

# Living with Parkinson's Traveling with Parkinson's



In 2006, the Parkinson's Disease Foundation (PDF) asked me to write an article that provided tips to help people with Parkinson's disease (PD) travel more easily. I still receive calls and emails about it and PDF tells me it is still a popular item on their website. This emphasizes to us that travel is still an important topic for you.

My travel experiences have been mostly positive, but occasionally, a story will surface reminding me of the need to discuss the topic of travel. For instance, in the summer of 2012, my colleagues on PDF's People with Parkinson's Advisory Council (PPAC) all saw the news story about a passenger with Parkinson's disease who was mistaken for being intoxicated before boarding a flight. The airline has since apologized.

Whatever your viewpoint on this story, we know that the passenger did not reveal he had special needs. For the PPAC-ers, this brought up an important question: When you travel, how do you ask for extra help and how much should be revealed concerning your condition? As a group, PPAC decided it was time for an updated article on travel and PD, reiterating our major points, and adding one about disclosure.

## Planning Ahead

Back in 2006, I shared my own story of traveling from Cincinnati (see box on back page) because it shows how important it is for a person with Parkinson's to anticipate the difficulties that may arise while engaging in this common task. Whether you're traveling for work or pleasure, plan, plan, plan! This has been made easier through the amount of information available online.

Are you traveling by air, train, bus, boat or car? Does each mode of transportation offer the accessibility you need, or extra time to board? If you are sightseeing, particularly outside of the United States, make sure you inquire about specific accommodations. For instance, if you use a wheelchair or other mobility aid, confirm that your hotel room is wheelchair accessible and request a room near the elevator. Inquire about special accommodations that most hotels will offer at no extra charge, such as shower seats. Confirm ahead of time whether the sites you want to visit offer wheelchair rentals and are wheelchair accessible.

While making reservations for a plane or boat trip, ask about parking for your car. Many facilities offer free or discounted parking if you display a "handicapped" placard or license plate.

Once you have made your travel plans, keep them straight by carrying a printed itinerary, complete with emergency contact information. Leave a copy of this with a friend or relative in case you need to be reached. It is imperative to carry with you a cell phone for communicating in times of need. If you are traveling overseas, be sure to have the address and contact information for the US Embassy. It is wise to have your passport with you at all times or locked in a hotel safe.

## Packing

A case of nerves about having forgotten something can ruin days of a vacation, worsening PD symptoms. Efficient packing can make a big difference, so make a checklist of essentials beforehand — passports, tickets, money and special items.

Sort out your outfits complete with socks, undergarments and shoes. Include Parkinson's-friendly clothing and accessories, such as wrinkle-free items with elastic waistbands, pull-overs or closures other than buttons for ease in dressing. Toiletries and personal hygiene items are easier to handle if you have a compartment-type bag. Bags that can hang on the back of a door are convenient, providing easy access to each compartment. Take needed assistive equipment (such as a walker),

*(over please)*



and always take a cane or walking stick, making certain your name is well displayed on each item.

### Managing Your Medications

Keeping your medications in check can be crucial to enjoying a trip. To avoid being caught shorthanded, carry extra medication in labeled containers, in your purse or carry-on bag at all times. Do NOT put your medications in your “checked” bag when flying.

Bring or request a bottle of water to help you take your pills, as well as a light snack if needed, to prevent nausea. If you run into a situation in which you are without medication, a local pharmacist can negotiate with your home doctor/pharmacist to fill an emergency prescription. To speed up the process in these cases, always travel with an updated list of your medications, along with information on dosages, scheduled times for dosing and notations of allergies and needed telephone numbers. This information will also be essential if you end up visiting a doctor’s office or emergency room while traveling. If you experience motion sickness, check with your pharmacist for interactions before taking any anti-nausea or over-the-counter medications.

### Communicating Your Needs

Now that you are ready to go, how can you make sure your needs are met during your trip? Anticipate Murphy’s Law: “If anything can go wrong, it will!” To minimize these “wrongs,” request special assistance at the time you make your reservations. If you are flying, remember that security regulations have tightened. Get to the airport a minimum of two hours before the flight. If you have undergone deep brain stimulation, a note from your doctor will allow you to bypass electronic security.

In my experience, airlines and most other major modes of transportation will go out of their way to accommodate customers, or patrons, with special needs. But what are your rights? By law you have the right to travel alone in the US without discrimination. Even if you are traveling with a care partner, you can request early boarding on any airline if needed, and aren’t required to give advance notice (destinations outside the United States may require advance notice). Airlines must provide assistance getting on and off the plane (e.g., service personnel,

### Peggy’s Story



Several years ago, I arrived at the airport 90 minutes ahead of time for a flight to Cincinnati. After my ride dropped me off, I realized that my terminal was a half-mile away. “I can do that,” I said, and I started walking. But I overestimated how far I could walk! After suffering an emotional breakdown, I was rescued by airline personnel who held the flight for me.

ground wheelchairs, service wheelchairs, ramps and mechanical lifts). There are similar regulations in Europe and Canada. You must also have room to store any wheelchairs, canes and other equipment in the cabin and close to your seat.

Since these accommodations are available, I recommend asking for extra help, and then repeating your needs several times. For example, if you need an electric cart or wheelchair service, tell the ticketing agent, then tell the airline representative when you are boarding the plane, and as a final check, give the flight attendant a friendly reminder just before landing. Do not assume that you “may” be functioning well later — it is better to be safe than sorry.

Do you have to reveal that you have Parkinson’s? Absolutely not. Once you state that you have special needs, or need extra time to board a plane, that’s all you have to say. No one needs to know why, unless you want to tell them.

### Enjoy!

Now that you have planned everything in advance, enjoy your well-deserved trip. Make sure your sightseeing schedule is flexible, and build in mini-rests and one nap every day. When driving or riding for long periods of time, stop frequently to stretch or walk around, as well as for bathroom breaks. Traveling does not have to end when Parkinson’s advances. Enjoy yourself!

*Peggy Willocks, a member of PDF’s PPAC, has lived with PD for 18 years. She resides in Johnson City, TN, and is a former elementary school principal.*

If you have or believe you have Parkinson’s disease, then promptly consult a physician and follow your physician’s advice. This publication is not a substitute for a physician’s diagnosis of Parkinson’s disease or for a physician’s prescription of drugs, treatment or operations for Parkinson’s disease.

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