

TRAVELING WITH PARKINSON'S: THE REWARDS OF A WELL-PLANNED TRIP WITH YOUR TRAVELING PARTNER

Compiled by Davis Phinney Foundation Ambassador Gail Gitin

I acquired many tips while traveling with my husband who had Parkinson's. I learned some of this firsthand (the hard way), and I learned some of this through connections with other care partners.

We all know traveling can be stressful under the best of circumstances; you are almost guaranteed to have unexpected challenges even if you plan down to the last detail. Hope this helps and you have smooth travels!

Personal Preparation

1. Be sure to carry all meds with you in your personal or carry-on bag along with contact info for all physicians and your list of meds. Take photos of the bottles and save them on your phone. This way you'll have record of the you dosage, refill information, the name of the prescribing doctor, and pharmacy.
2. Pack a small emergency kit with band aids, gauze pads, and a self-sticking wrap.
3. It is a good idea to also carry wet wipes plus a full change of clothes in the event of food or bathroom accidents. If your partner is willing to wear Depends (adult absorbent briefs) during the trip, this will be added insurance in an unforeseen problem like having to sit in your seat for too long waiting for take-off.

Airline Preparation

4. Choose flights during the late morning or early afternoon when your person with Parkinson's (PWP) is in the most ON state (avoid very early morning or late evening).
5. Choose seats close to the bathroom and get one seat on the aisle. Pay for "economy plus" for more space when possible. Check seatguru.com for advice on best seats for your airline/flight.
6. Stay hydrated and take proper snacks that do not interfere with medication. Ask your person early and often to visit the toilet. Becoming dehydrated is an unwise tactic, as it contributes to confusion.
7. Consider making your security and passport control easier by purchasing TSA Precheck or Global Entry. Some credit cards include this in their small print.
8. Let the airlines know about your mobility needs and consider asking for a wheelchair even though you might not use one on a regular basis at home

9. Take advantage of early boarding when they invite anyone who needs a little extra time to board. Ask at the gate and they often will come find you to be sure you get on first.

10. Be prepared. Rehearse your plans with your person. Inform them of each step necessary to get from point A to point B especially if you booked all the travel. Symptoms will ratchet up with stress as you know, being prepared will help. I experienced this with my husband when he started to shake uncontrollably in the taxi on our way to the airport. This extreme symptom had never happened before and lasted until we were on the flight. It didn't happen again until our return flight. My husband was confused as to why this was happening, and it put me in panic mode. This can happen for many reasons including slower thinking, compromised decision making, and all the challenges to executive functioning. Fear is often the outcome. We survived by keeping a level head and taking each step slowly to allow him to calm down. Again, please PLAN AHEAD and review each step before you travel with your partner at the beginning of the trip so everyone can mentally walk through the experience.

Travel Insurance

11. Get travel insurance. This can help avoid financial losses if you cannot make the trip as well as help to cover problems while you are away. Medicare and/or your additional insurance may not cover overseas travel. Consider choosing an insurance policy that includes medical evacuation (Medivac) in case of an emergency and covers you to accompany your person.

12. If on a group trip, research the insurance policy that is offered by the trip company. The problem with this type of insurance is if you have to cancel the trip, you may only get a voucher for future travel with them not cash back. Read the fine print. And be sure pre-existing conditions are covered.

13. US web site: travel.state.gov for overview and suggestions for where you will travel. View all policies at insuremytrip.com or other consolidator to see which plan suits you.

14. Book direct flights when possible (no matter the extra cost). My own lesson was learned when we had to change planes, but the connection required a tram ride to our next gate. You can also opt for a wheelchair to meet you at your gate, but you must allow additional time between flights. This can be tedious and exhausting for you both.

Airports, Rental Cars, and Getting Around in Cities

15. Get a ride to drop you off directly on the check-in level at the airport. It is a big help as opposed to using your own car, parking and then having to walk with luggage and your PWP to the terminal.

16. Get to the airport, ship dock, or other departure point early. Allow lots of extra time to cut down on the stress of being late.

17. Know what to expect when you get to your destination and have to transfer to the rental car area—not all are located in the terminal. Once, I needed to push the wheelchair and our luggage to an elevated tram that took us to the rental car agency. This could have been avoided if I took my husband and the luggage just outside baggage pickup and hired a cab to drive us to the rental car agency. Even when the cars are advertised as being at the airport, it does not mean that they are at the airport. Most airports and major rental companies will have maps online to show you what is involved.

18. Take care in your planning to consider that some of the old cities in the world are made up of cobblestone streets and extremely narrow sidewalks that may be just inches from the very narrow roads. This happened to us in Mexico where uneven narrow streets with cars just off the curbs became a harrowing experience and way too challenging for my PWP.

Hotel Considerations

19. Call or write ahead to confirm if the hotel/rental unit has elevator access from entry to your floor. Some hotels and vacation rentals do not have elevators. My experience with this was an older condo in Steamboat, CO which had an elevator, *but I failed to ask if the elevator stopped on our floor*. The elevator started on the 3rd floor from the hill entrance but only went down to the 2nd floor. We had to walk down two flights of steps with luggage to the ground level.

20. It is possible to end up in a bedroom with an extra high bed frame where you must leap or get pulled into the bed. You might find this problem in an historic B&B. The challenge becomes worse in the middle of the night when the bathroom is often visited. This can ruin sleep for both of you and can be an additional hazard in the event your partner should fall out of bed.

21. Ask for a room near the elevator.

22. Call ahead and ask the venue if they have accessible entrances.

Plan to Arrive Early; Think of Safety

23. Have the address and a photo of where you are staying on your partner's phone in case your person goes for a walk in a strange location and gets lost. Put a piece of paper or a card in their pocket with the location and your phone number.

24. Pace yourself, slow down, and build in rest times. Skip cocktail hour and save the energy for the main event.

25. Book early dining seatings (especially if on a cruise) rather than eating late into the night.

26. If you have a family event or a tour scheduled, you might plan to arrive one to two days early to allow time to adjust to new surroundings and time zone changes.

27. Bring a change of clothing to the event in case of an accident while eating or using the toilet on your tours. Be sure to at least bring some wipes.

28. Secure a handicapped room with a walk-in shower, where possible. If your PWP uses urinals at night for convenience and safety, think about shipping them to your first destination, use them during your trip and then throw them out when ready to leave. I have done this when staying with friends. *Buy on Amazon to be shipped to your destination (always let your hosts or hotel to expect a package).*

29. Before leaving home set your watch or phone alarms for the proper pill times. *Less to remember makes for a better outcome.*

30. Durable Healthcare Power of Attorney (HCPOA) is a document stating who has the authority to make medical decisions on your behalf. Be sure to have one for you and your PWP.

31. Take at least two night lights to help find your way in a strange bedroom with low light.

32. If your destination is a two-day drive or less, 6-7 hrs each day, and you plan on being there awhile, consider driving. You can throw everything you need and everything you might need into the car. If you PWP no longer drives, consider having someone go with you to help drive. You might opt to buy the spare driver a round-trip plane ticket to get them home and back at the end of your trip to help drive home if that's an option.

Care Partner Needs

33. HEY, I ALMOST FORGOT ABOUT YOU. SURE, TYPICALLY YOU ARE THE ONE RUNNING AROUND DOING EVERYTHING FOR EVERYONE ELSE. This time take care of yourself first. This means start making a list and more lists of what YOU need and start early putting these things aside. If you start your packing early and finish early, you just might have enough time to chill.

Take a breath and then know you will have time to complete the rest of your tasks.

I just invested in Apple Air-tags. It is not a problem to put it in the pocket of your traveling partner or hang it from a belt loop. Also attach one to your luggage. I also keep one in my handbag. With your added responsibility you will have brain overload, and it is not uncommon to leave something behind or encounter sticky hands that will walk off with your possessions while you are juggling so many items.

Of course, we all know that there are bound to be many surprises. Return safely and always smile; and remember when things go awry that "this too shall pass."