WHAT SHOULD YOU EXPECT AFTER BEING DIAGNOSED WITH PARKINSON’S?
(page 5)

Educate. Empower.

Supporting you through Parkinson's and Beyond!

Inside this issue:
- Traveling with Parkinson Disease page 6
- Ask the Doctor page 9
- Depression and Parkinson Disease page 11
Letter from the Executive Director

Welcome to the first ever double issues of The Network magazine!

This side is dedicated to helping you manage your Parkinson disease, but flip it over and – voila! – It is dedicated to the needs of all the wonderful caregivers out there. Let us know what you think.

In this section, you will not be disappointed as you read through the articles covering exercise, travel, helpful tips for the newly diagnosed, and some exciting recently passed legislation that should help greatly in understanding better the effects of PD on the American population. You’ll also find an “Ask the Doctor” section. One of the most valuable services WPA offers is access to the wisdom of the neurologists on our eight-member Medical Advisory Committee. These doctors are on the frontlines of what is happening regarding Parkinson’s diagnosis and treatment, and we are honored to be able to have them tackle topics that you have told us are on your mind!

I hope this special issue gives you a taste of the variety of thoughts and activities happening in the PD community – both nationally and locally! We are so excited about the strong growth of our programming at WPA: more educational events in more places, more support to Parkinson’s exercise & support groups, more educational materials, and more outreach to underserved populations (e.g. rural communities, newly diagnosed, communities of color). All of this is driven by your input and your support.

Getting more real help into your hands, it is the only reason we exist. Feel free to reach out to me with your thoughts, questions, and comments!

Thanks,
Gary
garyg@wiparkinson.org
In September, the president signed a bill that increases federal research funding and takes important steps to better support our nation’s care partners. Through its tireless advocacy work, the Parkinson’s community played a role in the passage of this important law.

LAW BOLSTERS FUNDING FOR RESEARCH

A critical provision provides funding for the National Neurological Conditions Surveillance System. This database will capture demographic information on people living with neurological diseases, which is key to helping researchers target their work and increase understanding of these conditions. While it was signed into law in late 2016, the database was never funded or implemented. But with the passage of this bill, it now can become a reality. (As the law does not specify which diseases the National Neurological Conditions Surveillance System will track, work is being done with the Centers for Disease Control and Prevention, which will house the database, to push for the inclusion of Parkinson’s.)

The law also includes a $2 billion funding increase for the National Institutes of Health (NIH). The NIH is the largest public funder of Parkinson’s research, investing $169 million in the disease in 2017. This funding boost is key to supporting the foundational research being done to better understand, diagnose and treat various health conditions.

Throughout 2018, the Parkinson’s community made a strong push for these funding priorities. Thousands of people with Parkinson’s and their loved ones sent their lawmakers more than 46,000 emails asking for money for the database and the NIH. These funding successes are a testament to the critical work of Parkinson’s advocates across the country.

NEW COUNCIL SEeks to Better Support Care Partners

Another significant provision in the law provides $300,000 to fund activities outlined in the RAISE Family Caregivers Act. This act was signed into law in January 2018, thanks in part to the advocacy efforts of the Parkinson’s community, and directs the government to create a national strategy to better support the estimated 40 million care partners across the country. The $300,000 will be used to create a Family Caregiving Advisory Council, which will identify actions that communities, providers, policymakers, and others can take to better assist care partners.

Wisconsin Parkinson Association participated in these efforts through our involvement with the United Parkinson’s Advocacy Council, which is comprised of state, regional, and national PD organizations. Information in this article was provided by Michael J. Fox Foundation for Parkinson’s Research.

What should you expect AFTER BEING DIAGNOSED WITH PARKINSON’S?

By Dr. Sarah King, PT, DPT, Invigorate PT & Wellness

FIRST, A DISCLAIMER: THERE WILL BE NO DOOMSDAY TALK HERE. I PROMISE.

This is a safe space and I promise to avoid any fearmongering or worst-case-scenario prophesizing. A new diagnosis of Parkinson’s can be overwhelming, and I’m here to offer some practical, powerful information you can use to educate and empower yourself on this new, unfamiliar journey.

I know the urge is strong, but please don’t run away.

I work daily with clients who are downright terrified after their diagnosis. They finally ended up in a neurologist’s office with a few benign symptoms and their doctor’s feedback was vague. That can be scary!

They frantically search for answers and come in with a list of fears and concerns. “What can I expect?” they ask. “How will this play out?”

Here’s the truth. I don’t know. I don’t have a crystal ball. And neither does your physician. Or your spouse. Or the internet. No one knows what’s in store for your future, whether you have Parkinson’s or not.

You can either look at this as terrifying, or you can look at this as empowering because, in the end, you still have the power to choose your path forward.

Yes, it’s true that Parkinson’s is classified as a “degenerative neurological disease.” And no, we do not have a cure for Parkinson’s at this time. However, that is all we know about Parkinson’s, as far as prognosis is concerned.

Many people have been diagnosed with Parkinson’s, and every single one of them is different. You have a different background, different presentation, and a different support system. You have so many different individual things going on that it’s impossible to predict what your experience will be with Parkinson’s.

On the other hand, we do have a lot of promising research developing that’s beginning to shed some light on what can be done to prevent Parkinson’s, prevent the worsening of symptoms, and the most effective treatment methods and techniques.

We need to focus on what we know will help improve your symptoms now and maximize your longevity and your independence for the long run.

I want to just encourage you to do the two most powerful things that you can immediately after diagnosis:

#1 Educate Yourself

#2 Empower Yourself

The more you know about what you can do to be proactive right now to help yourself with your symptoms, the better your outcomes will be. The people who are invested in their own health are the ones that have the best outcomes.

When you were diagnosed, most likely you felt like all the power left you. You were made to think that someone or something else holds the key to your diagnosis. You can take the power back by educating yourself and being an advocate within your treatment plan.

Parkinson’s is challenging. I’m not saying everything’s coming up roses or that if you do all of these things, your Parkinson’s symptoms will disappear. What I am saying is that you can do everything in your power to learn. If you’re reading this, you’ve already started. The important thing is to educate and empower yourself every single day.

If you do that, then your tomorrow will be better than it would have been otherwise.

Dr. Sarah King, PT, DPT, owns Invigorate PT & Wellness in Austin Texas, where she specializes in helping clients diagnosed with Parkinson disease defy their diagnosis through physical therapy, personal training, and more. For more information visit invigatorpt.com.
PREPARING FOR A SUCCESSFUL TRIP
✔ Create a checklist so you can be prepared but won’t over pack.
✔ Choose comfort over fashion. Pack comfortable clothes and walking shoes that will allow you to move freely.
✔ Carry several days of extra medications in their original, labeled containers.
✔ If traveling to a different time zone, talk with your doctor about making adjustments to your medications.
✔ Organize travel and activities during “on” times when PD symptoms are minimal.
✔ Carry the names of your doctor, insurance company, emergency contacts, and medications in your wallet or purse.
✔ Pack snacks and carry a water bottle to take medications.

TRANSPORTATION
✔ Get an early start. Heavy traffic and long security lines can leave you feeling pressured.
✔ Consider alternatives to flying. Airports can be stressful for anyone, with or without Parkinson’s disease, and planes generally don’t have much space to move around or stretch. Consider traveling by car, train, or boat, which may be easier and more enjoyable than flying.
✔ Ask for handicap assistance. Request a non-stop flight and an aisle seat.
✔ Apply for TSA pre-check so you don’t have to take off your jacket and shoes.
✔ Ask for a wheelchair at the airport – whether you need one or not. This will help put you on the fast track in an airport, which can help reduce stress.
✔ Use the bathroom right before boarding the plane. Airplane bathrooms are often small and not handicapped-accessible.

ACCOMMODATIONS
✔ Plot your course before you get there. Research your destination and stops along the way to ensure hotels and rest stops can accommodate your needs.
✔ When making hotel reservations, request a handicapped-accessible room on the ground floor or near an elevator.

GENERAL TIPS
✔ Always try to travel with a companion.
✔ Carry identification stating that you have Parkinson disease.
✔ Wear comfortable, loose-fitting clothing and good walking shoes.
✔ Considering bringing a cane or walker, even if you don’t normally use them.
✔ Try to add a rest day for your trip, and schedule long layovers when possible. Take stretch breaks and exercise breaks when you can.
✔ Don’t try to fit too many activities into each day – allow for down time.
✔ Drink plenty of water, and make sure you eat your meals on time.
✔ If you have had deep brain stimulation, bring a certificate from the DBS manufacturer or your doctor.
✔ Try to stick with your routines from home, including taking medicine at the same time and exercising a similar amount.
✔ If you need assistance at any point, do not hesitate to ask. A little help will make your trip go more smoothly.

LASTLY…
Enjoy yourself, even if it’s at a slower pace than you’re used to! 😊

With the holidays approaching, you may be planning trips to visit family and friends. Parkinson disease can present additional challenges when traveling, so here are some tips to make sure you can travel with ease and enjoy your trip!
In the Kitchen

1. If you plan to purchase new appliances, consider a stove with a smooth top that is much easier to clean. Select a side-by-side refrigerator/freezer, so that you can store both frozen and refrigerated items at eye level.

2. Store dishes, utensils, and food in locations closest to where you use them:
   - Store dishes and glasses over the dishwasher or sink; hang pots and pans near the stove; and keep frequently used items on the countertop or in another convenient location.
   - Avoid stacking or piling objects on top of each other.
   - Label drawers and cabinets with a description or photo of the contents.
   - Use a lazy Susan on the kitchen table, countertop, or inside deep cabinets.

3. Look for a cutting board with a raised side to minimize spilling diced food. Boards with stainless steel prongs help hold foods in place while you cut.

4. Purchase a dustpan attached to a long handle so that you won’t have to bend over, or try a child’s broom from a sitting position to avoid bending over.

In the Bathroom

5. If the doorway is too narrow to manage, remove the door and replace it with a tension rod and an opaque or black shower curtain liner. This will provide more clearance for wheelchair users, as well as those who use a walker or require assistance.

6. Purchase a telescoping mirror that clamps to the side wall of the vanity or sits on the counter.

7. If you have separate controls for hot and cold water, consider installing wrist blades. Wrist blades are wide, wind-type handles that can be operated by pushing with the forearm, wrist, or heel of hand.

8. Install kitchen faucets in bathrooms. They are longer and project farther into the sink basin.

9. Install an automatic faucet. Some models turn on and off with slight pressure; others are activated by an electric eye.

10. Purchase an inexpensive resin or webbed outdoor chair or bench so you can sit while bathing or showering. This will reduce your risk of slipping in the shower.

11. Consider a removable shower head on a flexible, hand-held extension hose.

12. Purchase an adjustable portable toilet seat to increase the height. Some raised seats provide armrests and all attach easily to any toilet.

I have decided to put off carbidopa/levadopa until my symptoms are no longer manageable. Are there any long-term concerns in my doing so in relation to my Parkinson’s symptoms?

Dr. Finseth: It is common for patients to resist starting medications for a variety of reasons: they don’t like taking medications or they have heard bad things about the medications or fear that they will become resistant to medication. It has never been studied as to what long-term effects may occur with delaying medication, but generally speaking there are likely no significant long-term concerns over withholding Parkinson’s medications in early diagnosis stage.

That being said, I see no real advantage to withholding medication. Delaying the start of medication does not make you respond better later in the illness and does not appear to alleviate medication fluctuations that can occur later in the disease, as these are felt to occur based on the stage of the illness itself and do not appear to be influenced by when medications are started. I also think that starting medication early offers several potential advantages such as improving quality of life and makes participating in exercise and therapy both easier and potentially more effective. Undoubtedly, the decision on when to start medications and what medications to use is complex and requires an individualized approach depending on severity of symptoms and your personal goals.
EXERCISE GROUP SPOTLIGHT:

Chris Potter, DPT,
Aurora Medical Center Grafton

I like to tell my patients that exercise has many facets. We can exercise for cardiovascular fitness, strength, balance and range of motion, or stretching. With Parkinson disease our focus is on amplitude training. When we pay attention to how much effort we put into a specific movement we are creating greater body awareness and increasing our own dopamine production. I am a Doctor of Physical Therapy and along with our speech therapist Emily Belter, SLP-CCC, we offer a community-based twice-weekly LSVT skills class to Parkinson’s patients that have graduated from four weeks of LSVT training and want to maintain and continue to improve their skills. Our skills class goal is to incorporate that high effort with movements progressing with dual task, cognitive challenges, and voice. We also encourage spouse or caregiver participation.

We hold our drop-in class two times a week at the Aurora Grafton Outpatient Medical Building. In order to keep things challenging and interesting we like to come up with themes for each class. These themes change with the seasons and holidays, incorporating what’s happening here in Wisconsin. Most recently we’ve had baseball theme motions such as catching a ball over the wall and swinging a bat as a tribute to the Milwaukee Brewers playoff run. Last winter we came up with an Olympic themed class including mimicking figure skating, curling with a medicine ball, cross country skiing with trekking poles, and slalom on a scooter. Each football season brings our touchdown celebration competition! We also walk together for the Parkinson’s Foundation Moving Day, which was an opportunity to invite extended families while raising funds for Parkinson’s research.

Another thing we’ve added to the class about once a month is educational “tidbits.” We will take articles from this magazine or questions from the class and present them while we are starting. At the end of class we usually share snacks organized by our sign-up sheet and discuss any questions.

When we started our class over a year ago we were open to class suggestions steer our focus so that we can practice these tasks daily.

As our group has evolved we initiated community outings this summer. We have been to a local farmers market, a Chinook’s baseball game, and an outdoor music venue with food trucks and a good old fashioned Wisconsin beer garden. These outings give us opportunities to practice big amplitude movement in the community. We also walk together for the Parkinson’s Foundation Moving Day, which was an opportunity to invite extended families while raising funds for Parkinson’s research.

What is depression?

Depression is a medical illness. Specifically, depression is a mood disorder that is caused by an imbalance, or unevenness, of a chemical in the brain. The term “mood” refers to an emotional state that affects how a person thinks or acts.

With depression, a person generally may feel great sadness or a loss of interest in things he or she used to enjoy. An imbalance of serotonin, a neurotransmitter (chemical) in the brain, has been linked to depression, along with other chemicals, such as norepinephrine and dopamine.

Is depression common?

About 16.2 million adult Americans suffer from what is known as major depressive disorder. Around the world, 350 million people suffer depression. Depression is responsible for the loss of $33 to $44 billion a year in the form of absenteeism, reduced productivity, and medical expenses. Depression is also common in patients with Parkinson disease; an estimated 50 percent have some form of depression. Often, depression begins years before the patient has any of the physical symptoms of Parkinson disease. This is caused by a decrease in chemicals, such as dopamine, within the brain as Parkinson disease begins. Depression in Parkinson disease affects quality of life, as much as (and sometimes more than) the movement problems themselves.

What are the signs of depression?

If you have several of the following symptoms for longer than two weeks at a time, you should contact your doctor:

- Depressed mood
- Loss of interest or pleasure in activities
- Sleep disturbances (unable to sleep, or sleeping for long periods of time)
- Change in appetite
- Excessive fatigue
- Sudden change in level of physical activity
- Difficulty with concentration or making decisions
- Irritability
- Feelings of worthlessness
- Excessive guilt
- Constant low self-esteem
- Thoughts of death

There also are physical signs of depression, which include:

- Downcast eyes
- Slow speech
- Flattened expressions
- Slow movement or fatigue that may be similar to the symptoms of Parkinson disease
- Slower movement or fatigue that can actually make the physical effects of Parkinson disease worse, so it’s important to recognize and treat these symptoms right away.

Information provided from cleavelandclinic.org. If you have questions or concerns, talk to your doctor.
WPA hosted our 7th Annual WPA Open Against Parkinson Disease on September 11, 2018 at The Legend at Bristlecone in Hartland, WI. This golf outing and dinner is the only fundraiser WPA coordinates, and the money raised supports hope, community, support, and resources for people with Parkinson’s and their loved ones.

During dinner, attendees heard from Pat Burhans, who together with her husband Jerry, serves as a long-distance caregiver for her daughter who has Parkinson’s and lives in St. Louis. Pat is also a support group facilitator in the Janesville area.

We had 117 golfers and over 175 people for dinner. Thank you to Financial Strategies, Inc. and HeatTek, Inc., our presenting sponsors. Please visit wiparkinson.org for a full listing of sponsors – and more photos.

THANK YOU TO ALL WHO SUPPORTED THIS EVENT!
PUNT PARKINSON’S with the Pack

This year, the Barbian/Felder family really outdid themselves! Every year, they coordinate “Sam’s GDPD Open & Punt Parkinson’s with the Pack” as a fundraiser for WPA, and this year they raised over $11,450! Thank you all for your hard work and support!

Another unique community fundraiser was developed this year by Erika Dahlgren and her family, in honor of Erika’s mom Kim Wolff who has Parkinson’s. By selling packs of greeting cards, the Dahlgren/Wolff family raised $820 to benefit Parkinson’s support groups around the state. Thank you!

11TH ANNUAL Bottle Milwaukee Softball Tournament in Memory of Tim Puthoff

A huge thank you to Matt & Megan Puthoff, Kim McCloud, and the team at The Bottle Milwaukee for hosting another awesome Softball Tournament in Memory of Tim Puthoff. They raised over $6,000 this year!

Congrats to the winning team from Fire on Water in Milwaukee. They won this beautiful bat carved by Antonio Holgren!

More programs are being planned around the state. Visit wiparkinson.org for more information!

Save the Date!

Annual Holiday Reception

December 5, 2018 | 4:30-7:00pm
Westmoor Country Club, Brookfield
5 TIPS FOR DIFFICULT CONVERSATIONS WITH LOVED ONES (page 6)

Observe. Communicate.

Inside this issue:

How to Plan for Aging Without a Family Caregiver page 5
Caregiver Perspective: A Daughter and A Nurse page 7
Caregivers’ Book Club page 9
We are excited to present a unique issue of The Network that is aimed at YOU as a caregiver, in addition to your loved one with Parkinson’s.

Caregiving is tough. Caregiving is tiring. But most of all, caregiving is one of the highest examples of human love.

With 10,000 people turning 65 every day, one thing is certain: more of us will become caregivers. For that reason, starting with the formation of our Caregiver’s Committee in November 2017, Wisconsin Parkinson Association is fully committed to making sure that all those caring for someone with Parkinson’s are cared for themselves.

A recent Wall Street Journal article noted that today 34 million Americans provide unpaid care to a family member over the age of 50. Often, the needs of these caregivers are put on the back burner – or forgotten – to the detriment of themselves, and their loved one.

Caregiving programming is so important that we have dedicated half of this issue to the topic. Like all of our programs, we want our efforts that assist and support caregivers to be driven by those who come with real life experience – YOU. I am hopeful that in addition to reading through the information we have gathered here, you will take the time to complete our first ever caregiver survey. Only with your input will we have the foundation that we need to provide both valuable information and front-line services to you, and all those caring for a loved one with Parkinson’s.

After making your way through this special issue, please let me know what you think as well as ideas on how we can serve you, and the entire PD community, even better!

Thanks,
Gary

Welcome to the first ever double issues of The Network magazine!
COMBATTING LONELINESS AND ISOLATION:

The Role of Senior Centers

Cathy Loomans
Fond du Lac Senior Center

Elvis asked, “Are You Lonesome Tonight?” and Hank Williams sang that “I’m So Lonesome I Could Cry.” Petula Clark encouraged us to go “Downtown” when we were lonely. Feelings of loneliness have been around for a long time but now more than ever, the research is telling us that there are significant health risks associated with loneliness and isolation. The epidemic of chronic loneliness has even compelled the United Kingdom to appoint a Minister of Loneliness to start combatting the issue on a national scale.

Feeling lonely at times is normal. Some studies say that up to 40% of seniors feel lonely on a regular basis. When you or someone you love is living with a chronic illness, those numbers can reach 70%. The challenge is that if you are too young to go – many centers serve people 50 and over – we aren’t your grandma’s senior centers!

Senior centers can serve a variety of needs from recreational activities, congregate meal sites, or a clearinghouse for information related to aging. At our center in Fond du Lac, we have about 300 activities each month to meet the needs of the wide variety of people we serve. Some people come just for lunch, others may come for an exercise class, and others just stop in to shoot a game of pool or put a piece or two in our jigsaw puzzles. Regardless of why they stop, what everyone is doing when they walk in the door is combatting loneliness.

As we watch friendships develop, we also watch loneliness fade.

So many times we hear the saying that we can’t take care of others if we aren’t taking care of ourselves first. Reaching out to your local senior center is a great first step in taking care of yourself. I’d encourage you to check out what your center has to offer, and I wish you well on your journey to social wellness.

A recent study from the Bureau of Labor Statistics shows that there are an estimated 40 million unpaid caregivers of adults ages 65 and older in the United States today. Of that group, nine out of ten are providing care for a parent or relative. What happens when our older adults do not have a spouse or never had children? Or their children live hundreds of miles away?

First, a self-assessment of needs should be done. This is the first step in determining what kind of help and support will best suit your circumstances. This is something that can be done early on and updated as needed. Here are some questions to consider:

- What type of help is needed to live as independently as possible? (Nutrition services, dressing, bathing, lifting, medication management, supervision, companionship, housekeeping, transportation, home modification)
- What type of help may be needed in the future?
- Who will help you arrange for services?
- How much money is available to pay for outside resources? Is anything covered by insurance?
- What days and times do you need help?
- What types of help are your friends willing to provide?

Community Resource Options for Care:

There are many resources available to our aging adults. When older adults come to us, we will help identify their critical needs and then engage our partners for the necessary resources for services that we do not provide. It’s important for our older adults to know what resources are available. For example:

Home Care: Home Care agencies provide supportive services to help our older adults continue living at home as safely and independently as possible. This could include help with housekeeping, cooking, companionship, bathing, and other activities of daily living. These needs will be assessed and combined with other community resources when necessary.

Nutrition Programs: There are many different programs that will provide meals in a group setting such as churches, senior centers, community centers, etc. for a minimal charge. For homebound individuals, unable to shop or prepare meals, home-delivered meals may be an option. Programs such as Meals on Wheels are offered in most communities and funded partially through government monies. This delivery includes a friendly visit and quick safety check for you.

Transportation Services: The Americans with Disabilities Act requires transit agencies to provide curb-to-curb transit service to individuals unable to use regular public transportation. This usually consists of wheelchair-accessible vans or taxis. They are usually free or low cost. Discounted taxi and ride-sharing services might also be available in your community.

Medication Management: Many pharmacies will work with a doctor’s order to set up pre-packaged medication that will be delivered to the home with date and times for medication administration.

Continued on page 13
For Difficult Conversations with Loved Ones

1. **Make sure your concerns are valid.** Observe and check in with your loved one to see if they are genuinely struggling.

2. **Approach with love and concern so it doesn’t feel like a confrontation.** Remember that your role is to support your loved one and help them be as independent as possible—not to take over.

3. **Communicate effectively and openly.** Use “I” statements to avoid putting them on the defensive. Rephrase what your loved one said to reiterate their feelings and validate their concerns.

4. **Allow an open discussion.** Invite your loved one to share their input and perspective instead of just stating your thoughts.

5. **Incorporate other family members or loved ones.** Another friend or family member can help moderate the conversation and may provide a helpful and trusted point of view in the eyes of your family member.

Difficult conversations are essential at times, and hopefully with these tips in mind, you and your loved ones can reach successful outcomes.

CAREGIVER PERSPECTIVE:
A Daughter and a Nurse

Before I became a Movement Disorder Nurse, I was the daughter of a person with Parkinson’s. It is where my passion is, personally and professionally: I am an advocate for those with Parkinson disease and their caregivers. As a nurse, a patient’s caregiver is a great asset and an integral part of the treatment team, often they are whom I personally speak with. Starting from—or prior to—diagnosis, the caregiver lends help physically and emotionally to the person afflicted. Caregivers often help coordinate appointments, monitor motor and non-motor symptoms, keep track of how medications are working, and help patients navigate the changes in daily living activities. As a Parkinson’s patient’s symptoms change, the role of the caregiver changes too. Like many things in life the one thing you can count on with Parkinson disease is change, and no two paths are the same.

I often hear from caregivers how yesterday the patient was able to physically do all activities and today they have times where they simply are frozen or have fallen. As a nurse and a daughter I find that not only are the fluctuations hard on the patient, they are hard on the caregiver to accept as well. It can make planning things in advance difficult, and change one’s life into “we can, if the timing is right.”

I see many extraordinary caregivers, and there are days where I can see the strain Parkinson disease causes. Often a caregiver just wants to “go back” to being the spouse, friend, or family member. As a nurse, this is where focusing on the team aspect of care becomes necessary. When medications need an adjustment, the more information the better. We need to know when the patient takes the medication, and when “on” and “off” times occur, so we can maximize the “on” times.

Helping patients and caregivers balance “on” and “off” times can help the caregivers and patients take notice, and can allow the caregiver to return to being the spouse, the friend, or the family member again. Trying as much as possible to take advantage of those moments to capture back the relationship with the patient, not the Parkinson disease, is important.

In my personal life and my professional life, I also see caregivers struggle to accept the unpredictability of living with Parkinson’s, and grieving the life they thought they would have. This is where I feel having

Continued on page 13
## Basic Concepts for People who Help People with PD

1. **Go with the flow.** Periodically, the person with PD may experience hallucinations or delusions. It may be helpful to say, “I’m sure you see the little girl), but it’s really the medication (or the Parkinson disease) that’s causing you to see (her). I’ll call the doctor and see how we can make (her) disappear.” Then redirect the person and say something like, “Let’s get a glass of ice tea. Come and help me.”

2. **Be encouraging.** Whether it’s getting the person with PD to exercise, eat, dress, or do any other activity, have a positive, patient, and encouraging attitude. Allow the person with PD to do as much for herself as possible.

3. **Expect the person with PD to participate in daily activities as much as he can.** Such activities like setting the table, folding laundry, and putting away groceries keep one active and involved in everyday living.

4. **Give verbal cues when necessary:** “Walk with me to the bedroom.” Talk the person with PD through activities like dressing and bathing. Be patient and encouraging to minimize the stress of the situation.

5. **Encourage the person with PD to attend a support group meeting.** If that’s not possible, try to arrange a one-on-one get together with another person with PD. If speech problems are not a factor, these “meetings” can be over the phone. Take care of yourself too, and consider finding a caregivers’ support group.

6. **Contact the local fire department about any special needs the person with PD might have should a fire emergency occur.** In an emergency, the dispatcher will be able to tell firefighters where to look for the person needing assistance and what special equipment or rescue procedures might be necessary. Communities vary as to how they record and retrieve information; in some communities information between fire, police, and emergency medical services is not shared. Even if your community has 911 emergency services, you should contact your local fire department and emergency service agencies independently, before tragedy strikes.

### CAREGIVERS' Book Club

As a Caregiver, finding time to take care of yourself can be difficult. Just like for your loved one with Parkinson’s, education is one of the best ways to support yourself. Here are some book recommendations from WPA’s Caregiver Committee. Enjoy!

- “Shake, Rattle & Roll With It: Living and Laughing with Parkinson’s” by Vikki Claflin
- “Everything You Need to Know About Caregiving for Parkinson’s Disease” by Lianna Marie
- “Can’t We Talk About Something More Pleasant?” by Roz Chast
- “A Bittersweet Season: Caring for Our Aging Parents – and Ourselves” by Jane Gross
- “Caring for Your Parents: The Complete AARP Guide” by Hugh Delehanty & Elinor Ginsler
- “Chicken Soup for the Soul: Family Caregivers: 101 Stories of Love, Sacrifice, and Bonding” by Joan Lunden & Amy Newmark
- “No Saints Around Here: A Caregiver’s Days” by Susan Allen Toth
- “Delay the Disease – Exercise and Parkinson’s Disease” by David Zid
- “The Caregiver’s Survival Handbook: Caring for Your Aging Parents Without Losing Yourself” by Alexis Abramson, PhD
- “The Caregiving Wife’s Handbook” by Diana Denholm
- “A Parkinson’s Primer: An Indispensable Guide to Parkinson’s Disease for Patients and Their Families” by John M. Vine
- “Good Bye Parkinson’s, Hello Life!” by Alex Kerten
- “Both Sides Now: A Journey from Researcher to Patient” by Dr. Alice Lazzarini, PhD
- “Parkinson’s Disease: 300 Tips for Making Life Easier” by Shelley Peterman Schwartz
- “Goodbye Parkinson’s, Hello Life!” by Alex Kerten
- “The Caregiving Wife’s Handbook” by Diana Denholm
- “A Parkinson’s Primer: An Indispensable Guide to Parkinson’s Disease for Patients and Their Families” by John M. Vine
- “Good Bye Parkinson’s, Hello Life!” by Alex Kerten
- “Both Sides Now: A Journey from Researcher to Patient” by Dr. Alice Lazzarini, PhD
- “Parkinson’s Disease: 300 Tips for Making Life Easier” by Shelley Peterman Schwartz
- “Delay the Disease – Exercise and Parkinson’s Disease” by David Zid
- “The Caregiver’s Survival Handbook: Caring for Your Aging Parents Without Losing Yourself” by Alexis Abramson, PhD
- “Parkinson’s Disease: 300 Tips for Making Life Easier” by Shelley Peterman Schwartz
- “Delay the Disease – Exercise and Parkinson’s Disease” by David Zid
- “The Caregiver’s Survival Handbook: Caring for Your Aging Parents Without Losing Yourself” by Alexis Abramson, PhD
Laurie Couillard joined WPA in June 2018 as director of group engagement. Her role is to oversee all support and exercise groups across the state, reaching out to the PD community and visiting with members to learn more about the needs, successes, and concerns of each group, and assessing ways WPA can best support those with PD and their loved ones.

Laurie has visited with many groups all over the state so far, and if she hasn’t been to your group meeting yet – she’s probably planning on it! Here are some photos from her recent visits.

Support Groups & Exercise Groups

AROUND WISCONSIN

Special Needs Trusts are created to help preserve the assets of people with disabilities without endangering their eligibility for public benefits or placement on waiting lists.

What is a Disability or Special Needs Trust?

Under federal and state law, people with disabilities who have more than $2,000 in available assets are not eligible for means-tested public benefits such as Medicaid and Supplemental Security Income (SSI) from the government. “Means testing” is a determination by the government of whether an individual is eligible for public assistance based on income and assets. Typically people with disabilities with assets more than $2,000 must “spend down” their assets before they can apply and receive public benefits.

With a traditional trust, like a revocable living trust, assets are counted as income and may prevent the disabled person from qualifying for means-tested public benefits. However, a statute under the Medicaid law allows the creation of a Disability or Special Needs Trust (SNT). Assets in a SNT are not counted as income under Medicaid and Supplemental Security Income (SSI), and the assets in a SNT will not affect the beneficiary’s ability to receive public benefits.

Why set up a Special Needs Trust?

Because of the limitations on assets to qualify for means-tested public benefits, a person with a disability with assets of more than $2,000 only has two choices: immediately spend all the money, or put the money in a SNT. With large sums, it is often impossible to spend all the money and not create an available asset. Gifted assets have a five-year “look back” restriction. However, by putting their assets into a SNT, a person with a disability can receive public benefits and conserve his or her assets. These assets can be later used to pay for certain expenses which will improve the quality of their life.

Are there restrictions on a Special Needs Trust?

There are five general restrictions on a SNT:

1. The SNT must be an irrevocable trust (i.e., the funds cannot be returned).
2. The funds can only be spent for the sole benefit of the Beneficiary.
3. Depending on the type of means-tested public benefits received, there may be restrictions on what expenses the SNT can pay for.
4. The funds may not be paid directly to the Beneficiary.
5. The Beneficiary must be disabled as defined by the Social Security Administration.

How is a Special Needs Trust Created?

In its simplest form, a Trust account application form is completed and signed off by a licensed Wisconsin attorney. The trust application form is submitted to the trust manager, like WisPACT, for review. If the application meets the requirements for a Special Needs Trust, it is forwarded to the Trustee, and the trust is created. This process usually takes 1-2 weeks, but at WisPACT can expedited under certain circumstances.

How does a Special Needs Trust Work?

When a Beneficiary needs something to be paid for, a Request for Distribution (RFD) is submitted to the trust manager. The RFD is reviewed to ensure it is legal and will not interfere with the Beneficiary’s ability to receive means-tested public benefits, then is sent to the Trustee for payment

For more information, contact WisPACT at www.wispact.org or (608) 268-6006.
On October 10, we hosted an open house at our new office in Brookfield! We were excited to show off how our new space will allow us to better serve YOU! Thank you to Caribou Coffee & Einstein’s Bagels in Brookfield for donating coffee and bagels, and to Panera Bread in Brookfield for donating cookies.

A HUGE thank you to the Prescott Family Foundation for their generous support of our move and a financial grant that allowed us to purchase new furniture for this office.

In partnership with LSVT Global, WPA recently hosted a training for therapists on the LSVT BIG program. Our goal was to increase the number of LSVT BIG therapy opportunities throughout Wisconsin and beyond. LSVT BIG is a proven program to increase movement and activity in people with Parkinson disease.

**LSVT BIG Training**

Jeremy Otte from WPA, Sue Bettenhausen from Senior Helpers, Michael Dietrich from Heritage Muskego, support group facilitator Pat Burhans, and WPA Board Member Peter Ginn.

WPA Board Member Dick Schumann, Raven Hamilton from WPA, WPA Board Member Cheryl Prescott, and Nancy Beyer; Parkinson’s Dance Instructor Susanne Carter, Carolyn Hahn from WPA, and WPA Board Members Jim Cantrell and Dick Schumann.

Colleen Foley is a Certified Senior Advisor and the Owner of Always Best Care Senior Services. For more information, call 262-439-8616 or visit alwaysbestcare.com/wi/brookfield.

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

**How to Plan for Aging Without a Family Caregiver**

**Adult Daycare:** Services may include care and supervision, small group and individual activities, nutritious meals, transportation, care management, recreation and exercises, nursing care, education, dispensing medications, and assistance with activities of daily living.

**Neighborhood Outreach Programs:** Depending on where you live there are many organizations right in your neighborhood who will help with home repairs and modifications, yard work, and snow removal. Some are free, and others will charge a very minimal fee.

Don’t hesitate to ask for help. The purpose of community agencies and resources is to provide services to individuals who need help. Make sure your plan is completed and updated regularly.

We have many individuals who will sign up for our services before they even need them. Being proactive with your needs will help you to stay in your home independently and safely for as long as you desire.

**Caregiver Perspective:**

Would you like to receive The Network magazine? If you do not receive The Network quarterly, join our mailing list at 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.

other caregivers to talk to, support from family and friends, support groups, and a great counselor are extremely beneficial. Being a caregiver can be a lot to handle, and it is OKAY to ask for help. You need to have someone to lean on. There may be times when you are angry and that’s ok. It’s important to feel all the feelings you need to. If you are supporting a caregiver, please be forgiving, as sometimes he or she may simply need to vent and feel your support.

I think about the old adage: A person is only as good to others as they are to themselves. As a caregiver, be mindful of caring for yourself along the way. As the disease progresses reach out for support, whether it be for respite help or resources, and take care of both yourself and your loved one.
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.

For more information on groups in your area, visit wiparkinson.org or call 414-312-6990.