

PARKINSON SOCIETY
SOUTHWESTERN ONTARIO

CAREPARTNER'S TOOLKIT

pssso.ca

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ABOUT US

When you or someone you love is diagnosed with Parkinson's, the first question often asked is "Where do I go?" Our answer is simple: *home*. Parkinson Society Southwestern Ontario is *home*. Home for all those living with Parkinson's Disease in Southwestern Ontario. Home for you to find services, workshops, and groups dedicated to growing the support and community around Parkinson's Disease. Home for education and research initiatives built on spreading awareness, care, and support for Parkinson's Disease. But most importantly, *home* for You.

Please note all information provided in this toolkit is for information purposes only. Please be sure to ask your healthcare professional before addressing any of these topics on your own.

INTRODUCTION

Care is defined as physical, emotional, and spiritual support for your loved one as their Parkinson's Disease progresses.

It is important to take care of yourself in order to be able to take care of someone diagnosed with Parkinson's Disease.

CAREPARTNER STORY



“ Dave is cheerful, brave, and resilient. As a carepartner, I am his ally and his advocate. I always have his back, and I frequently kick his butt. ”

Kelly Campbell-Brown
David's Carepartner



**David Brown, Kelly's
husband**

My husband David was diagnosed eleven years ago with YOPD. Initially, being a carepartner was rather like being 'voluntold' vs. volunteering. There is no choice. I was not, suddenly, more kind. The diagnosis did not grant me patience; birds did not leave the trees to trill around me. My strengths are organizational.

I have the capacity to do, ask, and say the tough things that need to be done, asked, and said. Dave is cheerful, brave, and resilient. As a carepartner, I am his ally and his advocate. I always have his back, and I frequently kick his butt. We were asked if we have any encouraging care partner tips. Together, we came up with three: *First*, maximize doctor appointments; it makes no sense to ask the smart question afterward on the way home in the car. Before the appointment, separately, we rank three things that we consider to be top of mind. Next, we see if those priorities, as a couple, match. Once we arrive at a game plan for his visit, I try to fast-track all "time eaters" such as refill requests or medication lists.

We always go out for lunch afterward. It's a tradition that we look forward to. If we go home it's easy to wander off to a task. A lunch date means that you must look each other in the face and talk. *Second*, get (and stay) informed; I have learned so much from attending PSSO conferences and webinars! There are resources available through the PSSO, and others, from videos to long reads, to info-graphics.

Sign up for research; it feels good to know that you are contributing to advancing PD care. *Third*, please know that you are not alone. Nothing beats the real connection with folks at PSSO Support Groups. Yes, that first group will likely be scary. You will find kindness that will help sustain you on this journey. PD is relentless. As a caregiver, you may experience feelings of resentment and grief. A support group is a safe space to voice those feelings and gain coping skills. What we learned in the last eleven years is this — don't waste time.



Kelly
David's Carepartner



Time is precious. Looking back, we prioritized mundane things, like David folding the laundry, for too long. In the end, we are pretty sure, there is no merit badge for laundry folding. He only has so much energy to spend. We want to spend it wisely and memorably.

Six months ago David had DBS surgery. The change is remarkable — not without challenges — but, as they say, “a new lease on life.” Now we start to learn, yet again, and we go forward together.

RELATIONSHIP CHANGES

Relationships can change between carepartners and patients regarding intimacy and sexuality.

But these can be explored by openly communicating about sex and using non-verbal sexual expressions which may also change as Parkinson's Disease can cause stiffness and slowness in facial expressions. This can convey the message of lack of interest, “facial masking”, thus it is essential to rely on verbal communication and listening to one another.

Parkinson's Disease patients may experience sexual dysfunction e.g., pain, limited movements, fatigue, and emotional changes. It may be helpful to express intimacy in broader terms e.g., through affirmative touch, or sharing time.

Dopamine agonist drugs can lead to the development of compulsive behaviors such as hypersexuality, this should be discussed with a neurologist to adjust the drug dosage and it may be helpful to consider sex therapy.

WHAT CAN I DO TO CARE FOR MY LOVED ONE?

1. UNDERSTAND WHAT PARKINSON'S DISEASE IS AND CARE STRATEGIES
2. INCLUDE YOUR FAMILY IN CARE STRATEGIES AND ASK FOR THEIR OBSERVATIONS ON YOUR LOVED ONE
3. ENGAGE IN SELF-CARE
4. MAINTAIN OPEN COMMUNICATION WITH THE PATIENT
5. ENGAGE IN STRESS REDUCTION STRATEGIES
6. ASK PROFESSIONALS SPECIFIC QUESTIONS ABOUT THE PATIENT AND PROVIDE THEM WITH DETAILS ON THE PATIENT'S BEHAVIOR
7. SUPPORT DECISIONS THAT THE HEALTHCARE TEAM AND PATIENT MAKE WHILE WEIGHING IN AND GIVING YOUR OPINIONS

WHAT CAN I DO TO CARE FOR MY LOVED ONE?

8. STAY CALM AND PATIENT

9. HELP CREATE A ROUTINE

10. CONSIDER CAUSES BEHIND BEHAVIOR

11. LIMIT DISTRACTIONS

12. SPEAK SLOWLY AND DON'T ARGUE OR CORRECT

13. JOIN A SUPPORT GROUP FOR CAREPARTNERS

14. TAKE BREAKS

15. FOCUS ON THE POSITIVE

16. ENGAGE IN ACTIVITIES WITH PATIENTS OUTSIDE OF CAREGIVING TASKS

TAKING CARE OF YOURSELF

1. Meditate: it can help you manage yourself while focusing on the present, allowing you to not focus on negative emotions and experiences you may be having.

2. Go for a walk or jog: this can help increase your physical health and reduce your stress as walking releases endorphins.

3. Try yoga: it may help reduce stiffness, and improve your strength.

4. Get enough sleep: this gives your body time to restore itself, and you will feel more energized.

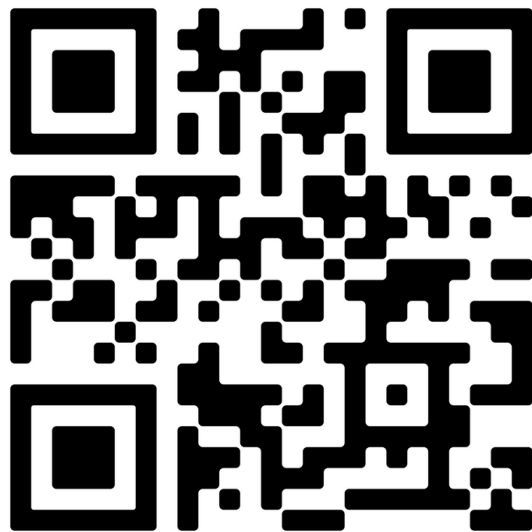
5. Journal your thoughts: it can help you reflect on your day and inspire you.

6. Listen to music: this can reduce your blood pressure and anxiety, making you more aware and in a better mood.

7. Try a colouring sheet: it can help express your creativity and help you relax.

TAKING CARE OF YOURSELF

SCAN THE QR CODE FOR
OUR OWN JOURNAL
SHEET, MEDITATION
LINK, MUSIC LINK, AND
COLOURING SHEETS



IF YOU ARE UNABLE TO SCAN THE QR CODE, CHECK OUT THE
TOOLKIT ON [PSSO.CA/RESOURCES/](https://pssso.ca/resources/) OR CONTACT OUR
OFFICE AT 1.888.851.7376 FOR A PRINT COPY.

COUNSELLING PROGRAM AT PARKINSON SOCIETY SOUTHWESTERN ONTARIO

It is often helpful to talk with someone about your challenges. Parkinson Society Southwestern Ontario offers counseling services that focus on supportive listening, identifying key concerns, processing issues, and mutual goal-setting for positive change through a solution-focused model.

By speaking to someone knowledgeable and compassionate about your situation, you can help tackle challenges that come your way.

You can use this link to book a free, short-term, confidential, and non-judgemental counseling appointment:

<https://pssso.ca/programs-services/counselling-program/>

or contact us at **1.888.851.7376**

SUPPORT GROUPS AT PARKINSON SOCIETY SOUTHWESTERN ONTARIO

Support Groups are a great way to join a community of other carepartners. Support groups can help nurture a positive and supportive environment helping you share your feelings and experiences. It may also help you cope with the challenges of being a carepartner. You can learn about new resources and coping methods while socializing with a supportive group.

You can use the link to see Parkinson Society Southwestern Ontario's support group listing and fill out an online support group form:

<https://pssso.ca/programs-services/support-groups/>

To join a young onset support group, use this link:

<https://pssso.ca/programs-services/young-onset-parkinsons-disease-yopd/>

or contact us at [1.888.851.7376](tel:18888517376)

RESOURCE APPENDIX

1. <https://www.parkinson.org/library/fact-sheets/intimacy#:~:text=pleasure%2C%20not%20performance.,Sex,effects%20can%20trigger%20sexual%20dysfunction.>
2. <https://parkinsonsdisease.net/living/positive-quotes>
3. <https://www.hopkinsmedicine.org/health/conditions-and-diseases/parkinsons-disease/your-relationship-staying-strong-despite-a-diagnosis-of-parkinson-disease#:~:text=It's%20not%20unusual%20for%20partners,the%20same%20ways%20as%20before.>
4. <https://www.parkinsonseurope.org/living-well/wellbeing/relationships-and-communication/relationships-and-parkinson-s/>

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