good night's sleep. You may find yourself asking the following questions: Do I stay up with them? Or try to settle them back to sleep? Do I force myself to try to go back to bed and then try to sleep?







### What is a care partner to do?

When your loved one has Parkinson's your advocacy role is ongoing; you cannot, however, forget to advocate for your own health and wellness too. Be sure you are bringing up sleep issues with both YOUR treating physician and your loved one's healthcare team. Having honest conversations with not only your loved one (if they are able) but with yourself can help you figure out next steps. If your loved one is cognitively unable to have this conversation or you feel like you need additional support, you may also want to consider including adult children or support network in the conversation.

Since these issues can be as varied as the people impacted by them, there is no one size fits all solution we can share in one magazine. Next steps can vary, but may include:

- » practical solutions like satin sheets/pjs for ease of movement in bed, a clear path and lighted access to the washroom, limiting liquids, and/or adjusting daytime naps.
- » purchasing mobility supplies for your loved one's safety and independence (i.e.: a bed rail, non-slip carpets, stability bars/poles).
- » consider accessing a day program if possible.
- » bringing in help (home care, family support, cleaning service, meals on wheels, etc.).
- » considering new sleeping arrangements (separate rooms); and
- » if your safety and/or your loved one's safety it may be time to consider a safer, alternate living arrangement such as a lodge or care facility.

Issues affecting sleep typically happen gradually over time; thankfully this means that we have an opportunity to seek support and create an action plan to improve sleep quality. We acknowledge that it can be hard to ask for help and advice; however, seeking support can open the door to solutions that help to promote your health and wellness. Remember, we are here for YOU as well!

#### Reference

<sup>1</sup> *How Adult Caregiving Impacts Sleep: a Systemic Review.* E. Byun, A. Lerdal, C. Gay, and K. Lee. *Curr Sleep Med Rep.* 2016; 2(4): 191-205. doi:10.1007/s40675-016-0058-8