



# WISCONSIN PARKINSON

MAGAZINE ISSUE NO. 104 | 2020

HOPE  
SUPPORT  
COMMUNITY  
RESOURCES

P.6

WHAT IF IT IS **NOT**

*Parkinson  
Disease?*

P.3

ASK THE  
EXECUTIVE  
DIRECTOR: A  
CONVERSATION  
WITH GARY  
GARLAND

P.5

PARKINSON'S  
AND DRIVING  
SAFETY



# In this Issue

- 4 Therapy for Parkinson's
- 5 Parkinson's and Driving Safety

## 6 WHAT IF IT IS NOT *Parkinson Disease?*

- 7 What is Essential Tremor?
- 8 Cognitive Impairment in Parkinson Disease
- 9 Medication Assistance
- 10 6 Ways to be a Great Long-Distance Caregiver
- 12 Charitable Gifting Options: Part II
- 13 Thriving with Parkinson's: Lynn Ettenheim



- 14 5 Technology Trends that Promote Independence
- 15 eBiking with Parkinson's
- 17 Support Groups & Exercise Groups
- 18 Support Group Feature: West Bend/Laurie Prochnow
- 19 WPA Happenings

## Credits

*Wisconsin Parkinson Magazine* is a publication for people with Parkinson disease, their families and friends, and any interested individuals and groups. It is published by Wisconsin Parkinson Association. Information provided concerning medical diagnosis, treatment, and research is not intended to answer individual problems but to report and explain current

information about Parkinson disease. You should always ask your physician about specific treatment issues. This magazine is funded by your donations. Your support helps those living with Parkinson disease by allowing us to enhance and expand our services to them and their families. For more information, visit [wiparkinson.org](http://wiparkinson.org).

### Staff

**Gary Garland**  
Executive Director  
[garyg@wiparkinson.org](mailto:garyg@wiparkinson.org)

**Laurie Couillard**  
Director of Group Engagement  
[lauriec@wiparkinson.org](mailto:lauriec@wiparkinson.org)

**Carolyn Hahn**  
Director of Communications  
[carolynh@wiparkinson.org](mailto:carolynh@wiparkinson.org)

**Raven Hamilton**  
Director of Administrative Services  
[ravenh@wiparkinson.org](mailto:ravenh@wiparkinson.org)

**Jeremy Otte**  
Director of Outreach & Education  
[jeremyo@wiparkinson.org](mailto:jeremyo@wiparkinson.org)

**Mary Spidell-Wood**  
Exercise Coordinator  
[maryw@wiparkinson.org](mailto:maryw@wiparkinson.org)

### Board of Directors

President  
**Jim Cantrell**

Vice President  
**Fred Moseley**

Secretary  
**Bob Norman**

Treasurer  
**Rob McDonald**

Past President  
**Dick Cosentino**

Board Members  
**Omar Andrade**

**Craig Barbian**

**Tom Brandt**

**Kate Brewer**

**Kristine Everson**

**Ken Foster**

**Peter Ginn**

**Kate McDonald**

**Ron Mohorek**

**Cheryl Prescott**

**Ginger Wooster**

Emeritus Members  
**Knut Apitz**  
**Keith Brewer**  
**Dick Schumann**

### Medical Advisory Committee

**Rachel Biemiller, MD**  
Gundersen Health System

**Karen Blindauer, MD**  
Froedtert & the Medical College of Wisconsin

**Ryan Brennan, MD**  
Froedtert & the Medical College of Wisconsin

**Taylor Finseth, MD**  
Aurora Health Care

**Kathryn Gaines, DO**  
Aurora Health Care

**Lisa Kokontis, MD**  
Neuroscience Group

**Michael Schonberger, DO**  
Gundersen Health System

**Katie Spangler, MD**  
Marshfield Clinic



# Ask the Executive Director



We sat down with WPA's executive director **GARY GARLAND** to learn a little more about his past – and WPA's future! Want to know more? Reach out to him at [gary@wiparkinson.org](mailto:gary@wiparkinson.org)

**Tell us a little about your background before coming to WPA three years ago.**

**What brought you here, and what has your impression been?**

I came from an anti-poverty, anti-hunger organization. It was very different in a lot of ways – especially in regards to the visibility of the organization. Hunger and poverty are on everyone's radar. In terms of an organization where people donate money, that's an issue at the top – right behind faith-based groups. Very visible. Parkinson disease? Not so much!

I remember going to my first interview with the board of directors here, and I asked them "what's the biggest issue WPA is facing?" They said, "Visibility. People just don't know us. And they need to."

Visibility equals involvement and engagement. That's become the challenge for WPA – to be visible, and to get people more engaged in the organization.

Where I came from previously, there were 100,000 people in the neighborhood, and about 5,000 were involved with us. Here at WPA, we've got about 2,000 in a state of 6 million.

On the positive side, that means that the people who are involved with us aren't on the periphery looking in – they are HERE. They live it. Our board of directors is made up of either people with Parkinson's, or people with a loved one with Parkinson's. Where I came from, they just didn't have that same connection. So it's great to see that level of involvement here.

The thing that stays in my mind every day that I'm here is how POSITIVE the Parkinson's community is. They have been dealt a tough hand with a very tough disease, but I can't think of a single incidence where I've met someone who is whining or grumbling about this disease. They remain positive, as do their loved ones.

**What do you think makes WPA special and unique?**

There are several great things!

We are the largest provider of FREE Parkinson's exercise in the state. We're the largest provider of FREE Parkinson's education programming in the state, too.

We go wherever there's a need! Who else starts an exercise class in Kiel? Or an education program in Janesville or Eau Claire? We do! That's our mission – that's why we're here.

Tied to that, we really seek out a couple of "underserved communities" to make sure they are not forgotten. We're focusing on people with Parkinson's in rural areas in Wisconsin, caregivers for a loved one with Parkinson's, and those who are newly diagnosed to make sure they have what they need moving forward.

Another area that makes WPA unique is what I call our "bottom-up" programming. If you have attended any of our programs, you know that we're going to ask you how we did, and what you want us to work on in the future. Our programs are not designed by our staff or board – they are designed by people who live out the Parkinson's journey.

continued on page 16

# Therapy for Parkinson's

By Michelle Jens, PTA

Doctors commonly order occupational and physical therapy to address the challenges, changes in function, and symptoms related to Parkinson's. People often ask, "Does that mean OT works my arms and PT works my legs?" That's when we, as therapists, answer a couple of questions:

## What's the difference between occupational therapy (OT) and physical therapy (PT) for patients with Parkinson disease?

### OT specializes and focuses on the following areas:

- ◆ Micrographia (small handwriting that slants toward page corners)
- ◆ Memory
- ◆ Medication management
- ◆ Hand-eye coordination and fine motor skills like opening jars, buttoning a shirt, and picking up objects between the thumb and fingers
- ◆ Activities of daily living. Examples include eating, drinking, bathing, dressing, toileting, and self-hygiene tasks
- ◆ Dining equipment including special cups, plates, and silverware to ensure that food and drink make it to the mouth. For example, a weighted spoon can decrease tremors
- ◆ Bath and toilet equipment to improve safety and ease. Some examples include shower chairs and toilet risers
- ◆ Upper body range of motion, strength, and coordination
- ◆ Meal prep
- ◆ Housework
- ◆ Job duties. Job setting adaptations, desk setup, or special equipment can help to maintain independence

### PT specializes and focuses on the following areas:

- ◆ Gait training (ambulation) to address freezing steps, festinating (involuntarily walking faster while shuffling the feet), step length, difficulty initiating steps or picking up the feet. A metronome or music beat can be used
- ◆ Environmental safety assessment of lighting, height of bed/chairs, flooring changes, narrow spaces, curb, ramp, and stair training
- ◆ Lower body range of motion, strength, and coordination
- ◆ Techniques to improve standing up on first attempt instead of falling backwards repeatedly
- ◆ Bed mobility and equipment to maintain independence
- ◆ Balance to decrease fall risks
- ◆ Stooped posture
- ◆ Pain
- ◆ Education in assistive devices and proper use. Examples include four wheeled walkers, front wheeled walkers, and canes
- ◆ Motor planning (the ability to plan and carry out a task). One example includes being able to approach a chair, turn, back up, and determine the proper distance to sit in the chair

## Why would someone with Parkinson's need both physical and occupation therapy?

While there can be some crossover with what each discipline does, both therapies focus on delaying the progression of the disease by retraining the connection between the mind and body. When Parkinson's symptoms worsen, they often occur in both the upper and lower body at the same time, necessitating both OT and PT, to address any of the potential tasks listed to the left.

Both OT and PT address rigid muscles. Greater flexibility is needed for OT to address dressing while it is needed for PT to teach someone how to move from sit to stand. In addition, both OT and PT address Bradykinesia (slow movements) and tremors. While OT may address hand tremors with weighted utensils, PT may address leg tremors with muscle relaxation, stretching, or weight-bearing activities.

When OT and PT are provided simultaneously, progress is typically quicker, resulting in greater independence and quality of life, as the whole body is addressed. 🍷

.....

**Michelle Jens, PTA** works for Greenfield Rehabilitation Agency, and leads a Parkinson's Movement & Music Class in partnership with WPA. To learn more, visit [grawi.com](http://grawi.com).

# Parkinson's and Driving Safety



**The topic of driving can be a sensitive subject for folks with Parkinson's disease (PD) and their care partners. Fortunately, just because one has a PD diagnosis does NOT necessarily mean that the freedom to drive needs to be taken away. There are many people with PD who continue to drive safely, years after they have been diagnosed.**

However, we know that PD progresses over time. Symptoms change. Medications may be added and others stopped. Side effects from medications can change. New health problems may arise that make controlling PD more difficult. Because of these things, driving safety is an issue that requires re-evaluation from time to time. Independence and safety are priorities that should both be honored, while recognizing that sometimes modifications may need to be considered.

## Things to consider when deciding whether to drive

Driving plays an important role in an individual's sense of independence, personal control, and self-reliance, so giving up driving can be very difficult. People living with PD should consider the following questions when deciding whether or not to drive:

- ◆ How is my vision? Can I see well at night? Can I distinguish colors, such as in traffic lights?
- ◆ Would I be putting my passenger (friend or loved one) at risk?
- ◆ How fast is my reaction time? Could I safely avoid a surprise obstacle in the road?
- ◆ Has anyone (friend or family member) commented negatively on my ability to drive?
- ◆ Can I handle multiple activities at the same time (whether driving or not)?
- ◆ Can I effectively and quickly turn the wheel or step on the brake with enough strength?

- ◆ Do my medications for PD (or other conditions) cause side effects like sleepiness, dizziness, blurred vision, or confusion?

These are understandable and important questions to be considered, but often people struggle with how to discuss the issue with loved ones or care partners. Sharing concerns or observations with a trusted friend or family member might be a good place to start.

In some cases, speaking with a doctor or professional, such as an occupational therapist, might be helpful. The American Occupational Therapy Association maintains a searchable database to help locate a Driving Rehabilitation Specialist so you or a family member may receive an assessment (<https://www.aota.org/Practice/Productive-Aging/Driving/driving-specialists-directory-search.aspx>).

Driver rehabilitation specialists work with people of all ages and abilities, evaluating, training, and exploring alternative transportation solutions.

Another tool for rating driving ability is offered by AAA at <https://seniordriving.aaa.com/evaluate-your-driving-ability/self-rating-tool/>. Local rehabilitation hospitals also sometimes offer assistance in driver evaluation and training.

When the time comes that a person with PD needs to give up driving, it is important to remember that there are options. Public transportation can be an option. Friends and family members are often happy to help, and it is important not to be afraid to ask. Also, look into special shuttle services through local organizations and community centers.

Socialization and staying active help manage Parkinson's symptoms. You don't have to stay home once you are no longer driving. 🗣️

Article from February 2020 issue of Dallas Area Parkinsonism Society newsletter.

[daps.us/sites/default/files/202002.pdf](https://daps.us/sites/default/files/202002.pdf)

# What if it is NOT *Parkinson Disease?*



By Dr. Luisa Solis-Cohen,  
Colorado Neurodiagnostics

There are a number of Parkinson disease 'look-alikes' that your neurologist will consider when weighing the diagnosis of Parkinson disease. Especially in the early stages, it can be quite difficult to differentiate Parkinson disease from the less common "atypical Parkinsonisms." Your neurologist will rely on a detailed medical history and physical examination to help differentiate among these options. In fact, even a DaT (dopamine transporter) scan will offer little help in such decision making. Here, you will find more information on the atypical Parkinsonisms.

**Progressive supranuclear palsy (PSP)** is suspected when there is early imbalance and unexplained falls in addition to other Parkinsonism symptoms. The name of this condition refers to the difficulty moving one's eyes in the vertical direction, a feature often seen later in the disease course. Other symptoms include personality changes and forgetfulness. Individuals with PSP may have a less robust response to levodopa. Often a more rapid disease progression is experienced.

**Multiple system atrophy (MSA)** refers to a subgroup of Parkinsonisms that affects numerous body systems early in the disease and often leads to a more rapid disease progression. In some individuals, the autonomic nervous system is affected, leading to early orthostatic hypotension, erectile dysfunction, and bladder habit changes. Other symptoms can include impaired speech, troubles swallowing, and difficulty breathing. Treatment is symptom-specific as levodopa provides little benefit.

**Dementia with Lewy bodies (DLB)** is the second most common cause of dementia in the elderly. While a person may have motor symptoms similar to Parkinson disease, the hallmarks of this condition are difficulty with thinking, fluctuating level of alertness,

and visual hallucinations. Typically the signs of dementia appear before or within the first year of Parkinsonian motor symptoms. Treatment is focused on cognition and hallucinations, but often includes low doses of levodopa.

**Corticobasal degeneration (CBD)** is the least common of the atypical Parkinsonisms. Often a person will describe difficulty with voluntary control of one side of the body; there can be involuntary postures or jerking movements of that side. Speech is often affected.

**Vascular Parkinsonism** is considered in individuals with stroke risk factors, such as high blood pressure, high cholesterol, and diabetes. This condition arises after multiple small strokes in the basal ganglia, one of the brain regions implicated in Parkinson disease. Gait difficulties and lower extremity stiffness are often the primary complaints. Symptoms can appear abruptly and there can be "step-wise" progression with periods of worsening followed by plateaus. This may or may not respond to levodopa, the gold standard medication used in Parkinson disease.

**Drug-induced Parkinsonism** can arise when dopamine levels in the brain are altered by certain drugs such as anti-nausea medications, antipsychotics or mood stabilizers, some calcium channel blockers, and stimulants such as amphetamines and cocaine. Symptoms often improve if the medication is discontinued, but this can take many months.

**Normal pressure hydrocephalus (NPH)** is characterized by difficulty walking, cognitive impairment and loss of bladder control. It results from excess cerebrospinal fluid surrounding the brain and diagnosis involves both brain imaging and examinations before and after a spinal tap. Treatment involves neurosurgical placement of a shunt to remove excess cerebrospinal fluid. 🍷





# What is

# Essential Tremor?

Essential tremor is a nervous system (neurological) disorder that causes involuntary and rhythmic shaking. It can affect almost any part of your body, but the trembling occurs most often in your hands – especially when you do simple tasks, such as drinking from a glass or tying shoelaces.

Essential tremor is usually not a dangerous condition, but it typically worsens over time and can be severe in some people. Essential tremor is sometimes confused with Parkinson disease.

Essential tremor can occur at any age but is most common in people age 40 and older.

## Symptoms

Essential tremor signs and symptoms:

- ◆ Begin gradually, usually more prominently on one side of the body
- ◆ Worsen with movement
- ◆ Usually occur in the hands first, affecting one hand or both hands
- ◆ Can include a "yes-yes" or "no-no" motion of the head
- ◆ May be aggravated by emotional stress, fatigue, caffeine, or temperature extremes

## Essential tremor vs. Parkinson disease

Many people associate tremors with Parkinson disease, but the two conditions differ in key ways:

- ◆ **Timing of tremors.** Essential tremor of the hands usually occurs when you use your hands. Tremors from Parkinson disease are most prominent when your hands are at rest.
- ◆ **Associated conditions.** Essential tremor doesn't cause other health problems, but Parkinson disease is associated with stooped posture, slow movement, and shuffling gait. However, people with essential tremor sometimes develop other neurological signs and symptoms, such as an unsteady gait (ataxia).
- ◆ **Parts of body affected.** Essential tremor mainly involves your hands, head, and voice. Parkinson disease tremors usually start in your hands, and can affect your legs, chin, and other parts of your body.

## Causes

About half of essential tremor cases appear to result from a genetic mutation. This form is referred to as familial tremor. It isn't clear what causes essential tremor in people without a known genetic mutation.

## Risk factors

Known risk factors for essential tremor include:

- ◆ **Genetic mutation.** The inherited variety of essential tremor (familial tremor) is an autosomal dominant disorder. A defective gene from just one parent is needed to pass on the condition. If you have a parent with a genetic mutation for essential tremor, you have a 50 percent chance of developing the disorder yourself.
- ◆ **Age.** Essential tremor is more common in people age 40 and older.

## Complications

Essential tremor isn't life-threatening, but symptoms often worsen over time. If the tremors become severe, you might find it difficult to:

- ◆ Hold a cup or glass without spilling
- ◆ Eat normally
- ◆ Put on makeup or shave
- ◆ Talk, if your voice box or tongue is affected
- ◆ Write legibly 📝

Information provided by Mayo Clinic.

# Cognitive

# Impairment in Parkinson Disease



## What types of cognitive problems can happen in Parkinson disease?

Many people with Parkinson disease (PD) have good memory and thinking (cognition) and function normally. However, while forgetfulness may occur with normal aging, more serious trouble with attention, thinking, and memory can occur as PD advances.

Common cognitive problems in PD include difficulty with:

- ◆ Paying attention or concentrating
- ◆ Planning events, like organizing a busy day
- ◆ Following a complicated conversation or solving complex problems
- ◆ Forming thoughts quickly
- ◆ Remembering events or event details, although hints or clues often bring the memory back

When changes are small, without a serious effect on your daily life, this is called mild cognitive impairment. When changes are severe enough to affect day-to-day activities, this is called dementia.

## Why do cognitive problems happen?

Changes in mental ability happen as PD starts to affect the parts of

your brain that control attention, thinking, and memory. In most cases, this only happens later in the disease, or as people age, usually over age 65.

## Hallucinations and Delusions

Many people with PD who have cognitive impairment can also have hallucinations or delusions. Hallucinations are when people, while awake, see or hear things that are not really there. In PD, hallucinations are mostly visual. They may include “seeing” animals or people that are not there. At first, most people recognize that hallucinations are not real. Later on, it may become harder to tell what is real and what is not. PD patients may also have illusions such as thinking a spot on the wall is an insect.

Delusions are false beliefs that are not based on reality or fact. Common delusions include thinking there are extra people living in the house, your spouse is cheating, or someone is stealing from you. This usually happens in more advanced PD.

Mild hallucinations that you easily recognize as hallucinations do not need treatment. It is important that your doctor checks that you do not have an infection, especially of the urinary tract, or you are not

on a medication that can cause hallucinations and delusions.

Hallucinations and delusions often can be treated by adjusting medications, like those for sleep or pain. If these problems continue despite these changes, your doctor may try reducing some of your PD medications. If that does not help, or it makes your movement worse, then your doctor may prescribe medication used to help cognition. In addition, clozapine or quetiapine may help hallucinations or delusions but may cause sleepiness as a side effect. Clozapine also requires regular blood testing.

## What can I do for cognitive problems?

Cognitive function may be helped with proper exercise, diet, sleep, and blood pressure control.

Talk to your doctor if problems with thinking, memory, or making decisions start to affect your daily routines. Your doctor may want to do cognitive tests. Review your medications as medications used to treat PD or other medical conditions sometimes make cognition worse. Using pill boxes and medication reminders may help.

continued on page 12





# Medication Assistance

*Have you recently been prescribed a new medication to manage your Parkinson disease symptoms?*

**You were feeling excited about managing some troublesome symptoms and addressing concerns with your quality of life. You take the prescription to get filled and find out your insurance covers a lot less of the medication than you were expecting and now it's beyond your budget. You are left feeling frustrated and less sure about your symptom management.**

If this happens to you, there are several options you can explore. First, follow up with the prescribing physician. Their office can appeal the claim with your insurance and justify the prescription. Also, they may know if there are prescription assistance programs for this specific medication.

You can also take charge and call the pharmaceutical company directly. If you look up the medication name, you will find the pharmaceutical company and their patient assistance phone number. Many of them will work with you to appeal your denial, get information from your Parkinson's physician, and then provide some financial assistance – if still needed – once they have appealed your claim. Don't have a computer? Call Wisconsin Parkinson Association and we will assist you in tracking down the information you need.

Pharmaceutical patient assistance programs will vary from company to company, and their criteria for assistance will vary from case to case. You will need to work with the company that provides the medication and work within the parameters they have set. Many

of them will have assistance in getting your appeals heard, while others will also provide some form of financial assistance on the cost of your medication. The best thing you can do is to call them and learn about their programs and how they can assist you in getting a medication that has been prescribed to assist with your current symptoms.

**If you get financial assistance from the pharmaceutical company, but still find you are having issues with the cost of the medication, please contact WPA. We can provide you with other organizations that provide assistance, such as:**

- ◆ **The Assistance Fund**  
[tafcares.org/program-listing/](http://tafcares.org/program-listing/)
- ◆ **NeedyMeds.org**

There are a number of ways to get assistance with the cost of your Parkinson's and other medications. Please explore your options and reach out for assistance. With enough effort, you can find a number of resources to get you back to feeling hopeful about a new treatment and look forward to a better quality of life as you better address and manage your current symptoms. 🌱

# 6 Ways to be a Great Long-Distance

By Claire Wentz, Caring from Afar

At some point, you may end up being a caregiver for one of your senior loved ones. Whether your parent or your grandparent needs your assistance, you might be wondering if you can fulfill this role without moving them into your home or relocating to be closer to them. Today, it is easy to be a long-distance caregiver for a loved one who is still able to maintain a certain degree of independence but may have limited mobility or need someone to keep them on track with their medication schedule and regular doctor's appointments.

Of course, some seniors with conditions like dementia or Alzheimer's will need daily, in-home care, but for seniors with conditions like Parkinson's, support from a long-distance caregiver can be extremely helpful. If you are about to take on long-distance caregiving responsibilities, here are a few tips to help you fulfill your loved one's needs while living in another city or state.

## 1 Navigating Medicare

If you are becoming a long-distance caregiver for your senior loved one, it's crucial for you to understand the Medicare system. You and your loved one should be aware that Medicare has an Annual Election Period from October 15 through December 7.

If your loved one needs to make changes to their Medicare plan, this is the only time of year that they can do it, so make sure that you are prepared with all of the necessary paperwork before mid-October. This checklist should include their Medicare card, their previous medical bills, and other documents.

Both you and your loved one should also discuss options for long-term care in an assisted living facility if it becomes necessary. Since Medicare does not cover extended stays in assisted living facilities, you should familiarize yourself with Medicaid and what kind of coverage your loved one would be eligible for.

Are you concerned that your loved one will not be able to advocate for their own health care needs in the future? Talk to them about naming a trusted relative as power of attorney.

## 2 Schedule Regular Check-Ins

Even if you have to travel to see your loved one, it's important to visit them on a regular basis so that you can see how they're doing. Yes, you can call them or video chat with them a few times each week to get an idea of how things are going, but when you spend time with them in person, you'll be able to get a read on how they're really feeling. If you can't see them as often as you would like, ask another family member to check in on them sometimes.

## 3 Assist With Home Modifications

Although your loved one may be perfectly capable of managing most of their own daily tasks, they may not be able to move around their home as easily as they did in the past. For example, a senior who recently had a hip replacement might be unable to walk up the stairs, while someone with Parkinson's may feel more comfortable bathing with a shower chair.

If you think that your loved one would benefit from certain home modifications, recommend a reputable contractor. This will give you peace of mind when you're not physically around to help them.

## 4 Medical Alert System

A medical alert system is a must for any long-distance caregiver and their loved one. It will notify you if your loved one needs immediate medical attention.

According to PCMag, seniors can choose from several varieties of medical alert systems, including wearable devices like bracelets

# Caregiver



or necklaces, fitness trackers, cellular alert systems, and more. Choose one that works for your loved one's lifestyle.

## 5 Digital Pill Dispenser

Many seniors take some kind of medication to manage a chronic medical condition. Whether your loved one takes medication for Parkinson's or high cholesterol, you should make it a point to ensure that they are taking their pills on time.

You may want to set up a digital pill dispenser for your loved one. A digital pill dispenser will notify you when your loved one takes their medication, so you can get in touch with them if they forget. According to GlobalRPh, seniors who use these dispensers are more likely to take

their medications as prescribed. If they frequently forget to take their medication, you can ask their doctor for help to remedy the situation.

## 6 Hire a House Call Service

Yes, you'll want to stop by and visit your loved one when you have the chance. But what if they need medical attention, and you're not there to assist them? Or what if they have a doctor's appointment scheduled, but they're not able to drive safely?

Hiring a house call service can fill in the gaps when you're not around. During house calls, doctors can provide many beneficial services, and your loved one can receive care in the comfort of their own home.

Whether you are moving in with a loved one to help them or handling these responsibilities from afar, becoming a caregiver can be challenging. Thankfully, the technology we have today makes it possible to look out for your senior loved one's best interests, even when you can't see them every day. 🍷

**Claire Wentz**

is a contributor to Caring from Afar.

For more information, visit

[caringfromafar.com](http://caringfromafar.com).



# Charitable Gifting Options: PART II

Part I of this article appeared in Issue 103. Visit [wiparkinson.org](http://wiparkinson.org) to read that article if you missed it!

By Jim Cantrell, Financial Strategies, Inc.

## Leaving a Charitable Legacy

Leaving money to charity in your will or trust or naming a charity as a beneficiary is one way to make a lasting impact in the world. If you would like to make a significant donation but are concerned that you may need this money to provide for your own care, you could leave the money to charity after you are gone. As a member of Wisconsin Parkinson Association's board of directors, I know how these memorials can help a charity fulfill its mission. It also sends a message to the charity of how important their service is to you.

If you have an IRA, it may be better to name the charity as beneficiary of your IRA than leave them a Roth IRA or other assets. Your heirs would likely pay tax on your IRA money after they inherit it, the charity usually will not. Your heirs will most likely receive a Roth IRA without

taxes, and appreciated assets will likely get a step up in basis, meaning the tax liability should be relatively low.


If you name a charity as the beneficiary of your IRA, it is a good idea to establish a separate IRA with the charity as the beneficiary. This makes it a little easier for the charity to receive the funds. If there are multiple beneficiaries, there will be multiple steps to take to receive the funds. This is not an irrevocable designation. You can change your beneficiaries as often as you like.

You could also consider purchasing a life insurance policy and designating the charity as the beneficiary. This can leverage your gift if the total premiums paid for the policy are less than the death benefit. Alternatively, you could name the charity as the beneficiary on an IRA, then replace that money with

life insurance naming your children as beneficiaries. This way the charity still receives a gift, but the children pay less tax on their inheritance.

There are other ways to leave a charitable legacy, such as Charitable Lead Trusts and Charitable Remainder Trusts. These strategies get a little more complicated and can be costly. If you have very large charitable inclinations, you should consider these.

All of these strategies can seem complicated, so it is imperative to seek the advice of a qualified financial planner.

**Someone once said, "It is better to give than to receive." (Paraphrase of Acts 20:35b) I believe this to be true, and I hope that these charitable giving tips will make your giving even a little better.** 

**Jim Cantrell** is a certified financial planning professional with 30 years of experience. He is the president of Financial Strategies, Inc. a fee-only, comprehensive wealth management and financial planning firm in Brookfield, WI. He has been a member of NAPFA (National Association of Personal Financial Advisors) since 1996 and has served as chair and president of the NAPFA Midwest Regional Board and served on NAPFA's national board of directors. Jim currently serves as president of Wisconsin Parkinson Association's board of directors.

## continued from page 8 | Cognitive Impairment in Parkinson Disease


If memory problems become severe then:

- ◆ Discuss with your family and doctor plans for future living arrangements, including home care or a care facility.
- ◆ Let a trusted caregiver have power of attorney, depending on local legal requirements. If you are no longer able, this person will have

the right to speak for you, arrange your finances, pay your bills, and more. Without a power of attorney, these needs can quickly become complicated and expensive.

- ◆ Be sure your estate and will are current. You will not be able to change your will if you have severe, cognitive problems.

### Are There Treatments?

Some medications can help and have been studied in PD patients with dementia. Some people who take these medications notice good improvement while others notice little change. Talk to your doctor for more information. 

.....  
Information from International Parkinson and Movement Disorder Society.

# Thriving with Parkinson's:

# Lynn Ettenheim



By Craig Barbian, WPA Board Member

Anyone dealing with Parkinson disease will tell you that PD is for the birds. But Lynn Ettenheim has made that disparaging remark not only an apt description of the disease itself, but has managed to put a positive spin on it in her own unique way by using it as the name of her business.

“For the Birds” is the name Lynn chose for her post-Parkinson’s diagnosis endeavor making birdhouses and feeders. Lynn, diagnosed with Parkinson’s in 2008, makes birdhouses as her own personal therapy for the disease.

Lynn first noticed her pinky finger inexplicably twitching, the same symptom, she noted, that Michael J. Fox first experienced. An auditor in the banking industry, Lynn was forced to retire in 2011 due to her continuing symptoms. But she was determined that although Parkinson’s may have ended one chapter of her life it would also be the start of a new career, albeit on a smaller scale.

The Parkinson’s diagnosis and her subsequent retirement gave her the opportunity to pursue other interests. After a couple of years of retirement Lynn, needing something to occupy her time, turned to making birdhouses and feeders.

Although she had no formal woodworking experience to speak of, Lynn has always enjoyed working with her hands. Along with regular exercise, building birdhouses became her outlet to keep busy. Her birdhouses reflect Lynn’s sense of whimsy, from her first birdhouse representing a church to airplanes and houses resembling stone cottages complete with a white picket fence.

Lynn sells her birdhouses at various local flea markets and craft fairs, particularly in the Thiensville and Mequon area. She generally charges around \$35 and has been told she should charge more. She still finds it hard to part with them because, she explained wistfully, “They’re all my children.”

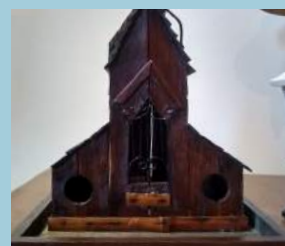
Having lived in California, Philadelphia, and New Jersey, Lynn loves traveling, and has visited Spain, Greece, and France several times. She has had to make some concessions to Parkinson’s though, including selling her condo and moving into an apartment in Cedarburg right down the hall from her daughter.

Although she does slow down her birdhouse construction during the winter months, like most people with Parkinson’s, Lynn swears by regular exercise, especially walking. She exercises at several local facilities and has taken martial arts classes in the past and is interested in taking boxing classes if she can find one in her area.

She also attends a monthly support group at the Jewish Community Center that she feels is very helpful in connecting with others with a shared experience. Her advice to others with Parkinson’s? “Exercise regularly, find something that you like doing for yourself. Try to be upbeat.” 🌻



**They say when life gives you lemons, make lemonade. Lynn Ettenheim does that one better. She makes birdhouses.**



# 5 Technology Trends that Promote Independence

By Rick Ziller, MOTR/L

Technology evolves so quickly, it can feel difficult to keep up! Learning just a few devices or apps can make a huge difference in your daily activities and can help you feel more connected to your loved ones. Here are a few ways to learn a little more.



## Smart Assistants

Smart assistants like Amazon Alexa, Google Assistant, Microsoft Cortana, and Apple's Siri have the potential to be extremely helpful in maintaining independence. By using voice commands, our homes and daily tasks can be automated - turn on and off the lights, make and answer phone calls, use the TV or microwave, order a pizza or even a ride. You can also program daily reminders to keep you on task or remember medications. Imagine the possibilities!



## Telehealth

Imagine going to a doctor's visit from the comfort of your own home. Virtual visits via secure video calls are increasingly possible. Health devices (blood pressure monitor, thermometer, etc.) and activity sensors can be wirelessly placed in a home to collect health information and monitor activity. Data is collected and can be securely shared. Alerts can be set up to notify you of any areas of concern.



## Internet Access

We live in a digital age and access to our devices is key to keeping in touch with the world. Luckily computers, tablets, and phones are almost completely accessible and customizable. Advanced accessibility settings exist for all devices. Adaptive keyboards and alternatives to the mouse like joysticks, trackballs, etc. exist. Devices can be controlled entirely by voice, eye gaze, a sip/puff device, or other means of access. Dictation programs and alternative communication systems readily exist. There is no reason to not be part of the digital age.



## Smartphone Applications

Apps, Apps, Apps! They are everywhere and can do just about anything. There are Parkinson's specific apps that track or assist with symptoms, medications, vocal health, caregiver schedules, stuttering, and dexterity. Apps can encourage and facilitate appropriate exercise and memory



work. Set reminders and get alerts for important tasks, apps can do that. There are Parkinson's specific social network apps to provide support and practical tips while combating loneliness and isolation. Stay in touch with family by video calling from a phone. If you need something, chances are there is an app that can deliver.



## Stand Alone Technology

Disease or symptom-specific technology is just starting to be explored. Mainstream smart watches can monitor specific health variables and detect falls in addition to having alert capabilities. Specialized utensils such as Liftwear or low tech ones help compensate for tremors while eating. Walk with Path is a visual cueing device to trigger walking. We are confident more options are on the horizon. 🕒

**Rick Ziller, MOTR/L** is an OT and owner of Adaptive Technology Resources in Germantown, Wisconsin. ATR's professionally trained staff work beside you to leverage cutting edge tools. With over 20 years of experience in assistive technology, their job and their passion is to provide the tools and training to help people pursue their goals without boundaries. For more information call 262-375-2020 or visit [adaptivetr.com](http://adaptivetr.com).



# eBiking with Parkinson's

**As the Wisconsin weather starts to turn nice again, you may be thinking about opening the windows and letting in the fresh air – or heading outside to get some exercise! Exercise is the only way to slow the progression of Parkinson's, and while any exercise is good exercise, countless studies have addressed the benefits of high intensity exercise.**

Parkinson disease can present changes in balance and stability, so while it might not be intuitive to start riding a bicycle after you've received a Parkinson's diagnosis, bike riding has many benefits. An electric bike, or eBike, can present a new option for someone who used to enjoy riding but has concerns about it now. Pedal assist eBikes mimic regular bikes. You engage the motor by pedaling, and you can adjust the level of assistance. This gives you as much help as you might need for when you're simply rolling along, when you want to go faster or when you need a push going up a hill.

We talked with Don Randall, who lives in Cedar Grove, Wisconsin, about his eBike. Don has had a pedal assist eBike for two years. He did ride a regular bike before that, but found that he was getting tired more. "I would get some place, but I had a hard time getting back!"

Don said his friends can't keep up with him now! In high gear, he can get up to 20-25 mile per hour. With the pedal assist, he is still working and exercising, but the motor helps him get where he's going.

In nice weather, Don rides as often as he can: daily if possible, or a couple of times a week. He has found one downside to the eBike: they are heavier than regular bikes. The battery pack and motor add about 12 pounds to the bike.

But that didn't stop Don, who logged over 1,100 miles last summer. And with nice weather just around the corner, Don is looking forward to getting back out there! 🍷

**"Over the years, it was becoming more and more difficult to pedal well and to move the bike down the road comfortably and safely. I was putting out too much energy, and when you have Parkinson's, energy is a precious commodity. I realized I was staying on a "regular" bike out of duty, habit, or overall well-being, but I wasn't enjoying it nearly as much. Riding an eBike still provides a workout because the settings are adjustable, but now I have an ear-to-ear grin on my face when I'm pedaling along. You can't put a price on that. Trading in my other bikes for an eBike has proven to be a vital move."**

*Davis Phinney*

**Olympic medalist,**  
two-time stage winner  
at the Tour de France and **Founder**  
of the Davis Phinney Foundation  
for Parkinson's



## How does WPA get funded?

It costs about a half a million dollars each year to carry out our mission.

About 20% of that comes from grants (from non-governmental foundations) and pharmaceutical sponsorships at our programs. That leaves 80% of our funding that comes from individuals. It's made up of about 1,600 people who give anywhere from \$5 to \$5,000 each year. We rely on individual giving from a relatively small subset of the state population with Parkinson's.

---

## Covering the whole state of Wisconsin must take a lot of resources, right? Where are all of your offices based?

We have a small staff of 5 full-time and 1 part-time employee – based in Brookfield. That's it!

People are often surprised at the amount of work we get done. Each year, we hold about 15 educational programs a year, we visit 150+ support and exercise groups across the state, we run 7 of our own exercise programs, and we put out this magazine that reaches about 5,000 several times a year. We do all that with a very efficient, dedicated, and effective staff.

We are very mission-focused. We know what we do well, and we are able to do that with a small staff! We are focused on our niche – helping people find a greater quality of life while living with Parkinson disease.

---

## What's ahead for the next couple of years?

A lot of what we'll do is continue to build on what we're doing – and do it better!

Take exercise, for example. Research shows the great benefits of exercise for people with Parkinson's, both physically and mentally. We have our Movement & Music program which now has 7 classes – our goal is to grow that to more underserved communities. We want to offer exercise classes in communities where exercise opportunities like that don't exist.

We'll continue to build our great education programs, and get them into more areas where they aren't happening now. We've done new programs in Janesville and Door County, and we'll continue to expand our reach there. We're also doing "Parkinson Disease: Basics & Beyond" programs which are a little shorter than our half-day programs. This is a great way to bring education to rural areas. We know Parkinson's is a difficult disease to manage, especially without the right information, so we'll continue to provide that.

We're also keeping our attention on strengthening support groups around the state. We want to make sure these mostly volunteer-run groups are strong for those who need them.

Overall, we'll continue to focus on caregivers, those who are newly diagnosed, and rural communities. We want to make sure these groups know they are not forgotten.

---

## This all sounds great! How can we get involved?

The best place to start is to come to one of our programs! You'll benefit from it, and you'll understand more who WPA is. You'll meet our staff and board members, and more importantly, talk to other people in the Parkinson's community. Better than anyone, WPA works to bring the Parkinson's community together!

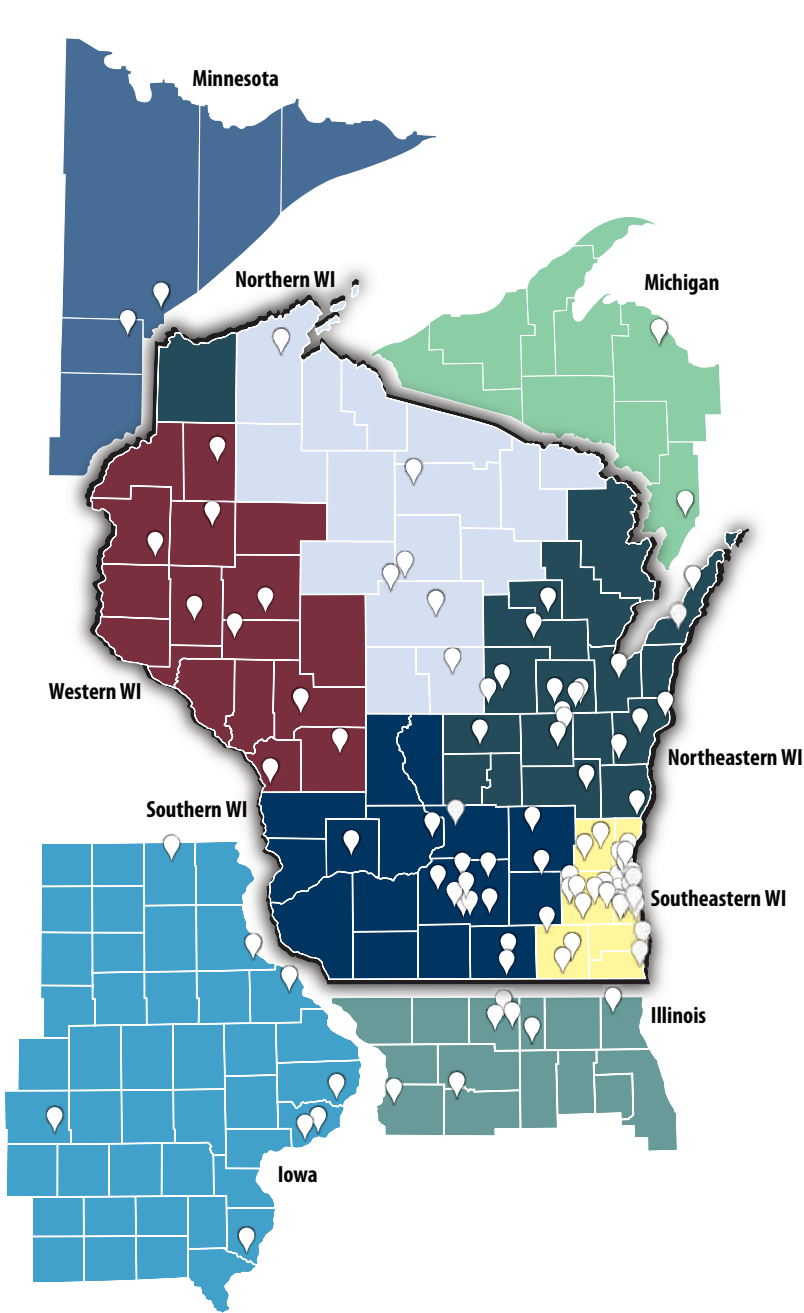
We also hope you choose to become a financial supporter. Like I said earlier, 80% of our support comes from individual supporters, so your donation are crucial to this work.

We have some other volunteer opportunities as well – reach out to me or anyone on our staff to learn more! 🙌



# Support Groups & Exercise Groups

WPA works with groups around Wisconsin and in surrounding areas. Groups include support groups, exercise groups, caregiver groups, and young-onset groups. Most groups are run by volunteer facilitators.



## Northeastern Wisconsin

Appleton  
Cedar Grove  
Fish Creek  
Fond du Lac  
Green Bay  
Greenville  
Keshena  
Kiel  
Kimberly  
King  
Manitowoc  
Menasha  
Neenah  
Oshkosh  
Shawano  
Sheboygan  
Sturgeon Bay  
Waupaca  
Wautoma

Milwaukee  
Mukwonago  
New Berlin  
Oak Creek  
Oconomowoc  
Racine  
St. Francis  
Summit  
Thiensville  
Waukesha  
Wauwatosa  
West Allis  
West Bend  
Whitefish Bay  
Whitewater

## Southern Wisconsin

Baraboo  
Beaver Dam  
Beloit  
Fitchburg  
Janesville  
Madison  
Middleton  
Oregon  
Portage  
Richland Center  
Stoughton  
Sun Prairie  
Verona  
Watertown  
Waunakee

## Northern Wisconsin

Athens  
Bayfield/Apostle Islands  
Colby  
Marshfield  
Minocqua  
Stevens Point  
Wausau

## Southeastern Wisconsin

Brookfield  
Brown Deer  
Burlington  
Cudahy  
Franklin  
Grafton  
Greendale  
Greenfield  
Hartford  
Hartland  
Kenosha  
Lake Geneva  
Mequon

## Western Wisconsin

Black River Falls  
Chippewa Falls  
Clear Lake  
Eau Claire  
La Crosse  
Menomonie  
Rice Lake  
Spooner  
Tomah

## Illinois

Dixon  
Lake Forest  
Lindenhurst  
Loves Park  
Moline  
Rockford  
Roscoe

Davenport  
Decorah  
Dubuque  
Guttenberg  
Newton

## Michigan

Menominee  
Negaunee

## Iowa

Bettendorf  
Burlington  
Clinton

## Minnesota

Cloquet  
Duluth



For more information  
on groups in your area,  
visit [wiparkinson.org](http://wiparkinson.org)  
or call 414-312-6990.



# Support Group Feature:

## West Bend Support Group

Some Parkinson's support groups across the state are run by volunteers, and many are run by employees in senior living communities, senior centers, or other businesses. The Parkinson's Support Group in West Bend was started in 2012 by an employee – the wellness nurse at Cedar Ridge Retirement Campus. Another employee was also involved, and in 2015, group member and volunteer Gary Schilling took over as facilitator. He stepped back from the facilitator role in late 2018, but he still remains an active participant!

Gary took his job seriously, and still is a great partner with WPA! He actively finds resources for the group members, such as speakers from the community for the group to learn from, and was instrumental in keeping this group active and growing over the 4 years he facilitated the meetings.

This support group is now facilitated by Laurie Couillard, WPA's director of group engagement. Laurie works with all support and exercise groups across the state, so she enjoys the opportunity to serve as facilitator and be more directly involved with this group.

The group currently has about 20 members, and meetings include both guest speakers and discussions, based on interests and requests by members. They are considering occasionally dividing meetings into two groups: people with Parkinson's, and caregivers.

In April, the group will be taking a "field trip" to AIMS Fitness in West Bend to try out Rock Steady Boxing, and in May, they will have a panel discussion on deep brain stimulation (DBS). Two members in the group have had DBS, so they will share their experiences, and Lisa Schwaller from Medtronic will be there to answer questions as well.

If you'd like to learn more about this group, reach out to Laurie at [lauriec@wiparkinson.org](mailto:lauriec@wiparkinson.org).



### Meeting details

**3rd Mondays at 1:00pm**  
**Cedar Ridge Retirement Campus**  
**2nd Floor – Grand Hall**  
**113 Cedar Ridge Drive**  
**West Bend, WI 53095**

### Wausau Support Group Facilitator:

*Laurie Prochnow*

Laurie Prochnow is a recruiter and a business owner in Wausau. She was diagnosed with Parkinson's 6 years ago, and she launched a PD Support Group in Wausau in early 2019.

Together with her company, Management Recruiters, Laurie put together this great video sharing some of the lessons she has learned over the last several years of having Parkinson's. **View the video at [wiparkinson.org/poor-me-or-lucky-me/](http://wiparkinson.org/poor-me-or-lucky-me/).**



# WPA Happenings

## Holiday Reception

We enjoyed a great Holiday Reception in early December! Thanks to the 200+ people who joined us, and to our sponsors who made the event possible.

Always Best Care • Financial Strategies, Inc. • Ken Foster • Froedtert & Medical College of Wisconsin • SYNERGY HomeCare



1 Erica Vitek, MOT, OTR, Aurora Health Care, with Bonnie Haber 2 Todd Seidl, Care Patrol, with Tom Delonay  
3 Patrick Barron, PT, FastBack Physical Therapy, with Lynn & Jim Cantrell, Financial Strategies, Inc. Jim is president of WPA's board of directors. 4 Pat Cochran, Jeannette Braun, Ellen Boettcher, and Ross Miller 5 Chris Lieber with Mary & Randy Peterson  
6 Members of the WPA Movement & Music class in Watertown, with Mary Wood, WPA's exercise coordinator (center)



## Neil Diamond Fundraiser

Huge thanks to Eric "Diamond" Ebert, a Neil Diamond tribute artist, who recently coordinated a fundraiser and concert to benefit WPA! Through Eric's hard work and the support of his friends and family, over 200 people attended and supported WPA through raffles, drawings and silent auction items. **The event raised over \$6,000!**



Eric "Diamond" Ebert as Neil Diamond poses with Carolyn Hahn, WPA's communication director



Neil Diamond takes the stage!



As always, visit our Facebook page for more photos: [facebook.com/wiparkinson](https://facebook.com/wiparkinson)

# Would you like to receive Wisconsin Parkinson Magazine?

If you do not receive *Wisconsin Parkinson Magazine* quarterly, join our mailing list at [wiparkinson.org](http://wiparkinson.org). You will receive this magazine, as well as periodic information about educational events, support & exercise groups, and other resources in your area. This magazine is funded by your donations. Your support helps those living with Parkinson disease by allowing us to enhance and expand our services to you and your families. For more information, visit [wiparkinson.org](http://wiparkinson.org).

*Wisconsin Parkinson Association provides hope, community, support, and resources for people with Parkinson's and their loved ones.*



WISCONSIN  
PARKINSON  
ASSOCIATION

414-312-6990  
[wiparkinson.org](http://wiparkinson.org)  
[mail@wiparkinson.org](mailto:mail@wiparkinson.org)

Wisconsin Parkinson Association  
16655 W. Bluemound Road, Suite 330  
Brookfield, WI 53005

NON-PROFIT  
U.S. POSTAGE PAID  
TWIN CITIES, MN  
PERMIT NO. 31688

## Upcoming Programs

### March 24

**Working Professionals  
with Parkinson's**  
Ruby Tap - Wauwatosa

### March 27

**Renew! Retreat**  
Ingleside Hotel - Pewaukee

### April 3

**Parkinson Disease Education**  
Stoney Creek Hotel & Conference  
Center - Rothschild

### April 27

**BluTender Battle Fundraiser**  
Blu at the Pfister - Milwaukee

### June 19

**Parkinson Disease Symposium**  
Red Lion Hotel Paper Valley -  
Appleton

### July 24

**Parkinson Disease Education**  
Lismore Hotel - Eau Claire

### July 31

**Parkinson Disease Education**  
Janesville

### September 15

**WPA Open Golf Outing & Dinner**  
The Legend at Bristlecone -  
Hartland

### September 24

**Parkinson Disease Education**  
The Ravine - Green Bay

### October 30

**Parkinson Disease Education**  
Stone Harbor - Sturgeon Bay

