



# PARKINSON'S CARE QUESTIONNAIRE

Name: \_\_\_\_\_ Age: \_\_\_\_\_

Date of Birth: \_\_\_\_\_

Healthcare Provider Name: \_\_\_\_\_

*What are your goals for this appointment?*

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*List your current or most bothersome problems or symptoms:*

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*Did you make the changes recommended during your last visit?*

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*Were your last treatment changes helpful? Explain:* \_\_\_\_\_

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*List any new medical problems or allergies since your last visit: \_\_\_\_\_*

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*Do you experience dyskinesia? (circle one) Yes / No*

*Do your medications wear “off” or stop working? (circle one) Yes / No*

*If yes, on average how long does each dose last? \_\_\_\_\_ hours*

*Have you had any falls since your last visit? (circle one) Yes / No*

*List any changes in your living arrangements: \_\_\_\_\_*

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*List prescription refills you need: \_\_\_\_\_*

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*Circle any problems that you had in the past month related to each specific area:*

**Movement**

Tremor	Stiffness	Slowness
Imbalance	Walking Problems	Frequent Falling
Movement Freezing	Involuntary Movements	Muscle Spasm/Cramping
Other (Explain): _____		



### Speech/Swallowing/Gastrointestinal

Speech Changes

Swallowing Problems

Drooling

Pneumonia

Weight Loss

Weight Gain

Aspiration

Nausea

Vomiting

Abdominal Pain

Facial Masking

Other (Explain): \_\_\_\_\_

### Bowel or Bladder/Autonomic/Other

Bladder Problems

Constipation

Diarrhea

Chills/Sweats

Fatigue

Leg Swelling

Dizziness/Lightheadedness

Fainting or Loss of Consciousness

Sexual Dysfunction

Other (Explain): \_\_\_\_\_

### Cognitive/Behavioral

Anxiety

Depression

Apathy

Sleep Problems

Daytime Sleepiness

Fatigue

Memory Loss

Confusion

Hallucinations

Paranoia

Delusions

Mania

Impulsive Spending, Sex or Gambling

Executive Function Difficulties (planning, decision-making, etc.)

Sudden, Uncontrolled Sleep "Attacks"

Other (Explain): \_\_\_\_\_

### Other

Fever

Chills

Headache

Joint Pain

Back Pain

Chest Pain

Neck Pain

Palpitations

Vision Change

Cough

Hearing Loss

Numbness/Tingling

Driving Challenges

**List any other concerns or problems that you have:** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_



# GOAL SUMMARY FOR DOCTOR VISITS

The best way to improve your health is by being an active participant. Complete this form during and between each visit with your Parkinson's doctor or other healthcare professionals on your wellness team. Record your action steps and progress between visits. Review your results with your wellness team at each visit.

*My goals for today's visit (date) \_\_\_\_ / \_\_\_\_ / \_\_\_\_ are:*

1. \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
2. \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
3. \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

*Action steps I will take to meet these goals are:*

1. \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



2. \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

3. \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
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*Progress I have made toward these goals:*

1. \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
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2. \_\_\_\_\_  
\_\_\_\_\_  
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\_\_\_\_\_

3. \_\_\_\_\_  
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*Obstacles or areas for improvement needed to reach these goals are:*

1. 

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2. 

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3. 

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**MAKE A FILE FOR COPIES OF THIS AND OTHER FORMS TO  
REFER BACK TO AS MARKERS OF YOUR TREATMENT OVER TIME.**



## EVERY VICTORY COUNTS

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# OVERALL MEDICATION LOG

LIST OF ALL MEDICATIONS					
MEDICATION	Started Medication	Ended Medication	Positive Effects	Negative Effects	Other Side Effects



# WELLNESS SELF-ASSESSMENT

Complete this self-assessment after reading the **Living Well Now** section.

For each section below, record two areas you would like to improve and steps you will take for improvement. For instance, if you have not seen your primary care physician in the past year for a yearly physical, this can be listed with the action step to make an appointment within the next month.

Then, pick the top three items (from any category) you listed that you would like to achieve in the next month.

## General Healthcare

*Check if Priority Item* ☐

This section focuses on general health items, such as preventative health screenings and blood pressure management.

1. Area of concern \_\_\_\_\_  
Actions to take \_\_\_\_\_
2. Area of concern \_\_\_\_\_  
Actions to take \_\_\_\_\_

## Parkinson's Self-Care

*Check if Priority Item* ☐

This section focuses on preparing for your doctor's visits, emergency and hospital stays. It can also include taking the steps to take charge of your medications and learning about specialists who can be on your wellness team.

1. Area of concern \_\_\_\_\_  
Actions to take \_\_\_\_\_
2. Area of concern \_\_\_\_\_  
Actions to take \_\_\_\_\_



## Physical Exercise

Check if Priority Item ☐

This section focuses on participation in exercise programs, improving symptoms such as pain, balance, decreased stamina and pursuing physical therapy.

1. Area of concern \_\_\_\_\_

Actions to take \_\_\_\_\_

2. Area of concern \_\_\_\_\_

Actions to take \_\_\_\_\_

## Diet and Nutrition

Check if Priority Item ☐

This section focuses on changes you would like to make in your diet.

1. Area of concern \_\_\_\_\_

Actions to take \_\_\_\_\_

2. Area of concern \_\_\_\_\_

Actions to take \_\_\_\_\_

## Emotional Health

Check if Priority Item ☐

This section focuses on treatment of depression, anxiety, apathy, stress reduction, relaxation, social engagement and spiritual growth.

1. Area of concern \_\_\_\_\_

Actions to take \_\_\_\_\_

2. Area of concern \_\_\_\_\_

Actions to take \_\_\_\_\_



# PRE-EXERCISE SELF-ASSESSMENT

Pre-exercise screening is a process allowing a doctor to review your medical and exercise history and assess risk factors that may impact your health and safety when engaging in an exercise program. If you are not exercising now and wish to begin, your primary care physician may call for pre-exercise testing, especially if you have heart or lung disease, high blood pressure or diabetes. With a neurological condition like Parkinson's, pre-exercise screening should be completed by a family doctor, clinical exercise specialist, clinical exercise physiologist or cardiologist.

Before starting a new exercise program, talk with your Parkinson's doctor about whether there are any safety concerns that specifically relate to your situation. This worksheet will allow you to assess both motor and non-motor symptoms that can impact your exercise. Although exercise is essential to living well with Parkinson's, it is important to consider and discuss with your doctor before you start or change your exercise routine.

Use the space below to check and describe symptoms or concerns you have related to exercise, as well as to record any recommendations from your wellness team about these concerns.

## Motor Symptoms

- ☐ Dystonia (muscle spasms) worsens before, during or after exercise.

Concern: \_\_\_\_\_

Recommendation: \_\_\_\_\_

*Ask your physical therapist to test your walking and balance and recommend exercises to include, as well as any to avoid.*

- ☐ Exercise seems to worsen my dyskinesia.

Concern: \_\_\_\_\_

Recommendation: \_\_\_\_\_

*Inform your doctor and discuss how to address your symptoms. You may be more prone to muscle tears during bouts of uncontrolled dyskinesia.*

- ☐ I'm unsure whether I should exercise when I am in an "off" state.

Concern: \_\_\_\_\_

Recommendation: \_\_\_\_\_

*If your medications wear "off," ask your doctor if you should avoid exercising when medications are not working well. Typically, stiffness, slowness and walking are worse when the medications are wearing "off," which can increase risk of injury.*

## Non-Motor Symptoms

- ☐ I have difficulty falling or staying asleep.

Concern: \_\_\_\_\_

Recommendation: \_\_\_\_\_

*Sleep problems can be improved with regular exercise, although avoid exercising close to bedtime. If you're taking sleep medications, ask your doctor if your medications can be reduced if exercise improves your sleep problems.*

- ☐ Exercise-induced fatigue is a problem for me.

Concern: \_\_\_\_\_

Recommendation: \_\_\_\_\_

*If fatigue is limiting your exercise plans, talk to your primary care doctor. Fatigue has many causes and may require an in-depth discussion to determine how to treat it.*

- ☐ If my anxiety or depression symptoms improve with exercise, should I change my medications?

Concern: \_\_\_\_\_

Recommendation: \_\_\_\_\_

*Exercise can have positive effects on emotional wellness. Ask your doctor whether mood control medications are still necessary if you are experiencing improvements as a result of exercise.*

- ☐ I feel tired during the day, making it difficult to exercise.

Concern: \_\_\_\_\_

Recommendation: \_\_\_\_\_

*Ask your doctor about ways to improve daytime sleepiness so that you can be more ready for exercise. You might need to plan exercise around times of day when you feel most alert and refreshed, as well as consider timing and nutrition of meals and snacks.*

- ☐ Overactive bladder limits my ability to exercise.

Concern: \_\_\_\_\_

Recommendation: \_\_\_\_\_

*Talk to your doctor if overactive bladder is limiting participation in exercise. Ask about minimum and maximum fluid intake per day for optimal hydration.*

- ☐ Could my medications influence my blood pressure while exercising?

Concern: \_\_\_\_\_

Recommendation: \_\_\_\_\_

*Talk to your doctor about whether the combination of your medications and exercise could alter your blood pressure. You might need to exercise at specific times of day to avoid either very low or high blood pressure.*

- ☐ I have low or fluctuating blood pressure.

Concern: \_\_\_\_\_

Recommendation: \_\_\_\_\_

*Low or fluctuating blood pressure can get worse if the intensity of your exercise is too much, so you may need to avoid certain exercises. Ask your doctor if your blood pressure is a concern to address when making your exercise plans.*

- ☐ I have attention or concentration difficulties.

Concern: \_\_\_\_\_

Recommendation: \_\_\_\_\_

*You might want to avoid complicated exercises and work individually with a trainer who can supervise you and keep you on task. Ask your doctor or physical therapist to determine whether your exercise program should be supervised.*

- ☐ I experience cognition problems (sometimes or often).

Concern: \_\_\_\_\_

Recommendation: \_\_\_\_\_

*Talk to your doctor about whether your cognitive health limits your exercise choices. For instance, you might not be able to swim alone or might need to use a treadmill only with supervision for safety.*

### Exercise Readiness

- ☐ I want to start a new exercise program.

Concern: \_\_\_\_\_

Recommendation: \_\_\_\_\_

*Ask your doctor for a referral to see a physical therapist before starting a new exercise program.*



**Describe your current level of activity:**

- ☐ I exercise regularly.
- ☐ I don't exercise regularly, but my lifestyle is somewhat active.
- ☐ I'm mostly sedentary.

***What do you do to exercise or to stay active?***

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***How often do you engage in physical activity?***

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**What fitness concerns do you have?**

- ☐ I want to increase my stamina and endurance.

***Activities I'd like to improve through increased cardiovascular fitness:***

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- ☐ I want to get stronger.

***Activities I'd like to perform better through increased strength:***

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- ☐ I want to be more flexible.

***Activities or mobility I'd like to improve through increased flexibility and balance:***

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**Notes:**

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# EXERCISE JOURNAL

Use this journal to record your daily exercise activity. Download and print additional copies at [parkinson.ca/evc](https://parkinson.ca/evc) to help you keep track of your progress over time.

Week of: \_\_\_\_\_

DAY		CARDIOVASCULAR	STRETCHING	STRENGTHENING	OTHER
Sunday	Activity				
	Duration				
Monday	Activity				
	Duration				
Tuesday	Activity				
	Duration				
Wednesday	Activity				
	Duration				
Thursday	Activity				
	Duration				
Friday	Activity				
	Duration				
Saturday	Activity				
	Duration				
Example	Activity	Walked outdoors	Seated stretches, standing stretches	10 lunges, 5 arm raises with 1 lb. weights	Took stairs to second floor office instead of using elevator
	Duration	20 minutes	10 minutes a.m., 10 minutes p.m.	15 minutes	—

EVERY VICTORY COUNTS

WORKSHEETS

# NUTRITION SELF-ASSESSMENT

Complete this self-assessment to determine what changes you can make in your diet to improve your wellness. Following these general guidelines can help you feel your best and address some common Parkinson's symptoms, such as constipation, fatigue, weight fluctuations and even various cognitive challenges. Refer to the "Diet and Nutrition" chapter in the **Living Well Now** section for detailed explanations of the nutrition information highlighted here. Be sure to discuss with your doctor and wellness team before making major changes to your diet.

See how your current diet stacks up with the recommendations below. If you can't check all the boxes in the first section, plan for what actions you will take to improve your basic nutrition. Which additional suggestions for optimal nutrition can you incorporate into your diet? Take a trip to your grocery store, local farmer's market or natural foods market to explore the possibilities. Make a list of new foods and supplements you'll incorporate into your diet. Exploring new flavors and cuisines can be fun!

## GENERAL GUIDELINES


### Daily Recommendations for Basic Nutrition

- ☐ Take a general multivitamin with calcium, phosphorous, vitamin B and D.
- ☐ Drink at least eight cups of fluid per day, including when you take your medication for general health and to avoid low blood pressure and constipation.
- ☐ Select healthy snacks such as fruits, nuts, yogurt, oats, milk or soy.
- ☐ Avoid processed foods high in sugar, "bad fats," unwanted chemicals and additives. These foods actually rob you of energy.
- ☐ Choose fresh, local and organic products if you can. This will increase the freshness, level of nutrients and limit pesticides or unnecessary additives.
- ☐ Be sure to consume adequate protein. Ask your doctor how much protein is right for you each day and when to best consume protein if you experience interactions with your medications.
- ☐ Avoid fad diets and supplements in high doses.

### Additional Suggestions for Optimal Nutrition

- ☐ Consuming antioxidants is essential brain and heart health. See below for suggestions on antioxidants to include in your diet.



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- ☐ Add omega-3s into your diet. Salmon, halibut, tuna, walnuts, almonds, ground flaxseed and fish oil tablets are good choices for omega-3s.
  - ☐ Aim for 20–30 grams of fiber daily from fruits, vegetables and wheat products to help with digestion and constipation.
  - ☐ Discuss with your doctor if you experience weight gain or weight loss. Some medical conditions can cause weight changes.
  - ☐ Determine whether you are getting adequate levels of calcium and vitamin D, which are important supplements for bone strength.
  - ☐ Consult the “Constipation Worksheet” and “Low Blood Pressure or Dizziness Worksheet” for more specific information tailored to these problems.

## ANTIOXIDANTS

The following high-nutrient foods are also high in antioxidants thought to be helpful in maintaining brain and heart health:

**Vitamin C:** green vegetables, tomatoes, strawberries, broccoli, citrus fruits and juices, apple juice, potatoes, kiwi, green, red and yellow peppers

**Vitamin E:** whole grains including brown rice, green vegetables, nuts, seeds, vegetable oils, wheat germ, papayas, avocados, sweet potatoes and peanut butter

**Vitamin A (Carotenoids):** sweet potatoes, carrots, tomatoes, kale, collard greens, apricots, cantaloupe, peaches, pumpkin, broccoli and pink grapefruit

**Selenium:** eggs, garlic, chicken, fish, grains, wheat germ and bran, Brazil nuts, shellfish and beans


**Lignans:** flaxseed and oil (omega-3 fatty oils), rye, oatmeal and barley


**Flavonoids:** soy, dark chocolate (70% cacao), red grapes, cranberries, green or white tea and pomegranate

**Lycopene:** watermelon, pink grapefruit and tomatoes

**Lutein:** spinach, kale, broccoli, kiwi, Brussels sprouts and other dark green vegetables

### Recommended foods that are rich in antioxidants and offer other health benefits:

- Ground flaxseed (provides fiber, omega-3 fatty acids and lignan)
  - Salmon (provides omega-3 fatty acids and selenium)
  - Soy products (provide protein and good source of all the essential amino acids, calcium, zinc, iron, magnesium, phosphorus, omega-3 fatty acids, fiber and B vitamins)
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- Whole grains (provide B vitamins, vitamin E, iron and magnesium)
  - Berries (provide vitamin C, folate, fiber and high antioxidant properties)
  - Green vegetables (provide vitamin A and C, calcium and iron)

**CoEnzyme Q10:** A 2014 study did not show added benefit when used early in Parkinson's. However, CoQ10 has not been shown to be harmful. Discuss with your doctor before adding this supplement to your diet.

**Antioxidant supplements** are also available, but should not be used in place of a healthy diet. Speak with your doctor about appropriate choices and brands when taken into consideration with your current medications.

**Make a list of items you will add to your regular diet:**

- |          |           |
|----------|-----------|
| 1. _____ | 6. _____  |
| 2. _____ | 7. _____  |
| 3. _____ | 8. _____  |
| 4. _____ | 9. _____  |
| 5. _____ | 10. _____ |

# **PARKINSON'S PSYCHOSIS**

## **SELF-ASSESSMENT**

Sometimes Parkinson's itself or side effects of medications can change your perception of reality, resulting in Parkinson's psychosis. Parkinson's psychosis typically takes the form of hallucinations (experiencing things visually or otherwise that are not really there), delusions (a false belief or impression that you hold to firmly, even though it is irrational or illogical) or both. Some people are aware what they are experiencing is not actually real, while others are not.

Review the statements below together with your care partner and discuss with your doctor if you are experiencing any of the following:

### **For People Living with Parkinson's**

- ☐ I've seen, heard or smelled things, such as people, animals or objects, that weren't actually there.
- ☐ I've had experiences, such as the vivid sensation of someone in the room with me or a brief vision of movement, when there was nothing actually there.
- ☐ I've looked at something and seen it appear briefly as something else. For example, words on a page appearing as insects.
- ☐ I've had beliefs or fears, such as my loved one abandoning me, being unfaithful or stealing from me.

### **For Care Partners and Family Members**

- ☐ My loved one has seen things, heard things or felt things that weren't actually there.
- ☐ My loved one has experienced any false beliefs toward me or others, such as believing someone is stealing from them or that I'm being unfaithful.
- ☐ These false beliefs or visualizations have affected our daily lives.

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**WORKSHEETS**

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# DEEP BRAIN STIMULATION (DBS) SELF-ASSESSMENT

## DEFINING AND ASSESSING EXPECTATIONS

One of the most important discussions you can have with your doctor and your family before considering or undergoing DBS surgery is about defining realistic expectations. You should ask your doctor about how DBS will change **your** symptoms and motor function, not just about how DBS can help Parkinson's symptoms in general. Setting appropriate expectations before surgery can help pave the way for greater satisfaction with results in the many years that follow. Complete this self-assessment and use it to guide the discussion with your doctor and family.

*What Parkinson's symptoms do you expect to be improved by DBS in order for you to be satisfied with the procedure outcome?*

- |          |          |
|----------|----------|
| 1. _____ | 4. _____ |
| 2. _____ | 5. _____ |
| 3. _____ | 6. _____ |

*Considering all your Parkinson's symptoms, place them in the appropriate categories below:*

**Symptoms That Improve with Medication**  
(most likely to respond to DBS)

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**Symptoms That Do Not Improve with Medication**  
(not likely to respond to DBS)

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**Other Bothersome Symptoms Not Listed**  
(discuss further with your doctor)

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▶ The symptoms that respond favorably to Parkinson's medications typically respond well to deep brain stimulation, with tremor being the exception. Even if tremor does not respond well to medications, it will typically respond well to stimulation. Stiffness, slowness, posture, gait shuffling and tremor generally improve noticeably with stimulation. People who have DBS typically experience more "on" time and less dyskinesia and "off" time, once the stimulation settings have been optimized.

Completing this worksheet can help guide you through the important process of determining whether DBS may be appropriate for you. Although each individual experiences varying symptoms and severity, understanding how your symptoms may or may not be managed by DBS is a key factor in determining whether or not you are a candidate for the surgery and whether the benefits you can reasonably expect merit undergoing the procedure.

**Other questions to think about and to discuss with your doctor:**

1. Do my Parkinson's symptoms bother me enough to undergo brain surgery?
2. Do I understand the risks associated with the surgical implantation of the hardware?
3. Have I asked the surgeon about his/her specific rates of surgical complications?
4. Are my expectations reasonable enough to proceed with a DBS work-up?
5. Do I have any medical conditions that increase my risks of complications during DBS surgery?
6. Do I have adequate access to medical professionals that can adjust the stimulation settings once I have the implantation (helping with my maintenance over time)?
7. Are there any medical, environmental or exercise considerations after DBS?
8. How long will the implanted neurostimulator last?
9. How long will I need to take off work?
10. How long will I be restricted from driving?
11. What is the process leading up to surgery like?
12. What can I expect during the surgery?
13. What can I expect after surgery?



# OUR RELATIONSHIP SELF-ASSESSMENT

Parkinson's can affect many of your relationships, especially with your partner. Communication is crucial: make time to talk openly and honestly with your partner about your relationship. Questions to consider as you have a candid conversation with your partner include:

*What has changed in our relationship that we are reluctant to discuss?*

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*What could I do to make the relationship stronger?*

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*What am I doing that is causing unnecessary stress on the relationship?*

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*What is working well?*

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*What needs more attention?*

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*Could we meet with a specialist for guidance?*

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# PARKINSON'S HOME SAFETY TIPS

We frequently ask people with Parkinson's, occupational therapists, physical therapists, and care partners what the most instrumental changes people with Parkinson's can make to their home. We have gathered that information and created this checklist as a great starting point to help make your home a great place to live comfortably and safely with Parkinson's.

## General Safety Guidelines

*Implement these updates everywhere in the house.*

- ☐ Decrease clutter. Place furniture so that you have wide walkways and can move around easily. Decreasing clutter in your physical space not only reduces tripping hazards but can also reduce freezing and mental clutter, allowing for greater focus and calm.
- ☐ Decrease visual clutter to minimize confusion.
- ☐ Install lever handle door knobs instead of circular knobs for easier opening.
- ☐ Install grab bars throughout your home. (If possible, seek advice from an occupational therapist (OT) on proper placement first.)
- ☐ Make sure chairs in the house are stable (not on wheels), have arm rests, and are the adequate seat height to make standing up and sitting down easier. (Your feet should be able to touch the floor and your legs and hips at about a 90-degree angle so you can stand easily.) Avoid purchasing sofas and arm chairs that are soft and low as they are difficult to get up from.
- ☐ If using a wheelchair or walker, always lock brakes after each use.
- ☐ Arrange your furniture to avoid multiple turns or maneuvers so you can easily access areas you use. These are the places where you are most likely to fall.
- ☐ Be sure a communication system is in place and easily accessible in every room and hallway that you use. (This could be a phone, alarm button, or medical alert necklace or bracelet.) This is important for people who are in the later stages of Parkinson's.
- ☐ Consider a doorbell that offers a camera view so you can see who is at the door.
- ☐ Give two to three trusted individuals keys to your home in case you need them to come by and let each of them know who is on your trusted list. Compile their contact information and share with each person if they're comfortable with that. Or use a lockbox and key, garage door remote code, or a smart lock so you can offer people easy access to your home.

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- ☐ Consider in-home exercise equipment for exercise solutions in bad weather. Exercise can improve gait, movement, and mental capacity throughout the day—even short bouts of 10-15 minutes can be helpful. A yoga mat or other foam pad for floor exercises is a great option.
  - ☐ If you exercise at home, make sure you have plenty of space to do your exercises.
  - ☐ Request a visit from a physical therapist (PT) or occupational therapist (OT) who knows the ins and out of Parkinson's or other neurological conditions to address your needs and offer solutions.
  - ☐ Use voice activated music devices (Alexa, Google Home, etc.) to assist with ungluing from a freeze. (Be sure to test the device to ensure it recognizes your voice.)
  - ☐ Be sure to remove or lock up all guns or other dangerous items so they are out of easy reach if you experience hallucinations or delusions.
  - ☐ Use smaller versions of standard items, such as narrow or small laundry baskets or a laundry basket to reduce floor or feet visibility issues when walking and carrying items.

### **Lighting & Electrical Outlets**

- ☐ Place lights so they are easily accessible.
- ☐ Make sure hallways and stairways are well-lit and use extra lighting to reduce shadows on steps.
- ☐ Use contrasting colors on light switch plates or get lighted switch plates to make finding switches easy in the dark.
- ☐ Use red lights at night to minimize sleep disruption.
- ☐ Put night lights in hallways between bedrooms and bathrooms. (Add motion sensor lights in these areas if possible.)
- ☐ Get lamps that you can turn on with one touch or with sound.
- ☐ If possible, install all electrical outlets about waist high so you don't have to bend down to access them.
- ☐ Put all electrical, extension and telephone cords out of the flow of foot traffic to reduce tripping hazards.





## Floors


- ☐ Consider installing hardwood flooring and tile throughout your house. If you redo your floors, consider flooring that includes horizontal lines or contrasting grout colors to help with freezing.
- ☐ Reduce or remove area rugs. (Any rugs used should be non-slip, rubber-backed, with a low pile that lies flat to the floor. Also, use adhesive liquid rug backing or tack down rugs to floor.)
- ☐ Change the paint color in rooms to lighter colors. It can give the illusion of more space and assist with freezing.
- ☐ Eliminate abrupt changes in surfaces (i.e. carpet to hardwood) because they can be a tripping hazard.

## Entryway & Stairs

- ☐ Install light switches (or motion sensors) at the top and bottom of the stairs and at every entryway.
- ☐ Put a piece of easy-to-see tape at the edge of each step to help with depth perception.
- ☐ Ensure there are handrails on both sides of all stairways (or areas with multiple steps) that run the full length of the stairs. Cueing may be needed to use the railing consistently.
- ☐ Avoid distractions such as carrying on a conversation or carrying multiple objects while going up or down the stairs. Always keep one hand free to use the rail.
- ☐ Use painter's tape to mark proper foot placement for routine tasks or to guide foot placement through doorways and around corners that might otherwise cause freezing.
- ☐ Add a seat or bench to the home entrance area to be able to rest or place items when entering the home.


## Bedrooms

- ☐ Make sure you can touch your feet to the floor when seated on your bed to make it easier to get in and out.
- ☐ Consider installing a side rail, a bedcane, a sturdy bedside table or a rope above the bed to assist with rolling and getting up. (You could also get a transfer pole professionally installed next to the bed.)

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- ☐ Put a bedside commode or handheld urinal next to the bed. This is ideal if you struggle to move easily upon waking. (For men, consider a condom catheter if nighttime movement is not easy.)
  - ☐ Always have a bottle of water at the bedside to assist in lowering your blood pressure in the morning if needed.
  - ☐ Securely place blocks, bricks, or other objects under the bed to slightly elevate the head of the bed and decrease the angle necessary to get out of the bed. This potentially decreases large drops in blood pressure with change in position from supine to sitting if you have neurogenic orthostatic hypotension (nOH).
  - ☐ If you have REM Sleep Behavior Disorder (RBD), reduce safety hazards (secure bedside lamps, lock up any weapons, remove clutter) in case you act your dreams out at night or fall out of bed. (Consider sleeping in separate beds.)
  - ☐ Consider putting a motion sensor in the bedroom with an alarm or light activation to alert your spouse if you get up in the middle of the night.
  - ☐ Consider a video or audio monitor if you sleep in separate bedrooms or a voice-activated intercom device.
  - ☐ Consider using a satin sheet for your bottom sheet to make it easier to roll over.
  - ☐ Make the bed with loose and light sheets that can be taken off or layered depending on the temperature. (No heating blankets.) Or, just use a light down comforter instead of sheets and blankets to reduce the chance of getting caught up in multiple sheets.
  - ☐ Place a flashlight in the nightstand or within easy reach in case your power goes out.
  - ☐ Keep a telephone within easy reach of the bed. It can serve as a flashlight, too.

## **Bathrooms**

- ☐ Install grab bars near the toilet, tub and in the shower. (If possible, get help from a PT or OT on proper placement.) (Be sure if you do it yourself, you must install it into a stud. Getting a professional to do it is best.)
- ☐ Ensure your toilet is at comfort height to make it easier to get up and down. (You can get a riser if you don't want to replace your toilet.)
- ☐ Professionally install a stable, purpose-made seat or bench in your shower.
- ☐ Make sure all bathtubs, showers floors, and exits from the shower are non-slip. (Use aqua socks in public showers.) Use alternatives such as non-slip strips applied to floors or tubs to replace suction cup bath mats.

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- ☐ Install faucets that turn on and off with one touch or are motion-sensored.
  - ☐ Make sure water temperature is consistent and not too hot. You can set your water heater for the home to a specific maximum setting.
  - ☐ Install handheld shower heads when possible to use while seated in the shower.
  - ☐ Make sure there is a phone or life alert button within easy reach of the shower, tub and toilet in case of an emergency. (Better yet, consider using a waterproof med alert device in the shower or tub.)

## **Kitchen**

- ☐ Install faucets that turn on and off with one touch and can do hot/cold with one hand.
- ☐ Consider appliances that automatically turn off after a certain length of time in case you forget.
- ☐ Put frequently used items in easy to access locations so you don't have to bend or reach to get them. (No step stools or ladders!)
- ☐ Create prep stations with all of the supplies for a task within easy reach of the work space (i.e., a coffee station).
- ☐ Consider trading your ceramic and glass dishes for those made with melamine, a more durable substance that rarely breaks when dropped.
- ☐ Change cabinet knobs to large easy-to-grip handles.
- ☐ Swap out large trash cans for smaller ones or ones with wheels to make it easier to take out the trash.
- ☐ Try "flicking fingers" periodically to help with tremor when performing kitchen tasks and eating.
- ☐ Purchase convenience foods that are pre-cut and washed to save time and limit the need to use sharp knives.
- ☐ Make opening jars easier by using a one-touch automatic jar opener.
- ☐ Use non-slip rubber matting to stabilize cutting boards, mixing bowls, dinnerware, or adaptive kitchen equipment.

# PARKINSON'S TRAVEL CHECKLIST

For the average person, traveling is a minor frustration. Security lines, delays, crowded airports and cramped and long lines at snack shops and restaurants are par for the course. However, if you're living with Parkinson's, those things aren't just frustrations, they can be so troublesome and aggravating to deal with that you choose to stay at home.


That's why we decided to reach out to our Davis Phinney Foundation Ambassadors, many of whom are avid travelers, to get their best tips for traveling with Parkinson's.

## Planning

- ☐ Travel by train rather than plane when possible. Trains have more leg room and no TSA.
- ☐ Allow time for transfers when purchasing tickets. Changing planes or trains takes longer than you expect.
- ☐ Travel when you're at your best. For example, travel in the morning if that's when your medications offer the most symptom relief.
- ☐ Make packing lists and save them. You might have different lists for road trips, weekend getaways and international trips. Update your lists each time you travel.
- ☐ Pack early but check the weather right before you leave in case you need to adjust what you bring.
- ☐ Put all paperwork in an easy-access location. Consider including an emergency contact list with information about your medical providers and caregivers.
- ☐ Arrive at the airport early.

## Medication Management

- ☐ Bring more than you need and know how to get more in a pinch.
- ☐ Store your medications in more than one location, including carry-on bags or on you if possible. Ask a travel partner to carry an extra dose.
- ☐ Set timers or alarms that remind you to take them on schedule.
- ☐ Plan a consistent schedule for taking your medication. For example, if you're going through multiple time zones, take your meds every four hours rather than at 1:00 and 5:00.
- ☐ Always carry a list of your medications with you and be ready to show them if asked. Be sure at least one set of your prescriptions are in Rx bottles with labels.

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- ☐ Get a letter from your doctor for liquid medications. TSA allows liquid medications above 3oz, but only with clear documentation. Keep these in your carry-on; not checked luggage.

### Getting Around

- ☐ Carry a cane or walking stick, even if you think you don't need it. Stress often makes Parkinson's symptoms worse, and travel is stressful.
- ☐ Arrange for a wheelchair to get through the airport, which helps in crowds and unfamiliar places.
- ☐ Ask for help if you need it. If help is offered, take it. This includes having someone carry your bags, taking advantage of extra time allowed for boarding, having someone get food for you, etc.
- ☐ Take a disposable plastic grocery bag with you so you can sit on it on the plane. Plastic reduces friction which makes it much easier to get out of your chair.
- ☐ Practice getting in and out of your airplane seat (or any seat) before you go.


### Communication


- ☐ Communicate clearly and frequently. "Nobody can read our cue cards so it's our job to let them know what's up." —Kathleen Kiddo
- ☐ Consider wearing or traveling with a card that says, "I've got Parkinson's and I need a bit more time and space. Thank you."

### Clothes

- ☐ Pack light. You can usually find anything you forgot at your destination.
- ☐ Travel in comfortable clothing that's easy to get on and off in bathrooms.
- ☐ Wear knee-high compression socks for car and air travel to promote blood flow and reduce swelling.
- ☐ Bring a change of clothes in your carry-on bag.

### Sleep and Rest

- ☐ Slow down and avoid overscheduling. Prioritize activities that are most important and conserve energy so you have it when it matters most.
  - ☐ Time your travel so you can rest when you arrive at your destination. For travel with significant time change, take a 1-2 hour nap upon arrival. Assimilate into the routine of the time zone as soon as possible.
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- ☐ Bring a sleep mask and earplugs, and maybe an inflatable neck pillow for additional comfort.
  - ☐ Let your travel companion(s) know when you're too tired to do certain activities. Rest is important.

### **Food & Drink**

- ☐ Keep food items at the ready to separate them at security.
- ☐ Fill your water bottle after security and between flights.
- ☐ Bring more snacks than you think you'll need on the plane in case of delay.

### **Exercise**

- ☐ Stand up to stretch every 30-45 minutes while in transport.
- ☐ Consider bringing a jump rope for simple, light, portable, aerobic exercise.
- ☐ Continue practicing the activities that make you feel well whenever possible. Maintaining routine is important during vacation and for when you return home.

### **Miscellaneous**

- ☐ Label loose objects with your name and cell number.
- ☐ Get a handicap placard.
- ☐ Check out the local Parkinson's offerings wherever you're travelling. If they don't have new skills to offer you, maybe you have skills to offer them.
- ☐ If you have DBS, bring the device wallet card from Medtronic (or alternate company). Security may ask for it. Tell them it's a "medical device" or say you have a pacemaker rather than explaining DBS. You can't go through the old-style security check machines or let them use wands to check you. Be prepared for a pat down.
- ☐ Travel with people who know you and can help with the unpredictability of Parkinson's.
- ☐ Maintain a sense of humor. Travel is difficult, but you'll get where you need to go eventually. "If you like to travel, then it's part of your living fully with Parkinson's."  
—Jill Ater