SNAPSHOT: 31st Annual Parkinson Symposium
06.23.17

Caregivers: Being prepared for an emergency

Panel on PD Exercise Programs

Causes and Prevention of Falls in Parkinson Disease
Credits

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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.

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Caregivers: Being prepared for an emergency

Causes and Prevention of Falls in Parkinson Disease
Gary Garland
WPA Executive Director

Things always seem to speed up in Wisconsin’s summers, don’t they? Well, that reality holds true as well for things happening around here at Wisconsin Parkinson Association – we are busy! Let me share some of the exciting activities that have taken place recently at WPA.

I’ll start with the activity you may be familiar with: our 31st Annual Parkinson Symposium held in Pewaukee on June 23. An amazing 260 people attended, making it one of Wisconsin’s largest Parkinson-related events in 2017, and the largest Symposium for WPA in over a decade! Attendees heard the latest on Parkinson’s research, exercise, nutrition, and caregiving as well as several other topics. It is always our honor to carry out our mission of providing education, awareness and support to those with Parkinson’s, as well as their family and medical staff. If you were there, thank you! If not, we hope to see you in 2018 and remember, getting help from WPA is always just a phone call away. Walking with you on this journey is why we are here – period.

The Symposium was preceded on June 22 by Support Group Facilitator Training attended by 29 of the most dedicated frontline Parkinson ambassadors. These individuals lead groups year-round throughout the state to ensure that the people affected by PD have access to the latest essential information on battling this disease. Attending this special gathering for the first time was a powerful reminder for me of who the real experts are in this work – you! After hearing such rich discussion of what works and what causes challenges in group leadership, my commitment is that WPA must begin asking “How do we get these leaders to share their expertise more often than once a year?”

Finally, on June 10 WPA’s board of directors and staff gathered to plan – based on our experience and your feedback – our priorities for the next year. The day launched fantastic discussion and debate, ultimately leading to four broad areas where we will put our attention:

➢ Strengthen programming and relationships
➢ Increase our visibility
➢ Continue to build financial strength
➢ Be great stewards of all resources that are shared with us

All of this exciting activity reinforces a message that has grown stronger each and every day of my first six months here – there is a lot to do in order to carry out our mission and it’s going to take more than the WPA board and staff to do it. We need you to be our partner in the work of that mission. Whether you partner by contacting us with an idea, generously sharing a financial gift, or telling your story to make the PD journey easier for another – we need you and we appreciate you!

I hope the rest of your summer is full of sun, fun and just the right amount of activity!

Thanks,
Gary

Gary Garland, Executive Director for Wisconsin Parkinson Association, and Linda Best, RN, Specialty Sales Representative for IMPAX Pharmaceuticals at the 31st Annual Parkinson Symposium.
The Parkinson Disease Symposium draws attendees from far and wide to learn more about Parkinson’s treatments and resources, and to connect with others who have PD. Many attendees are involved in one or more support groups. So for the last several years, WPA has led a training session for support group facilitators on the Thursday before the Symposium.

At the facilitator training, support group leaders shared the success and challenges their groups have experienced over the past year. Half of the nearly 30 attendees have been facilitating their support group for less than a year, so many were seeking advice and ideas from those who have been facilitating longer.

One of the most important goals of this year’s facilitator training was to hear directly from the facilitators on how things were going in their groups and to identify ways in which WPA can best support their efforts. Stemming from that discussion, here are some important ways in which WPA expects to increase our partnerships with these facilitators and the groups they lead:

> Create a speaker’s bureau in order to simplify the often challenging process of getting PD experts to attend group meetings.

> Step up our efforts to assist groups to publicize their meetings and reach potential new members.

> Check in with group facilitators more regularly to hear how things are going, see if they currently need any assistance from WPA, and share their efforts with WPA’s “audience.”

> Explore ways where we can more often bring together facilitators to exchange ideas and challenges and learn from the best teachers – each other!

> Develop publications and programming to better serve caregivers, those newly diagnosed with PD and the young onset community.

> Formalize a grant program to provide small financial support that would have a big impact on the effectiveness of groups and the quality of life of their members.

Many groups have grown over the last year, but they are all still happy to welcome new members! Several facilitators discussed how they have merged the social part of a support group meeting with a local exercise group, allowing participants to care for their mind and bodies at the same time.

Jan and Larry Nahrgang have recently stepped up to help facilitate their group in Davenport, Iowa. Jan appreciates how occasionally their group will split into two groups: people with PD in one group, and caregivers in another. She mentioned, “I don’t always understand what Larry’s going through, so being in a room with other caregivers is helpful to me.”
Jody Goratowski, RN, BSN joined the WPA staff in early 2005 as research coordinator for the former clinic, and in 2008 she became WPA’s outreach coordinator. In fall 2008, while addressing a support group in Rockford, Illinois, Jody suffered a cardiac arrhythmia and passed away the following week.

Gary Schilling, Jody’s father, has lived with Parkinson’s since 2004, and inspired Jody in her work with WPA. “Jody was dedicated to the cause and had a passion for her work. She really looked forward to support group meetings and being able to share the latest information on Parkinson’s. She was grateful that people afflicted with PD had a venue to share their stories and be a part of a group,” said Gary. “We like to think that her efforts made a big impact on today’s support groups.”

Jody’s sisters, Lori Griggs and Christine Kuhaupt, agreed with their father’s words. “Jody was never afraid to speak up and advocate for those unable to do so for themselves. She struggled on what direction she wanted her life to go until she found nursing school. That was truly her niche in life.”

"We like to think that her efforts made a big impact on today’s support groups.” – Gary Schilling

One of Jody’s special projects was WPA’s annual Support Group Facilitator Training. To sustain the memory of her work for people affected with Parkinson disease, this training is named in her memory.

Lori Anderson facilitates a group in Fond du Lac. “It’s so encouraging to me when someone comes who isn’t having a good day and isn’t feeling well. It’s a powerful reminder of how important this group is to them.”

Most facilitators are volunteers, and overwhelmingly, they discussed the importance of the work they are doing.

Whether you’re looking for education, a sense of community, or workout buddies, you can find it in a support or exercise group. Visit wiparkinson.org for a current list of over 130 support and exercise groups that WPA works with. If you don’t find what you’re looking for in your area, call our office – WE’D LOVE TO HELP YOU START A NEW GROUP!
2017 Parkinson Disease Symposium

“It was wonderful to learn more about PD, and to meet and interact with new friends!”

8 different sessions on topics relevant to people with PD

“Informative day, very well put together.”

28 Support Group Facilitators representing 21 groups

“I am always interested in the scientific side of PD – thank you!”

261 attendees from 96 cities in 3 states

“Great job at making research easy to understand!”

8 different sessions on topics relevant to people with PD

“Great job at making research easy to understand!”

2 sessions on exercise including a 100+ person dance party!

“My husband has been resisting exercise, but I think the sessions on exercise have finally convinced him of the importance!”

7 HOURS of education and networking

“The session on grief was great – very interactive with good information.”

TWO sessions for caregivers

“Thank you for the reminder that we aren’t alone here.”

forty-one sponsors and vendors supporting WPA’s work

“Great job at making research easy to understand!”

“I particularly appreciated the shared focus on people with PD as well as caregivers. We have separate problems and needs.”

“My husband has been resisting exercise, but I think the sessions on exercise have finally convinced him of the importance!”

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“Great job at making research easy to understand!”

“I particularly appreciated the shared focus on people with PD as well as caregivers. We have separate problems and needs.”
Communication experts are calling for changes in how scientists communicate with the public. Not only is it important for scientists to communicate their findings in simple terms, the public needs to be more conversant in scientific terminology and to be a critical ‘consumer’ of science.

In the opening session of the Symposium, scientist and speech-language pathologist Corinne Jones discussed what is known about the causes of Parkinson disease from a scientist’s perspective and gave tips on how the public can become more involved in science.

In order to understand how Parkinson disease impacts movement, we need to understand how movement is controlled. One of the main ways is through a structure in the middle of the brain called the basal ganglia. Neurons (brain cells) communicate with each other using neurotransmitters (chemicals) to pass along an electric pulse. The basal ganglia takes these signals from the cerebral cortex, along with dopamine signals from the substantia nigra in the brainstem to organize and drive motor movements.

Parkinson disease is a complex disease that impacts the body on many different levels. Researchers can study Parkinson disease by looking at behavior (such as movement), brain regions (such as the basal ganglia), cells (such as neurons), and molecules (such as dopamine). Parkinson disease is caused by the death of neurons in the substantia nigra that send dopamine to the basal ganglia. This results in reduction of movement, along with non-motor symptoms such as constipation, sleep-wake regulation, and mood changes. Parkinson disease brain pathology is related to age, genetic predispositions, and exposure to toxins in the environment.

A new theory of how pathology spreads in the brain is through the misfolding of proteins, known as the prion theory. Scientists don’t know the exact trigger of Parkinson disease, but we believe that it starts much sooner than the start of symptoms, such as tremor or difficulty walking. Early diagnosis and recognition of symptoms can lead to earlier treatment and potentially better outcomes.

While scientists believe we have a pretty good understanding of how Parkinson disease works, there are still a lot of questions. When we answer one question, it paves the way for new questions we hadn’t thought to ask about before. Our main goals are to find a cure for the disease and to improve how people with the disease manage their symptoms. We do this in many ways, from studying how cells grow and behave in a petri dish to studying how a person responds to a drug or other type of therapy. The public can help move science forward by speaking with scientists, participating in research studies, and being careful consumers of new research findings. Science is dependent on public support to move forward, and how scientists communicate can directly impact their ability to receive such support.

Together, we can work to cure Parkinson disease and to improve the lives of the people with the disease and their loved ones.

Corinne Jones is a PhD Candidate at the University of Wisconsin-Madison in the Department of Communication Sciences & Disorders and with the Neuroscience Training Program. Her research centers on early identification and treatment of swallowing disorders in people with Parkinson disease.
CAREGIVERS: Being prepared for an emergency

By Aimee Henry

Aimee Henry is a retired county social worker who worked in caregiver programming. She now serves as caregiver program manager for ERAs Senior Network (formerly Interfaith Senior Programs in Waukesha County). Aimee is a blogger for the Caregiver Connection, a facilitator for a caregiver support group in Sussex, and a caregiver advocate.

Steps in preparing an Emergency Caregiver Plan

Most caregivers feel overwhelmed when they are asked about an Emergency Caregiver Plan – they feel the task will take too much time and too much effort. In this breakout session, Aimee Henry assured attendees: you will feel less stress and anxiety if a plan is in place… no more sleepless nights! Aimee discussed the necessary steps to be prepared, and how to help your care receiver get the best care in your absence.

1 Develop an Emergency Caregiver or Caregiver Team

Determine who knows your care receiver the best (next to you) and knows their routine. It may be a family member, a friend, a home care agency or a long-term care facility. Have an honest and open discussion with them: would they feel comfortable taking over care for your care receiver for a day, a week, a month or forever? Once you have developed an “emergency care team,” share ALL of the following information with them. The emergency caregiver needs to feel confident with what is being asked of them, and feel that they have all the information and supplies that they will need.

2 Where will the care receiver’s care be done?

In their current home? Someone else’s home? In a respite care facility? Assisted care or nursing home? Have a list of all adaptive equipment used by your care receiver. If care is to continue at a respite facility or a long-term care facility, make a visit alone and then with your care receiver so that they are familiar with the setting. Pre-register and discuss how payment will be handled. Discuss any and all treatments, monitoring and target ranges, such as blood pressure or blood sugar testing. Make a schedule of your care receiver’s daily routine. Others will appreciate it, and your care receiver will adapt better.

3 Start collecting all the documents and information lists.

To compile a comprehensive list, begin with discussions with the care receiver, other family members, doctors’ offices and in-home agencies.

Participants took in all of the tips and information provided by Aimee to decrease the stress and anxiety of creating an Emergency Caregiver Plan.

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GRIEVING “life as we have known it”

By Melissa Minkley, MSW

Melissa Minkley is the co-founder of Healing Life’s Losses, LLC, an organization that is committed to offering services of education, training and support to those who are grieving and those who companion them. She also serves as the bereavement coordinator for Allay Home & Hospice and as the program director for Healing Hearts of Waukesha County, which provides grief support to children and families coping with an array of losses.

A long-term illness like Parkinson’s forces one to let go of “the way things used to be” and embrace the highs and lows along with the challenges and triumphs the disease offers. As we know, this is easier said than done! We long for the way life was before the diagnosis.

We do not always recognize that we are experiencing grief as we mourn the many different losses experienced due to the disease. Since grief is anything but predictable, we are blindsided by the roller coaster ride of emotions and behavioral effects of grief and loss. In this breakout session, Melissa Minkley addressed the grief process experienced due to a Parkinson’s diagnosis, for the person with the disease as well as their loved ones, and provided effective ways to honor the grief while working toward wholeness. Grief is a normal, natural and necessary response to all losses, and it is important that we take the time to honor it and intentionally work our way through the grief process.

The cliché “time heals all wounds” is only partially accurate. What we do during this time is crucial.

This session addressed the difference between grief and mourning, and helped identify some common responses to a medical diagnosis like Parkinson’s, while dispelling common myths about grief.

“Grief shared is grief diminished.”
– Rabbi Earl Grollman

Here are 4 key facts about grief Melissa shared:

1. The way out of grief is through it.
2. The very worst kind of grief is your own.
3. Grief is hard work.
4. Effective grief work is not done alone.

Participants listened as Melissa discussed the difference between grief and mourning, and effective ways to work towards wholeness.
Panel on PD EXERCISE PROGRAMS

By Darrell Jack, Rock Steady Boxing • Susanne Carter, BA, MS, CPT, Parkinson Dance Class • Erica Vitek, MOT, OTR, LSVT BIG

Darrell Jack owns and operates Fast Forward Fitness personal training. He holds a certification and is an affiliate of Rock Steady Boxing. He has a passion for impacting lives through positive messages, teaching correct fitness techniques and intense movements.

Susanne Carter is an occupational therapist at Aurora Sinai Medical Center in Milwaukee. She is certified in LSVT BIG and is a trained PWR! (Parkinson Wellness Recovery) Provider. Erica is an LSVT Global faculty member, traveling throughout the U.S. and internationally, providing LSVT BIG certification courses to occupational and physical therapists.

One of the highlights of the 2017 Symposium was the panel on PD exercise programs. The session started with Darrell Jack from Rock Steady Boxing demonstrating some boxing moves. Darrell shared that several studies have concluded that “forced, intense” exercise can slow the progression of Parkinson’s. In other words, when exercise is done at a volunteer rate, there is less benefit than when exercise is done in a format that pushes or forces someone out of their comfort zone.

Darrell told attendees how boxers train to improve balance, hand-eye coordination, speed, agility, muscle power and mental focus – all of which generally happen to be issues for people with Parkinson’s. So with boxing, instead of focusing on the specific symptoms of Parkinson’s, people can learn a new skill that is fun and a good stress reliever while addressing many of the symptoms of Parkinson’s.

Next, Susanne Carter talked about the Parkinson’s Dance Class, which is in two locations in the Milwaukee area. The dance classes are taught by professional dancers who bring an array of dance and movement talents that are helpful to people with Parkinson’s.

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Susanne touched on many great aspects of a dance class. Spark your imagination: “You still have an imagination, just light it up!” Use your senses: “Remember when you rolled down a hill as a kid?” Feel the beat: “Be careful. The rhythm is gonna get you!” Try something new and enjoy a group activity: “Feel the energy as you dance with others. You might make new friends.” Tap into your creativity: “We are all creative. We just need to let it come out.” Embrace the power of dance to unite your body and mind: “Dance brings things into clear

ESPN ranks boxing as the most intense form of training, in terms of degree of difficulty compared to 60 other sports. If “forced, intense” exercise is the proven form of exercise for people with Parkinson’s, then boxing is a good fit.

It’s more fun to tell your grandkids that you’re going to boxing class than to physical therapy!  
- Darrell Jack
focus and unites the power of the mind with the movements of the body.”

Susanne also shared that not only is it fun, but research also shows the positive impact dancing has on participants’ overall movement and quality of life. Participants have talked about feeling better physically, the emotional feeling of companionship and camaraderie, as well as feeling that general health has improved.

"Let’s all get up – get moving, and have fun!"

– Susanne Carter

Finally, Erica Vitek discussed the LSVT (Lee Silverman Voice Treatment) BIG program. LSVT BIG is a research-based, high intensity exercise that has been found effective to improve movement for people with Parkinson disease. The technique was built on the principles of LSVT LOUD, which is the gold standard treatment for soft voice occurring from Parkinson’s.

LSVT BIG is a standardized one-on-one therapy treatment protocol delivered by a certified physical or occupational therapist. The therapy consists of 4 sessions a week for 4 weeks, which allows for repetition and retraining of the body and brain. The focus during therapy is based on increasing the size or amplitude of movements to help with balance, walking, including freezing, fine motor coordination and self cares.

“The more you do each of these exercises, the better you will be at ALL of these exercises. When you’re dancing, make BIG movements. When you’re boxing, think BIG!”

– Erika Vitek
ARE YOU CARING TOO MUCH and Laughing Too Little?

By Lynda Markut, LCSW

Lynda Markut is a licensed Clinical Social Worker and has counseled individuals with mental health diagnosis and/or dementia and provided services to families for over 35 years. She is the education and family support coordinator at the Alzheimer’s Association of Southeastern Wisconsin where she also trains facilitators and facilitates Alzheimer’s Disease/Dementia support groups with a wellness focus. Her clinical, educational experience is coupled with 28 years of personal and practical experience gained while providing care to her loved ones.

In a very interactive breakout session, Lynda Markut helped care partners as well as people with Parkinson’s learn to utilize more humor in their lives and in their caregiving. Participants were reminded what happens when we don’t laugh, and how humor can be used as a barometer for how one is doing while caring. When you lose your sense of humor, it can mean that you are caring too much, need additional help, and perhaps have lost your focus on life while caregiving.

“Life goes by whether you’re having fun or not.”

Through funny stories, jokes, toys, and facts, everyone was reminded of the benefits of humor.

Physical benefits:
➢ Increased endorphins and dopamine
➢ Increased relaxation response
➢ Reduced pain and stress

Cognitive benefits of humor and mirth:
➢ Increased creativity
➢ Improved problem-solving ability
➢ Enhanced memory (for humorous material)
➢ Increased ability to cope with stress, by providing an alternative, less serious perspective on one’s problems

Participants were asked to think about some stressful situations and reminded just what stress does to our bodies. The stress of caregiving continues day after day and can lead to Super Stress.

Super Stress is compounded chronic stress, and can have a cluster of symptoms such as headaches, stomachaches, backaches. With Super Stress, you may also experience memory issues, fatigue, anxiety and depression. You may feel like life has lost its luster, and you lose your sense of humor and motivation. Anxious becomes the “new normal” and you may wake up exhausted and stay that way. (Taken from The SuperStress Solution, Roberta Lee, MD.)

Lynda discussed alternatives to Super Stress – humor is one of the best antidotes! Anyone can start or enhance their own humor responses by talking to friends, getting extra help, reading more comics, and watching less news. Participants were reminded to talk more with people who laugh and who can make them laugh. No one is saying that Parkinson disease is funny, but funny things happen when you have Parkinson’s or you are caring for someone with Parkinson’s. Each participant was also given a little toy to remind them to play, because “we don’t stop playing because we grow old, we grow old when we stop playing.”

“It’s in the darkroom of your mind where negatives develop.”
Causes and Prevention of Falls in Parkinson Disease

By Molly Agnew, DPT, NCS & Erin Brennan, DPT

Molly Agnew began treating patients with Parkinson disease at Froedtert’s Neurologic Rehabilitation Department in 2006 and has been an adjunct assistant professor in the Department of Physical Therapy at Marquette University since 2007. She is a board-certified clinical specialist in neurologic physical therapy and is LSVT certified.

Erin Brennan received her Doctorate of Physical Therapy from the University of Wisconsin-La Crosse. She is LSVT BIG certified and has worked in Froedtert Hospital’s Neurological Rehabilitation Department since 2012.

People with Parkinson disease are twice as likely to fall as a person without Parkinson disease. Falling frequently results in injury and can impact an individual’s mobility and quality of life. In this breakout session, attendees learned about factors for falling that can be related to mobility and non-mobility issues associated with a Parkinson disease diagnosis.

Motor or mobility-related symptoms of PD could include:

- Impaired postural reflexes
- Rigidity
- Slower movements
- Changes in walking patterns such as shuffling gait, poor foot clearance, short step length
- Forward posture

Some non-motor symptoms of Parkinson disease that can contribute to falling include:

- Visual and perceptual changes
- Drop in blood pressure related to position changes (moving from sitting to standing or getting out of bed)
- Fatigue
- Changes in cognitive processing
- Side effects of medication
- Depression
- Anxiety

Frequently seen movement difficulties in Parkinson disease include propulsion, freezing, retropulsion and impaired balance reactions. Strategies to manage propulsion/festation (rapid forward movement) include use of cueing to slow down movements, using larger movements or stopping.

Freezing commonly occurs with direction changes such as turning or backing up, and when encountering changes in environment including doorways, thresholds, confined spaces, and other changes in flooring. Starting with the stuck foot first can be helpful when initiating a movement or recovering from an episode of freezing. Verbal cues and other forms of external cues like rhythm such as counting, clapping, or use of a metronome can be helpful for freezing. Some individuals respond to visual or tactile cues as well.

Continued on page 18

Participants enjoyed the presentation on the causes and prevention of falls, presented by Molly and Erin.
The loss of dopamine in a person with Parkinson’s can lead to both motor and non-motor symptoms, including tremors, stiffness, slow movements, cognitive changes, and balance difficulties. There are a variety of ways to combat these symptoms, including medication and exercise. This breakout session focused on exercise as a target attack on PD.

Research has demonstrated that exercise acts as a natural “medicine” that can activate the same areas of the brain as medication, making exercise a valuable adjunct to medication in Parkinson’s treatment. Not only can exercise help improve Parkinson’s symptoms, it can delay the tolerance effects of medication. It can also slow the progression of Parkinson disease, prolonging functional mobility and independence. Additionally, it has been shown that being sedentary may actually result in further disease progression, therefore, it is recommended to begin exercising as soon as possible after diagnosis.

There are many exercise programs and activities available for people with Parkinson’s. The exercise program selected should be interesting and engaging to ensure full and continued participation. Any exercise can be adapted to a person’s level of abilities.

Each exercise program should include a warm-up, cardiac activity, strengthening and agility, and a cool-down. Intensity is especially important to consider when exercising. A moderate to high level of intensity is recommended – which means that it is difficult for the participant to hold a conversation while exercising. This will result in the greatest amount of brain change and provide neuroplastic and neuroprotective benefits. Big movements are also a primary focus in Parkinson’s exercise programs, as they help to address the stiffness and slow movements encountered by persons with Parkinson’s.

Many exercise programs have been developed for Parkinson’s, including LSVT BIG, PWR!, and Rock Steady Boxing. These programs incorporate specific exercise recommendations to aid in the fight against Parkinson’s. Group exercises can be beneficial for people with Parkinson’s, as they include an emphasis on intensity, provide accountability and supervision, and allow for social support.

... exercise acts as a natural “medicine” that can activate the same areas of the brain as medication.

For a list of exercise groups and classes in your area, visit wiparkinson.org. A physical therapist can also be a great resource for developing a customized exercise program. Exercise has amazing overall benefits that can empower individuals to take control over Parkinson’s disease.
Over the last several years, nutrition has been one of the most requested topics from Symposium attendees. In the final session of the day, we welcomed registered dietician Michelle McDonagh to share a comprehensive overview of nutrition for Parkinson disease. She discussed dietary considerations for drugs used to treat PD symptoms, methods to use food to improve PD symptoms, and the impact of PD on nutritional health status.

An interaction with protein can reduce the effectiveness of Levodopa so it is recommended that Levodopa medications are taken 30-60 minutes before a meal or 2 hours after a meal. For those who experience reduced effectiveness of Levodopa after several years using the medication a Protein Redistribution diet may be beneficial. The diet is essentially lower protein for the bulk of the day and high protein in the evening to ensure overall protein needs are met. It is important to work with your physician and dietician before pursuing a Protein Redistribution diet.

High intakes of fruit, vegetables and fish are inversely related to PD risk. Eating a diet filled with a variety of dark green, bright yellow/orange, red, blue/purple fruit and vegetables provides phytochemicals that reduce functional decline associated with aging and may even slow the progression of PD. Omega-3 fats found in oily fish, walnuts, chia seeds, flax and canola oil may help delay cognitive decline. Vitamin D receptors are plentiful in the brain and it is important for nerve signaling. Vitamin D deficiency is common in PD so routine screening of vitamin D levels is recommended as well as supplementation with vitamin D₃ as needed.

Constipation can occur due to slowed bowel motility, reduced fiber and fluid intake, and as a side effect of medications. Increasing fluid intake and dietary fiber with fruits, vegetables, whole grains and legumes can regulate bowel function. Many experience weight gain in the early stages of PD which is often related to the appetite stimulating effect of some of their medications. In order to avoid weight gain or to lose weight it is recommended to have regular meal times, avoid calorie-filled sweets and beverages, and high fat meals. Instead, include plenty of fruits, vegetables, whole grains, and lean protein in the diet and exercise regularly.

Those with swallowing difficulty or increased tremors may have the opposite problem with unintentional weight loss. Increased calorie intake with calorie dense food selection, increased meal frequency and supplementing with milk, juice, smoothies or commercial nutrition shakes is necessary to maintain or regain weight.
When Ellen Grys, RN started her job as Information & Assistance Specialist at the Portage County Aging & Disability Resource Center (ADRC), she knew there would be some unexpected aspects of her new job. One aspect that she hadn’t anticipated was running a Parkinson disease support group at the Lincoln Senior Center.

“The group came with the job,” Ellen said. “And I didn’t know about it until I started!”

Nine years later, with Ellen’s guidance, the group remains a great resource for people with PD in the Stevens Point area. They meet monthly on the 4th Tuesday of the month, taking December off. Ellen’s “day job” at the ADRC is a great connection for her, and helps her find speakers for the group meetings. Generally the group brings in a speaker for about two-thirds of meetings, and for the remaining meetings, they have sharing time, or planning ahead for future meetings.

“We like to mix up the topics. We have some speakers who are focused on issues specific to Parkinson’s, and some who aren’t Parkinson-focused.”

Some recent topics have included:

- Anxiety and depression in PD
- PWR!4Life program
- Hallucinations and delusions in PD
- ADRC Supports for Caregivers
- Medicare Part D open enrollment updates

Something else Ellen has learned over the last nine years: This group likes to have a snack! Ellen tells the story of Bill, a long time group member, who liked cookies. At one of the first meetings Ellen facilitated, she did not have time to get a snack for the group, so they only had coffee and water. Bill teased her all meeting about not being able to survive without a cookie. Since then Ellen has always made sure there was a snack! Bill has since passed away, but one of the last things from Bill was to remember the cookies. Whether its cookies or brownies, or something else, she has learned the importance of bringing a treat to their meetings!

Over the years facilitating the Parkinson Support Group has become one of the most enjoyable aspects of Ellen’s job and one that she will miss when the time comes to retire.

For more information on these support and exercise groups, as well as the other groups WPA works with, visit wiparkinson.org or call 414-312-6990.
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.
Causes and Prevention of Falls in Parkinson’s Disease

Not all falls are directly caused by Parkinson-related issues. Common changes associated with aging can affect balance and falls. Environmental hazards may include poor lighting, clutter, uneven surfaces like concrete or grass, slippery surfaces, young children, pets and their toys. To reduce the risk of drug interaction from multiple medications, talk with your doctor about ALL medications including over-the-counter drugs that you are taking. Fill prescriptions at one pharmacy so your pharmacist can also watch for possible drug interactions.

Attendees in this session learned ways to reduce environmental risks by addressing lighting, flooring, home and bathroom set-up, as well as ways to stay safe outside. Also discussed were the use of assistive devices and exercise recommendations. Recommendations for appropriate health care providers to consult with concerns about falling were shared.

Pets and kids toys are examples of environmental hazards that may cause falls.

CAREGIVERS: Being prepared for an emergency

Purchase a brightly colored binder for the items below and keep ALL items in one place!

- Compile lists and forms that are necessary, and will need to be updated on a regular basis as the journey continues.
- List all medical providers – including specialists, therapists, and health care agencies.
- List all prescribed and over-the-counter medications, including vitamins and supplements, with name, purpose, dosage and frequency given, as well as where the medications are kept.
- Note the name of the pharmacy you use.
- Include copies of legal and financial documents.
- Create a copy of your care receiver’s daily routine.
- Make copies of front and back of medical insurance cards.

Prepare an "Emergency To Go Bag" and have it clearly marked and ready to go in a moment’s notice.

Being prepared and having an emergency plan is necessary to help the care receiver and give you peace of mind for any unpredictable situations.
WPA News

WPA welcomes NEW BOARD MEMBER

We are pleased to welcome Brittany Rosales to our board of directors. Brittany works in Business Intelligence for Johnson Controls as market strategy analyst and lead IT analyst. She is a graduate of University of Wisconsin-Milwaukee.

RECENT EVENT

June 3 – Elkhorn

Thanks to Joe Schlicher and his family and friends, the 3rd Annual Movers & Shakers Golf Classic was a great success! This family-oriented golf and dinner event raised over $14,000 to donate to WPA! Thank you to Joe & Patty, and everyone who participated in and donated to this awesome event!

Movers & Shakers Golf Classic coordinator Joe Schlicher with Tom Pipines, formerly of Fox 6 Milwaukee, at the 2016 M&S Classic. Pipines participated in the outing and served as emcee and auctioneer again this year.

UPCOMING EVENT

6th Annual WPA Open Against Parkinson Disease

Presented by HeatTek, Inc. and Financial Strategies, Inc.

Tuesday, September 12, 2017

The Legend at Merrill Hills

Waukesha, Wisconsin

11 am  Registration

12 pm  Shotgun start with scramble format

5 pm  Silent Auction, Wine Pull, Cocktails, Networking

6 pm  Dinner, Program, Auction

Register by September 1

$1,000/foursome or $250/golfer

Includes lunch, on-course beverages, cocktail hour and plated dinner.

Don’t Golf? Come for the elegant dinner!

For $75 per guest, join us at 5 pm for cocktails, wine pull, silent auction and networking in the clubhouse overlooking the beautiful golf course.

To register or for more information, visit wiparkinson.org or call 414-312-6990.
Wisconsin Parkinson Association
2819 W. Highland Boulevard
Milwaukee, WI 53208

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 them and their families. For more information, visit wiparkinson.org.

The mission of the Wisconsin Parkinson Association is to expand medical professional and public awareness and understanding about Parkinson disease that will lead to maximum support, the best individual healthcare, assistance for caregivers and families, and increased funding for research.

Upcoming Events

August 22
Understanding Parkinson’s
Fond du Lac

August 29
Parkinson Disease: Living Well
Green Bay

September 12
6th Annual WPA Open
Waukesha

September 15
Parkinson Disease: Living Well
Brookfield

October 12
Parkinson Disease: The Basics & Beyond • Bayfield

December 6
Holiday Reception
Brookfield

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