

LIVING WELL WITH PARKINSON'S DISEASE

Summer 2024



Summer Travel Tips



1. Plan to bring all your Parkinson's medications and assistive equipment.

Wherever you travel, pack all the medications and dosages you will need, plus extras, in your carry-on bag. Pack all medications and a copy of the Parkinson's Foundation's Hospital Safety guide. Remember to include snacks, a water bottle and anything else you need to take with medication. Write your list of essentials before packing. Remember to pack your go-to outfits that make getting dressed a little easier — wrinkle-free items, shorts and pants with elastic waistbands — and assistive devices you regularly use.

2. Before your trip, check in with your Parkinson's doctor.

Before jetting off, speak to your Parkinson's doctor to ensure that you have all the medications you need.

3. Request assistance in airports.

Consider requesting special assistance at airports, such as a wheelchair or an electric cart service to help with luggage. This can make traveling much smoother and reduce stress. A physician's written certificate of need may be required, so make sure you call the airline ahead of time.

4. Call hotels to inquire about accessibility and special accommodations.

When staying at a hotel, call ahead to request a room with accessibility features, such as a room near the elevator or with wheelchair access. Additionally, if traveling from an airport, ask about transportation services ahead of time.

5. Continue to take medication as prescribed when changing time zones.

It is extremely important to take prescribed medications using your everyday intervals between doses. Set (or keep) your medication alarms the same as when you're home. Speak to your doctor if you have any questions.

6. Call our Helpline to find local resources.

Call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (1-800-473-4636) to find out if there are local Parkinson's resources (such as exercise classes and support groups) in the area you are visiting.

7. Check your medical insurance policy.

Be sure to check in with your health insurance before traveling so you are aware of any coverage or lack thereof.

8. Take your time, relax and enjoy.

Give yourself extra time for everything — enjoy longer meals, breaks between sites, coffee houses. Plan to see fewer sites so you enjoy them more, and when possible, book tickets for sites online ahead of time so you can minimize lines.

PD Patient Support Group
Meets the third Tuesday of every month from 2:00PM-3:30PM.

Caregivers Support Group
Meets the first Wednesday of every month from 2:00PM-3:30PM.

Deep Brain Stimulation (DBS) Information Sessions
Meets the first Friday of every month from 3:00PM-4:00PM.

To register for our support groups, and/or our DBS information sessions, please contact Erika Adelman, LCSW, SIFI at 929-695-0282.

Music and Movement Virtual Concert Series
Meets the first and third Wednesday of every month from 5:00PM-5:45PM. To register, please contact Hannah Lee at 212-305-9718.

Speech for PD
Meets every Tuesday and Thursday from 11:15AM-12:30PM. For more information and to register please contact Gemma Moya-Gale, Ph.D., CCC-SLP at gm2446@tc.columbia.edu.



Getting involved in support groups and programs such as the ones listed above as well as on the back, are opportunities to be a part of a community where you can get support, learn from others, be yourself, feel better understood, and you will be able to feel a sense of belonging. These programs can also help you cultivate self-esteem, personal growth, inspiration, and hope for the future!

Center Spotlight: TOPAZ

What is this study about?

TOPAZ is a clinical trial that explores minimizing fractures in patients who are diagnosed with Parkinson's and Parkinsonism that are fall risk using the drug zoledronate.

Who can participate?

Anyone with a diagnosis of Parkinson's Disease or Parkinsonism.

What is involved?

The study involves one at home infusion.

Who is the study sponsor?

Parkinson's Study Group

How much will it cost?

There is no cost to participate in this study.



For more information, please contact:

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Irving Medical Center
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New York, NY 10032

212-305-1303

www.columbianeurology.org/patient-care/movement-disorders

Parkinson's Foundation National Hotline:

1-800-473-4636

Make a Gift--Make a Difference

Wish to Donate?...

Should you be interested in discussing how you can help support our clinical, research, and patient care activities, please contact Matthew Reals, Senior Director of Development, at **212-304-7203** or mr3134@columbia.edu.

5 Tips for Navigating Parkinson's Related Life Changes



1. Acknowledge your grief or feelings of loss.

Throughout life, we experience change. Hobbies, careers, relationships and roles can further change and evolve with Parkinson's disease. When uncertainty feels like a frequent companion, life can be challenging. Honor your feelings around these changes.

2. Be kind to yourself.

Whether you are a person with Parkinson's or a care partner, it's important to recognize the challenges you face and take time out for self-care. Mindfulness can be helpful in processing change and practicing acceptance, and exercise can ease depression and other PD symptoms.

3. Lighten your load.

Connection — sharing your worries, your trials and your joys, and listening to the experiences of others walking their own path with Parkinson's — are good reminders that you are not alone. Whether talking to a trusted friend, reaching out to a local support group or connecting through an online discussion group, such as PD Conversations, you can begin to open up about your hopes and frustrations.

4. Build a care team.

People experience the symptoms of Parkinson's differently. Empower yourself with information on the disease management therapies that work best for you. Team-based care relies on various healthcare professionals with PD expertise to manage your symptoms on an as-needed basis.

5. Find reasons to hope.

Mental health care can help you work through change. This can include counseling and psychotherapy (talk therapy). Radical acceptance is when you acknowledge and honor the reality of life, as it is, in the moment. It can free you to channel your energy toward activities in which you find purpose, meaning and hope. For some, volunteering holds promise and purpose. Others find hope and community through raising awareness or sharing their story. In the face of continual change, exploring healthy coping techniques and finding mental wellness strategies that work for you can help you stay connected to what matters most.

If you have a question regarding Parkinson's and there's a treatment that you would like featured in the next newsletter, please email your questions and/or inquiries to Erika Adelman, LCSW, SIFI at era2142@cumc.columbia.edu.

The information published in this newsletter is not intended to replace, and should not be interpreted or relied upon, as professional advice, whether medical or otherwise. Please refer to your own professional for all advice concerning legal, medical, or other matters published in connection with this article.

"Don't count the days, make the days count."

-Muhammad Ali, diagnosed with PD in 1984