



PARKINSON'S:
*A Checklist for the
Newly Diagnosed*



DAVIS PHINNEY
Foundation For Parkinson's

every victory counts®

If you've been diagnosed with Parkinson's, you may be feeling overwhelmed, devastated, angry, confused or all of the above. We receive emails from people every day who have just heard the words, "You have Parkinson's." They want to know what to expect, what to do and if it really is possible to live well with Parkinson's.

To answer some of these questions, we decided to create this checklist for you. This is the result of collaboration between our staff, Davis Phinney Foundation Ambassadors and those in our community who said that finding us allowed them to accept their diagnosis and thrive in significant ways despite it.



ABOUT THE DAVIS PHINNEY FOUNDATION

Our goal at the Davis Phinney Foundation is to **help people with Parkinson's live well today**. We do this by providing essential information, practical tools, and inspiration to people living with Parkinson's and their care partners. We also host online educational events and intimate meetups, engage and support community leaders in the pursuit of creating Healthy Parkinson's Communities™, and fund early-phase, innovative research that focuses on factors that affect quality of life.

What to do every day...



- **Exercise.** A daily exercise regimen is incredibly important for staying healthy and slowing the progression of Parkinson's symptoms. It can be especially beneficial if you combine your exercise regimen with a social activity because it will allow you to interact with others and will also keep you accountable.
- **Take your medication on time, every time.** It can take some trial and error to find a medication and a schedule that works well for you; so, be patient with yourself and honest with your doctors about what's working and what's not when it comes to your medications. Once you find a schedule that works, stick to it.
- **Eat well.** Avoid processed foods and added sugars. Pay attention to what foods give you energy and make you feel cognitively clear and reduce or eliminate foods that do the opposite.
- **Take care of your oral health.** Dentists and speech and language pathologists recommend brushing three times a day, flossing once a day and rinsing with an alcohol-free mouthwash each time. Biotene is great if you experience dry mouth. Good oral hygiene can help prevent tooth decay and gum disease and protect the integrity of your teeth over the long term. In addition, an unhealthy mouth puts you at greater risk for developing serious health problems such as heart attack, stroke and poorly controlled diabetes.
- **Drink approximately 64 ounces of water.** Water not only makes you feel better, it helps your medications move through you more easily, it can improve digestion and reduce constipation and it can improve symptoms related to low blood pressure, especially if you have nOH.
- **Show gratitude to the people in your life who support and love you.** Those who express gratitude on a regular basis experience fewer aches and pains and tend to feel healthier and happier than those who don't.
- **Be your own best advocate.** You are the expert on your Parkinson's experience. By taking action and being clear and specific with your family, friends and healthcare providers, you can improve your care and your quality of life.
- **Practice mindfulness.** This could mean sitting in meditation, practicing yoga, going for a walk, singing, playing music, creating or just sitting and enjoying the quiet. This is time to take a breath, pause and remember that right now, you're okay.
- **Celebrate every day victories.** It can be difficult sometimes to find the victory in actions you used to take without even thinking about them. However, today is a new day, and it's important to acknowledge your efforts and accomplishments on a regular basis. As our founder, Davis Phinney, says, "Every Victory Counts!" They do; so, make a habit of celebrating them every day.

What to do every week...



- **Consider a weekly review.** Jot down how you have felt, slept and eaten. Note increases or decreases in symptoms. Rate your medication management. Write down your hopes for the week ahead.
- **Build muscle.** Many people know the benefits of high intensity cardio exercise for reducing Parkinson's symptoms but don't realize how valuable building muscle can be. Weight training on a regular basis can help reduce stiffness, slowness and tremor now and over the long term.
- **Take action on the symptoms you can control.** The most powerful actions you can take to control your symptoms are to adhere to your medication schedule, sleep well, exercise consistently, eat a healthy diet filled with whole foods and reduce stress.
- **Check in on your mood.** Receiving a diagnosis of Parkinson's is life changing. Some people experience depression long before a diagnosis comes. Some experience depression soon after it. And some, never experience it at all. The good news is that there are ways for you to manage your mood or anxiety. If you're finding it difficult to do the things you need to do to live well like exercise, sleep, connect with others, etc., consult a specialist to discuss your options.
- **Accept what you cannot change.** You do have Parkinson's and because of that, you may feel like many of your dreams flew out the window the day you received your diagnosis. Perhaps some of them have; however, now you have time to focus on new dreams. It is possible to live long, well and happy with Parkinson's.
- **Connect to your community.** Social isolation is common in people with Parkinson's, but it can have wide-ranging negative effects. Social isolation can exacerbate your symptoms, put you at risk for developing other health problems, increase your chances of experiencing depression, accelerate cognitive decline and decrease your quality of life. Attend a group exercise class, a support group meeting, an event at your community center or a religious function. Find out how good it can feel to connect.
- **Learn something new.** Learning and acquiring new information and experiences, especially ones that require complex thought processes, can stimulate brain cell growth, which may help you manage cognitive decline.



What to do every month...

□ **Reach out to a Davis Phinney Foundation Ambassador.**

Our Ambassadors are leaders and advocates in their communities who exemplify living well with Parkinson's. They have insights to offer on everything from Parkinson's medications and therapies to the best local exercise classes, local Parkinson's resources and support groups, top notch healthcare providers and more. Plus, they are inspiring people to connect with. You can find them at dpf.org/ambassadors.

□ **Organize your medical information and prepare in advance for meetings with your medical team.**

Be sure to write down any changes you've experienced, percentage of OFF time you have each day, other illnesses you've had and important questions you want to make sure to ask. If your doctor has a patient portal for you to send information, it's a good idea to set yourself a reminder to do this once a month.

□ **Spend a few moments researching clinical trials**

that may be available to people newly diagnosed with Parkinson's. Participating in clinical studies can be an empowering way to get involved in finding a cure. You can find clinical trials in your area at clinicaltrials.gov or foxtrialfinder.org.

What to do every year...



- **See a Movement Disorder Specialist.** A movement disorder specialist is a neurologist who has received specialized training in movement disorders such as Parkinson's. Finding one in your local area may be a challenge; however, as you will likely only see this doctor once a year or once every two years, traveling to see a good one can make a big difference in how you live with Parkinson's.
- **Get assessed by a physical therapist who specializes in Parkinson's** or other neurological disorders. Getting a yearly assessment is a great way to determine your strengths and weaknesses, set fitness and mobility goals and create a long-term plan to improve your quality of life.
- **Get your skin checked.** Research shows that people with Parkinson's are at a higher risk of developing melanoma; so, it's important to monitor your skin on a regular basis and work with your dermatologist if you notice any changes.
- **Get an annual check-up.** Even if you are working with a neurologist or movement disorder specialist, it's important to have an annual exam so your doctor can check your vitals, weight, heart rate, blood pressure, eyes, nose, throat and more. This is also a good time to get your blood work done, review your medications and make sure your doctor is up to date on your Parkinson's care.

- **Reflect.** Consider how things have changed for you in the past year. What are your symptoms? Do you feel like your treatments are working? Have you considered any new medical or alternative therapies? Does your medical team have any updates or suggestions you need to consider? Take stock of the past year so you can make the next year even better.
- **Set some goals for the upcoming year.** Plan a trip. Learn how to row. Try your hand at painting or sketching.
- **Consider new ways you can give back to your community.** Being of service is one of the best ways to engage with your community and also help you gain perspective on your own situation. One of the comments our Davis Phinney Foundation Ambassadors make is that giving back to their Parkinson's communities (or any community) is one of the very best things they've ever done to improve their quality of life.

And one more thing you can do today and anytime...

Choose joy.

Living with Parkinson's presents daily challenges. Choosing joy can improve your immune system, fight stress, increase longevity and bring more positive people into your life.

You can have both Parkinson's and joy.

What's Next

Want more ideas on how to live well with Parkinson's?

Check out our Every Victory Counts® suite of manuals! They provide essential information and inspiration to give you and your family members the tools you need to take control of your treatment and get the care you need to live well with Parkinson's today.

Learn more and request complimentary copies of the new Every Victory Counts manuals here: **www.EveryVictoryCounts.com**.



We hope this checklist is helpful to you. If you learn something along the way that you think should be included, please share your feedback and experience with us at **blog@dopf.org**. We are constantly updating our materials to serve our community in the best way possible, and we want to hear from you.

