

Minnesota Messenger

newsletter of the APDA Minnesota Chapter

Fall 2020 Edition



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8 Tips for Getting Through the Holidays with Parkinson's Disease

Nikki Louiselle (read more contributions from Nikki at <https://themighty.com/u/justshakeitoff/>)



My name is Nikki and I'm an overachiever. An overachiever with Parkinson's disease. This should make for some interesting conundrums over the holidays – you think?

Like many other situations over the two years since my diagnosis, the holidays open up the opportunity for some wonderful teaching moments — for myself. I've had to learn to adjust my holiday expectations and there seems no better time to share these revelations with fellow overachievers than this week.

The following are some of the things I have done to not only survive the holidays with Parkinson's disease, but maybe even thrive during the holidays with Parkinson's disease.

1. Be kind to yourself.

I think this may be the most important tip to follow, not only during the holiday season but all year long. Parkinson's and perfectionism are not a compatible couple. I find myself giving up a few of my perfectionist tendencies every day. What a beautiful gift to give one's self this time of year — a bit of patience and grace.

2. Shop online.

This is a huge one for me! Each year I seem to do more and more of my gift shopping online and each year I feel more and more of the burden of holiday shopping crowds, noise and chaos lift. During this time of COVID-19, shopping online is a safe option.

3. Wrap as you go.

My husband will get a real kick out of seeing this one because I have not been true to this tip myself this year. But it can really make a difference. Instead of having to spend an entire day (or four) wrapping all the treasures you plan to gift friends and family with, keep your paper, ribbons, gift bags and tissue easily accessible and wrap as the gifts arrive.

4. Adjust your expectations.

I get it. This one is really, really hard for overachievers. But once you've done it, it's also really, really liberating. Our tree is smaller this year, I didn't send out Christmas cards this year, and the winter-themed dinnerware is still safely packed away. And guess what? No one has said anything about any of it. At least out loud to me. So I'm going to let these things go this year, and I'm going to be OK with it.

5. Listen to your body and pace yourself.

I've had to work pretty hard on this one. I cannot do everything I used to do. I've had to learn to factor in "rest days" and I've had to learn not to be angry about these days. I'm learning to accept that these rest days are what allow me to be fully functioning and fully present on my most treasured days.

6. Accept help when it is offered.

This has been a hard one for me, the overachiever. I don't like to ask for help and I often struggle with accepting it even when it is authentically offered. I have had to adapt and to learn to both ask for and accept the assistance of others. If you usually host friends and family, make this year's celebration potluck-style. If a loved one offers to open their home for the celebration, try replying this year with a gracious "yes, thank you."

7. Adhere to your medication schedule.

This piece of advice is coming from experience, and not necessarily a positive experience. It is very important during the busyness of the holidays to remember to take your medications on time. The easiest way I have found to do this is to set a reminder alert on my phone.

8. Take breaks when needed.

This is often necessary when you're cooking, wrapping or baking, but it can also be necessary when you're visiting and celebrating. Parkinson's has affected both my balance and my strength and energy. Frequent breaks while preparing dinners and treats have become a must. Parkinson's has, unfortunately, also affected my tolerance for crowds and noise. Ten minutes in a quiet room or a slow stroll around the block in the fresh air can be rejuvenating for a spirit that may be overstimulated.

A Parkinson's diagnosis comes with its own set of challenges. When combined with the activities of the holidays, it is easy to feel overwhelmed. Parkinson's or not, go into this holiday season with an open mind and an open heart and embrace everything it has to offer



Letter from the President

Jamie Engebretson, President, APDA Board of Directors

Dear Readers,

On behalf of the APDA Minnesota Chapter, I hope you are staying safe and healthy. Our lives have been impacted in so many different ways this year and have forced us to look for new ways to connect with family and friends. For some, we have been pushed into technology that we have been avoiding for years. For others, we are learning how to social distance without losing the connections we crave as humans.

The APDA Minnesota Chapter has been working tirelessly to help keep you connected and feel supported. We explored ways to better serve our community, and with the uncertainty of this pandemic, we made the decision to increase our offerings of online exercise and education resources. If you have not already, I encourage you to sign up for electronic communications on our website. We have increased our communications in this format to provide weekly News You Can Use emails about upcoming events to participate in. Additionally, you will find the Minnesota Messenger on our website and linked on our Facebook page: APDA - Minnesota Chapter. Please like and follow to keep up-to-date with the latest MN information.

You may have noticed that we hired a new Chapter Coordinator this summer. We are pleased to have Karen Judge join the Minnesota Chapter team. She brings a significant amount of customer service experience and has jumped in feet first with progressing the APDA mission in our state alongside Anushka Shiell, our Information & Referral Coordinator.

As winter is just around the corner, I reflect on this unprecedented year. Despite everything that has occurred, APDA Minnesota Chapter has been able to hire a Chapter Coordinator, hold the Tango in the Night fundraising event, successfully conduct our first virtual Optimism Walk, and transition APDA programs to virtual formats in order to continue serving our PD community. This year has made us think outside the box and has helped strengthen our APDA family across the country.

As we move forward into the winter months, we look forward to continuing to partner with other APDA chapters across the country to bring you virtual education symposiums featuring top speakers across the nation. We are committed to continue offering virtual exercise classes, support groups, and APDA programs such as PRESS, Powerful Tools for Caregivers, and Connecting Through Art.

We at APDA Minnesota Chapter are optimistic about the future for people with PD and remain hopeful for a cure. We look forward to seeing you virtually at our upcoming events and wish you a blessed holiday season.

Sincerely,
Jamie Engebretson

Coordinator's Column

Anushka Shiell, APDA Minnesota Information & Referral Coordinator



Dear Readers,

I hope that you and your families are all doing well during these unprecedented times, and staying safe and healthy. As always, I encourage you to reach out to me with any questions that you have about Parkinson's disease, virtual resources, and informational literature about PD. You can reach me at 651-241-8297, or email me at anushka.shiell@allina.com.

So much about day-to-day life has changed since the last publication of the Minnesota Messenger was released in February. APDA Minnesota (and APDA across the country) has transitioned to virtual education and support events for the health and safety of our Parkinson's community.

Since March, APDA Minnesota has offered several great virtual programs, including two sessions of the Powerful Tools for Caregivers class, two sessions of the PRESS (Parkinson's Roadmap for Education and Support Services) support group for people diagnosed with PD within the last 5 years, and a Virtual Summer Parkinson's Symposium in collaboration with the Udall Center and the Parkinson's Foundation.

APDA Minnesota planned an exciting event in collaboration with APDA Wisconsin and Iowa. The Upper Midwest Virtual Parkinson's Symposium took place on November 19 and 20, 2020. We offered a fantastic two half-days of free education planned, covering a wide array of topics including finding purpose in later life / while living with a chronic disease, an update on PD treatment, challenging non-motor symptoms of PD, exercise science in PD, and more.

I strongly encourage you to submit your email address to us at apdamn@apdaparkinson.org so that you can receive our weekly email with information about free virtual exercise programs, support groups, and educational offerings that you can participate in. Please encourage other people in your life with an interest in Parkinson's disease to do so as well. We would love to see you at our many virtual programs, just like the Upper Midwest Virtual Parkinson's Symposium.

I would like to share an exciting update from all of us here at APDA Minnesota. We are thrilled to welcome Karen Judge as our new Chapter Coordinator. Karen came on board this summer. She coordinates our Patient Aid Scholarship program, as well as other important fundraising events like our Virtual Optimism Walk on September 13, 2020. Karen also sends out weekly emails with helpful information about virtual exercise programs, support groups, and educational offerings. If you would like to receive that communication, please submit your name and email address to Karen by emailing apdamn@apdaparkinson.org, or calling Karen at 651-356-4378.

I hope that all of you have a wonderful holiday season with your families. Take care and stay healthy.

Warmest regards,
Anushka

Easy Tips for Reclaiming the Pleasure of Food

Mary Jo Rasmussen



Sitting down to a good meal is one of the simple pleasures in life. A diminished sense of smell and taste, two common symptoms of Parkinson's Disease, can rob patients of that enjoyment and lead to a lack of interest in eating. That can mean not getting adequate nutrition. Here are some suggestions on making eating satisfying again.

Test Your Taste Buds

Flavor comes from five distinct tastes: salty, sweet, bitter, sour, and umami (the Japanese word for savory). When your senses of smell and taste start to wane, your first reaction may be to add more sugar or salt to your food, which is not the healthiest option. Let's look at other ways to amp up the flavor of your food.

By playing around with the balance of these five basic tastes, you can discover which ones you may still be able to distinguish, and which are most appealing. A good way to start is to sample each taste individually. Put a little lemon zest on your tongue to see if you can taste bitter. Try a bite of a dill pickle to check for sour. For umami, try some Parmesan cheese.

Once you know how you experience these flavors, you can incorporate them into your cooking. If you can taste and enjoy bitter, try a dish like lemon chicken or salad with radicchio. If you can taste sour, try cooking with rhubarb; adding vinegar to a dish can also amplify sour notes. Many foods will add umami; the list includes tomato paste, mushrooms, miso paste, and low sodium soy or fish sauce.

While spiciness is not technically one of the five tastes, you may also find you enjoy more spicy heat in your food than previously. Experiment with other assertive ingredients like onion and garlic as well.

Use Plenty of Herbs and Spices

Herbs and spices add flavor to your food without adding salt. Fresh herbs have a completely different flavor than their dried counterparts, so they are worth seeking out if your recipe calls for them. Dried herbs and spices are easy to keep handy, but make sure they haven't outlived their flavor potential. Spices start to lose intensity after as little as six months. You can still use them, but you may need to use more to get the expected result.

Heat and light will degrade your spices, so keep them in tightly covered containers in a cool, dark location like your pantry. Go through your dried spices periodically and do a little culling. If your container of tarragon is covered in dust and you can't remember the last time you used it, chances are it's past its prime. Going forward, take the guesswork out of freshness by getting in the habit of using a permanent marker to write the date on the jar before you put them on the shelf.

Purchase spices in small quantities so you can use them up quickly. If you shop somewhere that sells in bulk, you can buy just what you need for a recipe, or a small amount to experiment with. If you can't buy bulk, opt for smaller jars at the grocery.

While most cooks rely on ground spices, consider buying whole spices and grinding them yourself. Since spices primarily get their flavor from their essential oils, grinding right before you use them releases those oils for maximum potency. You'll need a mortar and pestle or an inexpensive blade-style coffee grinder for this. Toasting whole spices before grinding them is another way to boost flavor.

Spice blends are convenient, but read the ingredient list – many blends rely on salt as a main component. Try making your own blends (see the recipe for ras el hanout below). Customize them according to what you like to eat. You might want a taco seasoning, or a barbecue rub. Here's a list of herbs and spices commonly used in different cuisines to get you started:

Asian – ginger, garlic, star anise, five spice powder, Szechuan peppercorns

Indian – turmeric, cumin, coriander, curry, garam masala, cardamom, cayenne

Italian – basil, oregano, thyme, rosemary, sage, marjoram

Mexican – cumin, coriander, chili powder, cayenne, Mexican oregano

More Ways to Add Interest

Adding texture to a dish makes it more appealing when taste is diminished. Try topping a casserole with toasted breadcrumbs, adding nuts to banana bread, or floating crunchy croutons in a bowl of soup.

Roasting or grilling vegetables until they have a bit of char and some crispy bits adds a pleasant bitter note and tempting texture.

Contrast in temperature can be pleasing as well. Think warm apple pie with vanilla ice cream.

Make It Look Good

Finally, make your meal visually appealing. There is a reason that restaurants focus on the presentation of their food. There's an old adage that says we eat with our eyes first, and it's true – if something looks pretty on the plate, we assume it will taste good.



Arranging an attractive plate doesn't have to be time consuming or complicated. For example, instead of serving a tossed salad, consider making a composed salad: layer the greens on the bottom, then arrange other ingredients attractively on top. Add your choice of colorful extras like green, red, or yellow peppers; sliced beets; and sliced oranges. Serve poultry or meat alongside a vibrantly colored mix of vegetables. Swap out your regular pasta for store-bought spinach pasta to add an unexpected pop of color.

Food nourishes wellbeing, both physical and emotional. Using these tips and tricks can help you look forward to mealtime again.



Ras el Hanout is a Moroccan spice blend that has many variations. The name translates to “head of the shop” referring to the fact that it is made with the best spices available. While it contains many assertive ingredients, Ras el Hanout is not a spicy blend, but has more of a warming character. You can use it for both sweet and savory recipes. Try some in your favorite shortbread or brownie recipe.

- 1 teaspoon ground cumin
- 1 teaspoon ground ginger
- 1 teaspoon salt
- 3/4 teaspoon freshly ground black pepper
- 1/2 teaspoon ground cinnamon
- 1/2 teaspoon ground coriander seeds
- 1/2 teaspoon cayenne
- 1/2 teaspoon ground allspice
- 1/4 teaspoon ground cloves

APDA Optimism Walk 2020

This year's Optimism Walk looked and felt a bit different than our normal annual fundraising event. Despite the uncertainty of COVID-19 sweeping the nation, we were able to partner with APDA Rhode Island, Midwest, and Cape Cod Chapters to host our first virtual Optimism Walk. It was great to see everyone's faces live on September 12, and have the opportunity for people across the state and across the nation to join in this year's Optimism Walk.

In case you missed it, you can re-live the event here. It was a joy to share the various APDA programs and services, and hear the positive impact APDA has in helping people live their lives to the fullest. We reached our fundraising goal of \$40,000! We are so grateful for your support.

We would like to thank your national and local sponsors for their support of this year's event:

National Sponsors

Adamas, Amneal, Lundbeck, Sunovion

Local Silver Sponsors

Abbvie, Acorda Therapeutics, Kyowa Kirin, Medtronic

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Acadia Pharmaceuticals, Allina Health, G4 Consulting, Lurie, Noran Neurological Clinic, Udall Center of Excellence at the University of Minnesota

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We look forward to seeing you in person at the 2021 Optimism Walk!

Mental Health in the Time of COVID-19

Dr. Rebecca Gilbert, Chief Medical Officer, APDA



Many people are feeling tense and anxious in this difficult time. But for people with Parkinson's disease (PD), as well as for anyone with a chronic disease, this time can be more stressful than for those without health issues, for a number of reasons. It is important to take care of yourself both physically and mentally, so we will discuss some potential causes of increased stress, as well as ways to manage your stress and feel more at ease.

Increased risk from the virus can cause stress

First and foremost, concerns about COVID-19 can be more acutely felt by older adults and those with chronic medical issues, because members of these populations have an increased risk of complications from COVID-19 infection. Knowing that you may be personally affected in a more profound way than others can be very anxiety-provoking. Being properly informed can help you. APDA has compiled a helpful overview of information and resources regarding COVID-19 and Parkinson's.

Visit <https://www.apdaparkinson.org/article/covid-19-overview-for-pd-community/> to learn more about these information and resources.

Anxiety and depression are common in the PD population at baseline

Many people with PD already experience anxiety and depression as a non-motor feature of their PD, so a stressful situation like the current pandemic can make it even more challenging. Many with PD are reporting that anxiety has increased during this tense time. For some, levels of depression can increase as well.

Should mental health issues start to become overwhelming, we are here to help. Call the APDA Minnesota Information and Referral Center at 651-241-8297 for help finding a therapist or counselor, or email anushka.shiell@allina.com.

People with PD may need regular exercise and social interaction more than others

Many exercise, dance and movement classes have been postponed which can lead to people with PD asking questions like “will my condition deteriorate without my exercise class?” And “how can I adapt so I still get some movement in my day?” They also may feel a bit lonely or isolated without the social interaction they get by going to classes.

It is important for people with PD to make a concerted effort to continue exercising. Also, some types of exercise like yoga and tai chi are particularly good for helping reduce stress and encouraging a sense of calm. Thankfully, there are lots of simple and safe ways to exercise at home. Socially distanced outdoor exercise, like taking regular walks, is an option as well. APDA offers multiple different home exercise classes.

Email apdamn@apdaparkinson.org to receive our weekly email communication with information about how to join our various home exercise classes.

Kathy is a 73-year-old woman diagnosed with PD five years ago. Although COVID-19 is raising significant anxiety and concern for all her friends, she knows that her PD gives her unique concerns. “Because of my PD, I am extra anxious that I am not moving as much as before. Movement is so essential for me. I like to read, but I am afraid to sit for too long because I will get stiff”



People with PD have additional health concerns that can be hard to manage during the COVID-19 crisis

People with PD may have additional anxiety about issues specific to their situation. Potential concerns include:

Interacting with home health aides who leave and enter the home

Being in a rehab or nursing facility where infection can spread easily

The potential need of going to the Emergency Room or hospital for reasons unrelated to COVID-19 (for example, a urinary tract infection or an aspiration pneumonia)

These are all valid concerns and tricky scenarios to manage, and they can add to your stress levels and anxiety as you wonder “what’s the right thing to do?”

Your first step should be to talk to your doctor about the issue you’re facing. Weighing risks and benefits with your physician will lead you to the best solution for your particular circumstance. But the bottom line is that having PD may necessitate being in a situation that you would rather avoid at this time (like going to the ER). These added concerns can contribute to the anxiety of an already stressful situation.

For all these reasons, and more, it is very important for people with PD to find ways to manage their anxiety and maintain their mental health.

Kathy, for example, is very aware that “when I wake up, my anxiety is at its peak. I do meditation in the morning which is helpful.” Another way to manage stress is to take help when it is offered. Kathy says “I had to learn how to accept help – such as when someone volunteers to go grocery shopping for me. I had to get over that hurdle of not wanting to take anyone up on their offer.”



Ways to manage stress

There are many things you can do to help minimize stress. Here are some ideas:

- Establish daily routines: Having some structure to your day can keep you focused, motivated, and stimulated. Your normal schedule has likely been affected by COVID-19, but you can create a new structure for your days. Setting a schedule for your meals, exercise, social connections (including virtual social connections), and household chores, etc., can be helpful.
- Get fresh air every day: Take a walk or bike ride, remembering to maintain a 6-foot distance from others, or even simply spend some time in your yard or front porch.
- Continue to exercise at home. YouTube and APDA are a wealth of online exercise resources.
- Stay connected with family and friends online or on the phone. Make a point to reach out to someone every day. Join Smart Patients, APDA’s online support network and discussion forum that connects you with others in the PD community so you can share ideas, concerns, and advice. Visit <https://www.smartpatients.com/partners/apda> to learn more.
- Take a break from the news coverage of the pandemic and enjoy a new book, TV show, or another hobby.

Mental health via Telehealth

Many doctors, counselors, and therapists around the country have transitioned to telehealth visits during this time. This means that the visit is conducted either online or via the telephone instead of in person. The services of psychiatrists and mental health professionals are uniquely amenable to being offered through telehealth. If your anxiety and depression are particularly acute now, ask your neurologist for a telehealth referral to a psychiatrist or another mental health professional, such as a counselor or therapist.

Because of the increased need, the rules that govern telehealth have changed due to the COVID-19 crisis to help more people access services. For example, in the past, a physician was required to hold a medical license in the state in which the patient being treated via telemedicine lived. Now this is no longer a requirement and a physician can treat someone via telemedicine over state lines. It's important to get the care and support you need, so be sure to talk to your doctor.



Parkinson's Disease & Your Home Safety

Carol DerSarkissian, MD

Effects of Parkinson's disease, like fatigue and trouble getting around, can make daily living tougher. There are ways you can make your home life as easy as possible.

General safety guidelines

- Have emergency numbers (police, fire, poison control, and a neighbor's phone number) close by. Put them in an easily seen place, like on the fridge.
- Have a phone near you at all times. Keep a cell phone in your pocket. It'll be especially important if you fall.
- Make sure your smoke detectors work. You should test them about once a month. If possible, get interconnected ones so that if one goes off, they all go off.
- Avoid space heaters and electric blankets. They can be fire hazards.

How can I make my home easier to live in?

Not all of these recommendations may be right for you. Your occupational therapist or rehabilitation specialist can help determine which of these are best for you.

In your living room and bedrooms:

- Place furniture so that you have wide walkways. This will leave you plenty of space to move around.

- If you can, make outlets easily available for lamps and appliances. If you need extension cords, make sure they're secured with tape and out of the way, so you don't trip on them.

- Use chairs with straight backs, armrests, and firm seats. This will make it easier for you to get up and sit down. Firm cushions can add height and make it easier to move.

- Look for lamps that you can turn on with a touch or with sound.

- If possible, change your phones to ones with larger buttons. It'll make dialing easier. Have the numbers you call a lot programmed into speed dial.

- Install handrails along walls, hallways, and stairwells where there is nothing to hold on to.

- If you have trouble getting out of bed, talk to your occupational therapist about having a stationary pole or "trapeze" bar installed.



In your bathroom:

- Use an elevated toilet seat or safety rails to make it easier for you to get up. Don't use towel racks or bathroom tissue holders to help you stand.

- Put extended lever handles on your faucets. That will make them easier to turn.

- Put grab bars inside and outside your bathtub or shower. It will lower your risk of a slip and fall.

A bathtub transfer bench, or a shower chair with a back support can be useful, too.

- Non-slip mats or decals in the bathtub or shower stall can also be helpful.

- Get rid of small bathroom mats that may cause you to trip. A large rug that covers most of the floor with nonstick backing is a great alternative.

In your kitchen:

- Have at least one counter workspace lowered so you can reach it when you're sitting.

- Use an electric jar opener to loosen tough lids, and don't close jars or containers too tight when you're through with them.

Get help with lift-tab cans from an extended lever.

- Use pans with a wide base. That way, you're less likely to knock them over.

When you need to cut or peel vegetables, use a food processor.

Put utensils, pots, pans, and measuring cups on a pegboard or in an accessible cupboard. Lower storage space forces you to bend. When you do have to get things out of lower cupboards, sit.

·Use a spike board to keep vegetables and fruit still so you have both hands free to peel or chop them.

·Use plastic containers to avoid broken pieces.

Use a nonskid mat to keep bowls and plates steady.

·Store food and beverages in small, easy-to-manage containers, like a small pitcher vs. a large gallon jug.

·When you pour liquids, use two hands.

·Use scissors to open plastic packages.

·When you open boxes, use a box top opener.

· Use electric appliances whenever possible.

Other tips:

Make your environment as comfortable and pleasing to your senses as you can.

Keep your rooms in soothing colors to help relax you.

Use scented candles or potpourri in fragrances that make you feel at ease.

Keep photos and music that uplift your spirit at arm's reach.

If you'd like company during the day, think about a low-maintenance pet, like a bird, fish, or cat.

If a pet seems like too much, surround yourself with plants or flowers.

Make sure the temperature and climate make you feel good.

·The more comfortable and uplifting your environment, the more positive your attitude will be.



Get in Touch - APDA Minnesota Chapter

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