



# Frankly Speaking



PARKINSON FOUNDATION OF NORTHWEST OHIO

150 W. S. Boundary Dr., PMB#202, Perrysburg, OH 43551 • 1-800-438-5584 • www.pfnwo.org

Fall 2016

## 'Shaken' NOT Stirred

This year's Gala was held on October 7, 2016 and was a huge success! A big THANK YOU to everyone who came out and joined us! We had over 300 people in attendance! If you are not familiar with our Gala, it is a fun night that consists of dinner, dancing, silent auctions, games, etc. It's a night to forget about your illness and join others that are afflicted with Parkinson's and their families and have a good time.

This year's Gala raised over \$15,000 which goes directly back to the Northwest Ohio Parkinson's Community.

Some people have asked, "How did you come up with the Shaken Not Stirred name for the Gala?" We simply replied, "When you are first diagnosed with Parkinson's, you are shaken and not sure what life holds in store... but, after you research the illness, find all the resources that are available, and that you can still live a good life... you are not stirred."

Next year's Gala will be on October 6th. If you were unable to attend this year, please make sure you come out and join us next year. You are guaranteed to have a good time.

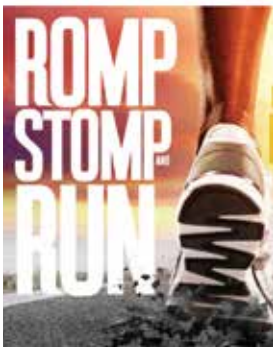


## We Romped, We Stomped, and We Ran!

Thank you for coming out and joining us for the 7th Annual Romp, Stomp and Run Family Day. The weather wasn't too good for us this year but we didn't let it stop us! Jeff Kramer and his crew put on a great event! A big thank you to all the volunteers – we could not have done this event without you. There were tons of raffle prizes, and a lot of activities to do.

Everyone had a great time! Special thanks to Kingston, The International Boxing Club and UTMIC for being part of our health fair and demonstrating all the services you can provide to the Parkinson's Community.

Proceeds from this event go directly back into the local community to help fund education, therapies, equipment, support groups, health fairs, etc. for those afflicted with PD. Plans are already underway for next year's Romp. So, if you were unable to make it out this year, please join us next year. We wouldn't want you to miss out on all the fun two years in a row!



## Our Christmas Wish for You!

May your home be filled with togetherness,  
Your heart be filled with love,  
And your soul be filled with song.

May you celebrate the beauty  
That lies within you  
And surrounds you.

May you see the great possibility  
Through every doorway  
And every smile.

May your memories spark thoughts  
Of happy times  
And lessons learned.

May you appreciate life  
For all that it has given you  
And all that it has in store for your future.

Merry Christmas and Happy New Year!  
– Parkinson Foundation of Northwest Ohio

# Coping Skills for Parkinson's Care Partners

**A** diagnosis of Parkinson's disease (PD) is a lifechanging experience not only for the person with PD, but also for the spouse, child, parent or friend who becomes the person's primary care partner.

Care partners take on many different responsibilities. Some of these may seem matter-of-course – for example, accompanying a loved one on visits to doctors, or doing the grocery shopping. Others, such as providing physical care, are more demanding. Whatever may be the nature of the task, the work of the care partner is essential to the well-being of a person with PD. Because PD progresses slowly, the care partner's role can last for decades. This journey can certainly bring rewards, but it can also bring difficult times. It is important for every care partner to remember that taking care of oneself is not the same as being selfish. By renewing your own energy and staying healthy, you can better support your loved one who lives with PD.

## Health of the Care Partner

As a care partner, you are likely focused on your loved one. Yet research shows that care partners – in general, not just those who care for loved ones with PD – face risks to their own physical and emotional health. This elevated risk can show up in a higher-than-average incidence of heart disease, high blood pressure and visits to the emergency room. Care partners have been shown to experience decreased immunity and sleep deprivation. Lack of sleep can lead to irritability and frustration. In addition, care partners experience higher-than-average rates of depression, anxiety and grief.

## Practicing the Art of Self-Compassion

In spite of all that care partners do for their loved ones, it is still easy to be self critical and to feel guilty for not doing more. I encourage you to be forgiving, and to treat yourself with the same kindness you would extend to a friend who had a concern or problem. Self-compassion is not an act of self-pity or self-indulgence, and research backs this up. It will prevent burnout and will allow you to move forward with the things you need to do every day.

## A Toolbox for Self-Care

Here are some tools for practicing self-compassion so you can maintain your physical and emotional health.

**Identify Stress Triggers:** A first step in self-care is identifying and acknowledging the sources of one's stress. A PD care partner once told me that she always felt irritable, and she felt bad about this. But when she kept a diary to record her emotions throughout the day, she was surprised to find that her irritability was not continuous throughout the day. Instead, it seemed to be triggered by certain specific situations – for example, having three things to do at once, or trying to get out the door and finding her spouse was not keeping pace, or when she was sleep deprived. Recognizing these triggers helped her find solutions to reduce stress.

**Build Support Networks:** You may feel that you do not want to burden others, but in fact most people are willing to help if asked; they just need help in knowing what to do. Families, friends and caregiver support groups provide a network of people who can help. If you cannot think of a specific task at the time when a person offers help, write down his or her name and ask if you can tell him or her later when a need arises.

In addition, consider talking with a counselor or therapist. Support groups also can be useful. Beyond being a place where people can express their emotions, support groups are a forum for exchanging resources.

If it fits your budget, hiring paid help can free up your time, so you can spend it meaningfully with your loved one. Often, in the rush of errands and medication schedules, quality time gets pushed to the bottom of the to-do list. One tip: make a priority list of caring responsibilities, then: (i) take on the most important ones yourself, and (ii) try to find someone else – paid or unpaid – to help out with the less important ones.

Finding paid help also can allow you to schedule guilt-free respite time. This should be a priority. Personal time promotes emotional health and rejuvenates energy to do the work of caregiving. I know one spouse caregiver who brings in someone to stay with his wife three days a week for two hours, to provide him the time he needs to exercise.

While finding paid help is ideal, it is easier said than done for families who are already under financial strain due to Parkinson's. In such situations, consider consulting a social worker or the state's Area Agency on Aging to learn about assistance that may be available.

**Communicate:** The first step in being able to communicate effectively – with a loved one, with a support network or in other social situations – is finding a way to understand and express emotions. Being a care partner can stir many, often conflicting feelings, such as guilt or frustration – as well as pride. Talk to a counselor, to members of a support group, or to trusted friends. Try writing in a journal or making art – both of which can be therapeutic ways to express emotions. An outlet of this kind can ease communication with a loved one, making it less charged and more meaningful.

Next, remember that communication changes when someone lives with PD. Because of the disease itself, people with PD often have difficulty showing facial expressions, and their voices can become more monotone. They may respond more slowly than they used to, and gesture less often. It is important to really look at the person with PD when speaking and ask, if unsure, what he or she is feeling and thinking. It may also help your partner to talk about his or her own feelings.

Another important area of communication is with the health care providers of your loved one. By being observant and well organized, and by making a habit of writing down questions, you will get more information and support from health care providers.



**Focus on the Positive:** This may sound unrealistic in the midst of a difficult situation. However, we all harbor some degree of optimism, and there are proven techniques for nurturing it.

**Be Flexible:** Especially when we are busy, it is easy to fall back on routines – even ones that no longer work. If this happens, the smart move is to step back, to identify the problem, to think up alternative solutions... and then to try them out. Being a creative problem solver is a key to decreasing stress.

### Treat Yourself With Care

Treating yourself with care is simply not a luxury; it is a necessity. It helps us rediscover the purpose and meaning in our lives. Doing the things that bring us pleasure – whether they are small rituals like enjoying a morning cup of coffee, following an exercise routine, practicing meditation, or simply spending time with positive friends – replenishes reserves of love, improves our health and adds depth to our experience of caring for a loved one.

*The unselfish effort to bring cheer to others will be the beginning of a happier life for ourselves.* – Helen Keller

## Are You Moving? Use It or Lose It!

### EXERCISE PROGRAMS

#### MOVERS & SHAKERS FITNESS CLASS:

##### Fremont American Legion

200 Buckland Avenue, Fremont, OH 43420  
Sessions currently ongoing  
For more information or to register contact:  
Lesley King at 419-334-6630

##### Veterans Affairs of Toledo, OH

Call your VA for information  
Arbors at Waterville  
Thursdays beginning March 12  
for 12 weeks  
11 a.m.-12 p.m. \$35 for session  
Reservations: Alyssa 419-878-3901

##### Hancock County 50 North

339 E. Melrose Ave, Findlay, OH 45840 –  
Fitzgerald Room  
Every Monday & Wednesday  
11:30 a.m.-12:15 p.m.  
Free to members of Hancock County  
50 North  
\$20 for non members for an 8 week session  
First week is FREE!  
Contact [fkasmarek@hancockseniors.org](mailto:fkasmarek@hancockseniors.org)  
To register or request more information:  
419-423-8496 ext. 2004

##### Kingston Care Center - Sylvania

4121 King Rd, Sylvania, OH 43560  
Thursdays 12-1 p.m. in our therapeutic pool  
beginning Feb. 5 for 8 weeks  
\$50/8 week session  
For more information or to register contact:  
Ashley at 419-517-8282 or  
[asautter@kingstonhealthcare.com](mailto:asautter@kingstonhealthcare.com)

##### Kingston Care Center - Perrysburg

345 E. Boundary Street  
Tuesday and Thursdays 11 a.m.-12 p.m.  
Amber Haas at 419-873-6100  
[ahaas@kingstonhealthcare.com](mailto:ahaas@kingstonhealthcare.com)

##### University of Toledo Main Campus

Health Education Building – Basketball  
Court#1, across the street from the Football  
Stadium at the bottom of the hill;  
Sessions Ongoing  
Sign up by calling Michelle Masterson  
at 419-530-6671

##### UT Health And Science Wellness Center

Tuesday & Thursday  
5:15 p.m.-6:15 p.m.  
[Michelle.Peterson@utoledo.edu](mailto:Michelle.Peterson@utoledo.edu)

##### Heartland Rehabilitation Services at Arrowhead Park

518 The Boulevard, Maumee Oh 43537  
Chair yoga at 2:30 on every Tuesday  
SilverSneakers Yoga instructor,  
419-897-9822

##### Wood County Committee on Aging

305 N Main St. – Bowling Green, OH 43402  
Thursdays 2-3 p.m.  
\$30 for a 12 week session  
Sessions Ongoing  
For more information or to register call:  
Program Department at  
419-353-5661 ext. 1013

##### St. Rita's Medical Center Auxiliary Conference Center

718 W. Market St., Lima, OH 45801  
Wednesdays 1-2 p.m., May thru November  
Cost: \$100 for 27 sessions

##### Putnam County YMCA

101 Putnam Parkway, Ottawa, OH  
Thursdays 1-2 p.m., May thru November  
Cost: \$100 for 27 session

##### Ft. Meigs YMCA

Tuesday and Thursdays from 3-4 p.m.  
Free To YMCA Members,

• \$40 for a nonmembers for 8 week session  
• twice a week. Register: 419-251-9622  
• For more information contact Patta Murray  
• [pmurray@ymcatoledo.org](mailto:pmurray@ymcatoledo.org)

##### Mennonite Memorial Home

• Bluffton, Ohio  
• Tuesdays and Fridays  
• Northwest Physical Therapy  
• 419-523-9003  
• [www.northwestphysicaltherapy.com](http://www.northwestphysicaltherapy.com)

##### Fulton County Health Center Rehab

• 138 E. Elm St.  
• Wauseon, Ohio 43567  
• Thursdays at 11:30  
• For more information call Becky or Karen  
• at 419-335-1919

##### Central Park West, Toledo OH

• Saturday 10-11 a.m.  
• 419-541-9622 [info@cpwhc.com](mailto:info@cpwhc.com)

##### Eastern Community YMCA, Oregon OH,

• Tuesday and Thursday, 4:30-5:30 p.m.  
• Susan Ruff 419-725-7844

##### YMCA Marion, Marion OH

• Monday and Wednesday 9-10 a.m.  
• Plus Saturday in the small pool 9-10 a.m.  
• 740-725-9622, [www.marionymca.com](http://www.marionymca.com)

##### KNOCK-OUT PARKINSON'S:

##### International Boxing Club

• 5963 Telegraph Rd. Toledo Ohio  
• Mondays, Wednesdays, Fridays  
• 9-10 a.m.  
• Contact Coach Harry Cummins  
• 419-244-8955

## Questions and Answers: Parkinson's Secrets, Myths and Misconceptions

**Q. At some point, people with Parkinson's were told that there is a lesser risk of breast cancer for those living with Parkinson's and a greater risk of melanoma for those that use Sinemet®. Are either of these claims correct?**

**A.** Compared with people who do not have Parkinson's disease, people with Parkinson's have been shown to have a higher risk of melanoma. This is an epidemiological association and the reasons for it are not fully understood. The increased risk of melanoma occurs in people with Parkinson's who have not yet started treatment with levodopa or other PD medications, and therefore does not appear to be caused by Parkinson's medications. It has also recently been shown that people with a family history of melanoma have a higher risk of PD than those without, suggesting that melanoma and PD may be biologically related. People with Parkinson's should therefore be vigilant about having abnormal skin lesions evaluated by a dermatologist.

There is a lower risk of a number of other cancers in people with Parkinson's than those without. This is particularly true for smoking-related cancers such as lung, bladder and laryngeal cancer, partially because people with PD tend not to have smoked in the past; but it is also true to a lesser extent for other cancers. The relationship between breast cancer and PD is less clear, but several studies actually suggest an increased risk of breast cancer in people with Parkinson's.

**Q. What would cause sudden declines in both mobility and balance, which for me, have then led to falls? I thought PD declined slowly, rather than changing extremely over the course of two months.**

**A.** You are correct – Parkinson's declines slowly, and not over hours, days or weeks. If PD symptoms worsen precipitously over a short period of time, then it is critical to search for secondary causes for these worsening symptoms. Potential causes for worsening Parkinson's symptoms may include medication changes (which may be intentional changes or due to medication error), infections (such as a urinary tract infection, cold or flu), other medical problems (e.g., dehydration, problems with the heart, lungs, kidneys, liver, etc.), and/or stress, sleep deprivation, etc.

**Q. Do vitamins help people with PD or is this just a myth?**

**A.** It is important for people with PD to eat a healthy, balanced diet to maintain their general health. Adequate vitamin D and calcium intake are important in people with low bone density to reduce the risk of fractures. We still do not know whether there are specific vitamins or supplements that affect the progression of PD – this is an active area of investigation in PD research studies, including current clinical trials.

**Q. Does excess protein interfere with medication absorption?**

**Is a diet available to avoid this?**

**A.** Protein in the diet is a problem for only a small percentage of people living with Parkinson's disease, and only for those taking Sinemet (or other medications that contain levodopa). A very small percentage of people living with Parkinson's who take levodopa notice a decreased level of benefit from a single dose of that drug when taken just before or with a meal high in protein. For the vast majority of these individuals, simply taking the dose 30 minutes prior to a meal or 45 minutes to an hour after the meal eliminates any problem. If this does not solve the problem, then ask your neurologist to refer you to a nutritionist or a dietitian for further recommendations on how to modify your diet to optimize your medications. But for the vast majority of people with Parkinson's – particularly early in the disease – dietary protein is not problematic.

**Q. Is it true that taking Sinemet earlier in PD, decreases the medication's long term usefulness? Does this apply to higher doses also?**

**A.** This is a myth. Levodopa is highly effective for many years, and its loss of efficacy has more to do with the progression of the disease than with the duration of treatment. Not all symptoms of PD respond to levodopa, and over time those symptoms become more prominent. Also, as the disease progresses, people tend to develop more side-effects from levodopa that can limit its use.

**Q. Does PD always progress?**

**A.** Parkinson's disease is always progressive, but the rate of progression is highly variable, and can be very slow in some people. If the symptoms do not increase in severity as time (usually years) passes, then other diagnoses may need to be considered.

**Q. I've been told that exercise is important. How truly important is exercise to a person with Parkinson's?**

**A.** Exercise is extremely important for people with PD – it helps to keep people mobile, keep muscles strong and well-toned, maintain overall health and prevent secondary consequences of immobility. Exercise is also known to improve mood and alleviate symptoms of depression and anxiety, and reduce the risk of development of cognitive impairment in the general population. Recent research has suggested that regular, daily exercise may help to slow the progression of PD, but additional studies need to be done to confirm this.

**WE'VE  
MOVED!**

Please note PFNWO's New Address: 150 W. S. Boundary Dr.,  
PMB#202, Perrysburg, OH 43551



*Believe in yourself and all that you are. Know that there is something inside you greater than any obstacle.* – Christian D. Larson

# Gift Ideas for People with Parkinson's

Christmas is round the corner and loved ones are beginning to frantically search shelves and the crevices of their minds as to what to get the loved one with Parkinson's disease for Christmas. Here are some ideas:

- **Electric toothbrush**

As the disease progresses, it becomes more difficult to not only hang onto a toothbrush but you can cause damage to the inside of your mouth if the tremors suddenly become out of control while brushing. This can be painful. There are several great ones out there.

- **Terrycloth bathrobe**

Any bathrobe would be nice, but terrycloth is much like a bath towel. When the PD patient showers, they can step out and immediately put on the robe and by the time they brush their teeth, brush/dry their hair, etc., they are dry and able to just get dressed. This eliminates the hassle of trying to dry off. It's also nice to have on cold evenings.

- **Cane**

As the disease progresses, balance becomes a big issue and this can affect the patient's motivation to walk or get out more. A walking stick or often known as – a cane – is a practical gift for someone with Parkinson's disease. There can be, however, cause to distinguish between these two terms. If your loved one is sensitive about his/her appearance regarding the advancement of the disease, you might consider an actual 'walking stick', often found in nature stores and/or sports stores. To make it more personal, you might even consider having it personalized.

- **Adopt a guide/service dog**

It is becoming more common to see guide/service/helper/assistance dogs used for several disabilities, including PD, Multiple Sclerosis, hearing disabilities and more. Not only do they 'help' their owner, they add companionship. One way these dogs have contributed to the assistance of PD patients is by stepping on their foot when the dog identifies the person is 'freezing' – their feet remain in place when walking while the rest of their body keeps going. This breaks the freeze and they can continue on without



a fall. There are dogs trained specifically for people with Parkinson's disease.

- **Gift certificate to a favorite or nearby salon**

As a person progresses through the stages of this disease, everything becomes more difficult. It becomes more difficult to dry your hair, take care of your fingernails and toenails. Because of this, it is not only a treat to have it done, but may become a necessity for someone else to do it. Why not make it 'professional' once in a while. Manicures aren't that pricey if you're just doing the basics and most of the time, you get a great hand and forearm massage out of it...



Speaking of massages, one of the frustrating things for a person with PD can be stiffness throughout their body. A gift certificate to a reputable masseuse would be more than welcome. Along the same lines, an herbal neck wrap is great for stiff necks.

- **Set them up with Skype**

If their laptop or PC comes equipped with a camera, set them up with Skype. They can talk to their friends and family without having to leave the house. You'll still want to get them out but this will make them feel more connected. Skype connects them not only in voice but through video as well.



- **Nook or Kindle reader**

Fine motor skills/movements are one of the hardest things for a person with PD, and that includes being able to not only turn pages, but also just holding a book open. It is sometimes easier to just hold a small object and scroll down as you read. While you're at it, tuck in a gift certificate to cover their first book purchase.

- **You**

The greatest gift you could give would be you. Often a Parkinson's patient is not as mobile as they once were and are confined a bit more than they'd like to be. A 'booklet' of coupons for lunch out, a walk in the park (with their new helper dog), dinner brought to their house, a movie date, etc. is the best gift of all.

## Another Way You Can Help Support PFNWO:

Welcome to **amazon smile**

You shop. Amazon gives.

- Go to smile.amazon.com - It is the same Amazon you know. Same Products, Same Prices, Same Service.
  - When purchasing items, please indicate Parkinson Foundation of NWO as your charitable organization of choice.
  - Amazon donates 0.5% of the price of your eligible AmazonSmile purchase to PFNWO
- ...And That's Worth Many Extra Smiles

Don't let anyone ever dull your Sparkle!

## Kroger Community Rewards Program

Buy from Kroger and a percentage of your sale will be donated to PFNWO. PFNWO Organization#: 81482



Visit [www.krogercommunityrewards.com](http://www.krogercommunityrewards.com) and register or re-enroll today.

**You need to re-enroll every year.** Any questions contact Program Coordinator: Barbara Harris at [barbarah0913@gmail.com](mailto:barbarah0913@gmail.com) or 419.448.9333

# Caregiving & the Holidays: from Stress to Success!

**F**or many caregivers the holiday season gives rise to stress, frustration and anger, instead of peace and good will.

Caregivers may feel resentful towards other family members who they feel have not offered enough assistance. Managing care for someone who has a cognitive impairment may leave caregivers feeling that they will not be able to participate as fully as they would like in family gatherings. Already feeling overwhelmed with caregiving tasks, stressed-out caregivers may view traditional holiday preparations as more of a drain of precious energy than a joy.

Following are some suggestions that may help make the holidays more enjoyable for you and your loved ones. Keep in mind that the holidays can, in fact, provide unique opportunities to seek better communication, connection and support from family and friends.

## **An opportunity for communication**

It's hard to know how much to communicate about a loved one's decline in cognitive functioning and personal care needs. Whom do you tell? How much do you tell?

Although it is understandable to have reservations about discussing a loved one's impairments, honest communication about the realities of the caregiving situation offers others the opportunity to respond with assistance. Sharing the truths of your situation may help reduce some of the feelings of isolation and lack of appreciation common in caregivers.

## **Holiday greetings and a brief note**

Some caregivers have had success in writing a brief note describing the person's condition and enclosing it in a holiday greeting card. This can be a nonthreatening way to inform distant or uninvolved relatives about the realities of the caregiving situation. If written in a tone that's not accusatory or guilt-inducing, family members may be more forthcoming with assistance or, at least, have a better understanding of the effort you are putting into providing care.

## **Let sleeping dogs lie?**

It is common for caregivers to be disappointed with family members who they feel are not "pulling their weight" in caregiving responsibilities. If this holds true for you, and your goal is to enjoy the holidays, you must decide how much and when to communicate this disappointment. Consider clearing the air before the holidays or perhaps resolve within yourself to put those feelings on hold, with the intention to discuss the matter after the holiday season passes. In the meantime, enjoy the holiday!

## **Be clear about your energy level**

Let family members know that your caregiving duties are keeping you very busy and that you only have so much energy for holiday preparation and hosting duties.

## **Accept the need to adapt**

Caregivers often have to adapt their traditional role or experience of the holidays. This may mean allowing another

family member to host more time-intensive festivities. You may need to modify the amount of time away from home to match the comfort level of your impaired loved one. You may also have to choose which events to attend based on which would be the simplest, least exhausting and most enjoyable for the person for whom you provide care – and for you.

## **Share your wish list**

- **Respite:** some caregivers ask for time off from caregiving duties as a gift for the holidays. This could mean another family member gives you a break. Sometimes asking for a Saturday off "in the next three months" is more accepted, as family members can then schedule it into their calendars. If this is not possible, perhaps they would consider paying for a home care worker or a stay at a respite facility. Your FCA Family Consultant can help you locate these resources in your area.
- **Home repairs:** Do light bulbs need changing, or grab bars need installation? That maddening pile of junk in the garage needs to go to the dump? Tasks such as these may be the perfect way for a family member to help out if providing personal care is too uncomfortable for them.
- **Care for you!** How about a gift certificate for a massage, facial or manicure? How about an opportunity to spend the day fishing or a walk in the outdoors?
- **Book your homecare worker early!** Speak with your home care worker or home care agency early about your holiday plans!

## **Schedule one-on-one time**

While caregiving, it is easy to get caught up in all the tasks of personal care and homemaking chores. Make a point of setting some time aside this holiday season to enjoy the person you care for in a relaxed, one-on-one context. The best activities are those which take advantage of long-term memory – usually less impaired in people with dementia. Try looking through family photo albums or unpacking holiday decorations, which may stimulate memories.

## **Reflect on the rewards**

Reflecting on the rewards of caregiving can help maintain your self-esteem. It may feel very rewarding to know that you are fulfilling a vow or promise you have made to the person for whom you provide care. Your caregiving may be an expression of living up to your personal ideals or religious beliefs. You may also be experiencing a great deal of growth as you learn new skills and meet challenges in ways you never imagined possible.

## **A little thank you goes a long way**

After the holidays, write a thank you note to family members or friends who spent time with your loved one. Emphasize the positive impact their visit or brief time spent with your loved one had on them. This may reinforce positive feelings from their visit and diminish any discomfort they experienced. They may then be more encouraged to visit again or be more supportive of your efforts.



# To Tell or Not to Tell?

By Claire Berman

**D**ecember 11, 2001 – the day that changed my life – was unseasonably mild. I had an appointment to see a renowned specialist in movement disorders to check out a slight tremor of my left hand. The streets around the medical center bustled with lunch-bound men and women edging past the halal food carts and outdoor vendors selling pashmina scarves, woolen mittens and African jewelry. Christmas was in the air.

I went inside, and located the designated office. The doctor was white-haired, a bit stooped, and looked his 80 plus years. “When did you first notice the tremor?” he asked. In November, I told him. Any stiffness in my legs? No. Did I have trouble getting out of a chair? A car? Had my handwriting changed? No, and no again. He had me move my hands, legs, touch a finger to my nose, then led me to a narrow hallway, instructing me to walk to its end, turn and come back.

“You’re in the early stages of Parkinson’s disease,” he said. “Drink a lot of water and exercise. See me in three months.” And that – word for word – was that.

I managed to make my way outside. The scene before me was much the same as it had been when I arrived, but all I saw was a blur. In disbelief, I found myself walking 30 blocks downtown to Bloomingdale’s, wanting to do something normal. Thoughts crowded my mind: what would this mean for me? How would I handle it? I bought a pair of gloves and came to a decision: I would share the diagnosis with my family, but with no one else. I swore them to secrecy.

“To tell or not to tell?” is a question that looms large for many people who are faced with a serious ailment. All I knew was that I needed time to learn about this illness. I needed privacy. More than anything, I feared being viewed by colleagues and friends as other, being treated with pity. I was concerned that the revelation might hurt my career as a writer. Would an editor take a chance on signing me to a book contract? Would people hire me to give a workshop? A keynote speech?

Keeping my Parkinson’s secret meant that not only did I have to cope alone with the disease and its progression; I also had to deal alone with the tension of trying to hide it. At dinner with friends, I would keep my left hand hidden under the table. At the evening’s close, I would turn to my husband and ask, “Do you think they noticed?”

Fact is, some did. The first disclosure came at dinner with a good friend. We were deep in conversation when she stopped in mid-sentence, her voice rising, to ask, “Claire, what is going on with your finger?” There it was – the fourth finger of my left hand, tapping away. Keeping a secret is not the same as lying, and I’d decided that I would not lie. “I have Parkinson’s,” I said... and then swore her to secrecy.

I changed doctors. For a time, my medications were able to control the tremor. Still, I found every outing, every encounter fraught with tension: would a sudden jerk of an arm or movement of a leg give me away?

Over time, I found myself compartmentalizing people into those who “officially” knew and others whom I suspected of knowing by the coded language that lets us secret-keepers know that they know. “How are you?” when asked with a

special intensity, is seen as a dead giveaway. “You’re looking very well” is another.

Should I tell? Slowly, tentatively, I tested the waters. My fears were not unfounded. One day, I received a phone call from a woman

at a renowned New England hospital where I’d given a talk that had been well received. “We want you back!” she said, offering to raise my fee. “Great,” I said, and in a burst of candor added, “I should tell you that I have Parkinson’s and sometimes my left hand trembles.” “No problem,” she said. “I’ll get back to you with the date.” But she never did.

Six or so years into the illness, I decided to tell all my friends, and found my candor met with their caring. Indeed, many confessed that they already knew – had known for some time, in fact – but they respected my choice to conceal it. Now they felt free to offer their love and support.

I’ve made new friends as well. Being “out” has enabled me to become active in the Parkinson’s disease community, to advocate for research and better services for people with Parkinson’s disease and their caregivers, to learn and to laugh with men and women who share my challenge... and my hope.



## Caregivers:

### Mankind’s Gift to Those in Need

by Brett Willoughby and dedicated to the “Fremont Group”

*Simply put, what is a caregiver? What do they do?  
Equally simply comes the reply, the concept is not new;  
A caregiver is a PERSON who gives care when needed,  
Not necessarily when asked, but if asked is quickly heeded.*

*Caregivers give so much and ask for nothing in return,  
Why do these PEOPLE do these “chores,” concern;  
What kinds of things do these caregivers give?  
That query usually comes from someone afraid to live.*

*“Afraid to live,” now what does that phrase mean?  
It means simply that to give of self to them is not too keen;  
Any normal caregiver gives whatever is required,  
Not for return but because of love inspired.*

*From the simplest of gestures, like getting one’s meds  
To offering consolation when a friend’s death  
brings tears to shed;  
These PEOPLE are always there come hell or high water,  
The “why” of the attention will never really matter.*

*Caregivers around the world know who they are,  
They could easily deserve a Hollywood Walk-of-Fame star;  
Suffice it to say these wonderful providers always give,  
They are better referred to as “CARE-GIVERS,” they CARE!*

150 W. S. Boundary Dr.  
PMB#202  
Perrysburg, OH 43551



Thank you for all your support during this year!  
Have a great Holiday and we will see you in 2017!

## Parkinson Foundation of Northwest Ohio Support Groups

*If you are new to a group, please call ahead to confirm meeting time and location\**

### Ashland County

2nd Tuesday 2 p.m.  
Belmont Tower  
2140 Center St.  
Ashland, OH  
John Rowsey  
419-289-1585

### Auglaize County

3rd Monday 2-3 p.m.  
Joint Township District Memorial  
Hospital, 200 St. Clair St.  
St. Mary's, OH 45885  
Linda Dicke 419-394-3335

### Group in Fulton County

St. Martins Lutheran Church  
203 S. Defiance St.  
Archbold, OH 43502  
Starts Dec 1st at 1 p.m.  
Bonnie Lauber 419-445-9516

### Hancock County

3rd Monday 1:00 p.m.  
St. Michael's Catholic Church  
750 Bright Rd.  
Findlay, OH 45840  
Mark & Deb Fisher  
419-423-4524

### Lima Area

1st Thursday of each month,  
2-3 p.m.  
NO meetings in December, January  
and February  
St. Rita's Auxiliary  
Conference Center  
718 W. Market St.  
Lima, Ohio 45801  
Beth Hartoon 419-226-9019

### Lucas County

2nd Thursday 1:30 p.m.  
*\*Meetings do not occur January,  
February & March*  
Boulevard Church of Christ  
7041 W. Sylvania Ave.  
Sylvania, OH 43560  
Carrie Boze 419-841-3070

### Parkinson Project of NW Ohio Young On-Set Group

2nd Wednesday 7 p.m.  
*\*Meets every Month EXCEPT July*  
Kingston Perrysburg Rehabilitation  
Center, 345 E. Boundary St.  
Toni & Bob Lesinski  
419-385-4330

### Perrysburg Zoar Lutheran Church

1st Thursday 2:30 p.m.  
314 E. Indiana Ave.  
Perrysburg, OH 43551  
Kristen Schuchmann  
419-383-6737

### ProMedica Memorial Hospital/

**Seneca County**  
PD Support Group  
2nd Tuesday 2 p.m.  
Meets every other month: Jan, Mar,  
May, Jul, Sept, Nov  
Fremont American Legion  
200 Buckland Ave.  
Fremont, OH 43420  
Lesley King 419-334-6630

### Putnam County

4th Wednesday  
11:15 a.m.-12:45 p.m.  
NO meetings in December, January  
and February  
Henry's Restaurant, 810 N. Locust  
St., Ottawa OH 45875  
Beth Hartoon 419-226-9019

### Sandusky

1st Thursday Each month,  
3-4:30 p.m.  
Firelands Hospital, South Campus  
Old Providence Chapel  
Hayes Ave.  
Sandusky, OH 44870  
Sandi Bodi 419-357-2895

### Tiffin Ohio

1-2:30 p.m.  
St. Francis Home, 182 St.  
Francis Ave., Tiffin  
Jean Overmier or Rachel  
Fabrizio at 419-447-2723

### Western Ohio

3rd Thursday 2 p.m.  
New location:  
Briarwood Village  
100 Don Desch Dr.  
Coldwater OH 45828  
Alicia Koester  
419-678-2851

### Williams County

3rd Monday 12:30 p.m.  
*\*Excluding County Holidays*  
Bryan Senior Center  
1201 South Portland  
Bryan, OH 43506-2079  
419-636-4047  
Laura Rohlf 419-924-2927

### CAREGIVER SUPPORT GROUPS

#### Toledo Caregivers (C.A.R.E.S.) Support Group

1st Monday 6:30 p.m.  
(except Holidays)  
Lutheran Village at Wolf Creek  
Assisted Living  
2001 Perrysburg-Holland Rd.  
Holland, OH 43528

Kristen Schuchmann  
419-383-6737  
Lisa Keaton 419-383-6770

#### The Waterford at Levis Commons Perrysburg

3rd Monday of the month  
6-7 p.m.  
Mike Zikar 866-333-2174

#### Shakin' Not Stirred's Monroe County and Contiguous Area Parkinson's Support Group

Monroe Charter Township  
4925 East Dunbar Rd.  
Monroe, Michigan  
3rd Wednesday of each month  
at 6:30 p.m.  
Jennifer Traver 734-497-5683

#### PFNWO Board Officers:

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*Vice President*  
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