

- 2022 -

FEBRUARY

Parkinson's Perspective

**Newsletter of the Colorado Springs Parkinson's Support Group
Colorado Parkinson Foundation, Inc.**

www.co-parkinson.org | (719) 884-0103

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The Colorado Springs
Parkinson's Support Group
(part of CPF) meets the second
Saturday of each month at 10AM
(with exceptions to be noted
in this newsletter).

February Meeting: Saturday, February 12th – 10:00 am – 1:30 pm
We will be Zooming and recording this meeting

Location: First United Methodist Church, 420 N Nevada Ave, downtown just south of St. Vrain.

9:30 am – Come early for a group sing-along with music therapist, Heather Johnson.
See more about Heather's business under **'Other Opportunities:'** later in this newsletter.

9:45 am – Everyone else come in a few minutes early to check in, greet other members and ask questions.

First time visitors: Be sure to sign in, get a name tag and proceed to the visitors' table for some special attention and information.

Knowledge is power and enables us all to live well, so plan to attend the meetings at First United Methodist Church.

February Program: Results of the 24 week CPF Study on the effects of a low-carb/healthy fat diet on PD

Speaker: Dr. Melanie Tidman, DHSc, M.A., OTR/L. MHP



About the Speaker: Dr. Tidman completed a Bachelor's degree in Occupational Therapy at Colorado State University, a Master's degree from the University of New Mexico, and her Doctorate in Health Science from AT Still University Doctorate in Health Science program in 2011. She is currently working on certification as a Metabolic Health Practitioner with the Society of Metabolic Health Practitioners and certification as a Nutrition Practitioner with the International Nutrition Network.

Dr. Tidman has 40 years of experience as an Occupational Therapist in Pediatrics, Intensive care, and Adult Physical Rehabilitation, emphasizing Neurology and Neurosurgery Rehabilitation. She owned and directed Tidman Therapy Services, a pediatric rehabilitation center, for 22 years, served patients with neurological and neurosurgical disorders in a Neurosurgery Intensive Care Unit for 20 years, and has expertise in all areas of inpatient and outpatient Adult Physical Rehabilitation

with specialized expertise in Parkinson's Disease, Stroke and Brain Injury.

In 2019, Dr. Tidman conducted a field research study for the CPF entitled **"The effects of a community-based exercise program on mobility, balance, cognition, ADL's and QOL in PD: a community partnership pilot study"** which was published in February 2020 in the Journal of Neurodegenerative Disease Management.

During her professional experience, Dr. Tidman has published several professional journal articles, is a contributing chapter author for an Occupational Therapy textbook, and has published the first two books in a series of educational guides for families of patients with neurological conditions. "Families in the ICU: A Survival Guide" was published in 2014, and the sequel book, "Families in the Rehab Center and Beyond" was published in 2017.

Dr. Tidman is an Adjunct Professor for A.T. Still University's Doctorate in Health Science program, Nova Southeastern University's Ph.D. in Occupational Therapy program, and Colorado Christian University's Masters in Healthcare Administration program. In addition to presenting at professional conferences, Dr. Tidman has particular interest in healthcare delivery and reform, patient-centered care, and instruction for doctoral students on professional writing for publication.

The February Potluck main dish – Italian!

If you would like to sign up to be one of the providers of a main dish or a side dish/dessert for the February meeting, you can sign up through our website or you can contact Bill Hicks at [REDACTED] or potluck@co-parkinson.org, no later than Wed. Feb 9th and tell him what you would like to bring.

If you'd like to go through the website, go to the "Events" page of the website and find the meeting you're volunteering for and select "Event Details". That will take you to the main sign-up page. In addition to the meeting information, you will see how many chefs and the number of servings per batch are needed. Click on "Sign Up" in the box and then select "Submit and Sign Up" which will take you to a page where you will select how many of the number of chefs you are signing up for. For example, if the # of servings requested is 10 but you're making 20 servings then the quantity you would select should be 2...the equivalent of 2 chefs. There is also a place for any comments you may have there. You must then provide your name & email address. When finished, select "Sign Up Now" and you will receive a confirmation email and your information will be sent to our potluck coordinator, Bill. This capability should help make Bill's job considerably easier. To return to the website, close the sign-up tab at the top of the screen.

Remember that bringing food for the potluck is voluntary. We look forward to seeing you there!

The President's Corner | Jill Reid - Acting President, CPF & CSPSG



One of my favorite Bible verses is Proverbs 4:23: "Guard your heart above all else for it determines the course of your life." The Hebrew of the Bible is a very rich language, and each of its words and the letters that make up each word have upwards of 70 layers of meaning. That's because Hebrew only has 8,000 words whereas English has more than 400,000 words. So each Hebrew word has many meanings and nuances, and our translations cannot readily capture all that they mean.

A prime example is the word we translate as "heart," *lev* or *levav*. The Hebrew word for "heart" doesn't just describe emotions; it refers to our minds and thoughts and attitudes as well. Your *lev* is the center of your inner life. So what Proverbs 4:23 is commanding us is to choose wisely what feelings, thoughts, and attitudes we dwell on and claim as our own because THEY determine how we perceive the circumstances of our lives, how we react to them, and how we make the most of what we have. That's right—we choose **all** the thoughts, emotions, and attitudes that we have, whether we're aware of it or not, and our choices determine the course of our lives.

Obviously, none of us chooses to have a chronic disease. But we certainly get to choose how we deal with Parkinson's and our attitudes toward it. Psychologists tell us that negative attitudes harm us in many ways: degrading our health, stealing our joy, pushing away our friends, and even harming our loved ones' health by causing them great stress. So the person with Parkinson's who truly loves others as he loves himself will do everything in his power to approach his life with Parkinson's with a positive attitude that leaves no room for "woe is me." Yes, Parkinson's is tough—but it's even tougher when it's coupled with a ruling negative attitude.

If you value and love your spouse or primary caregiver for all the wonderful things he or she does for you, you're going to want that person around for your entire Parkinson's journey. If your attitude and approach to Parkinson's causes him or her high levels of stress, you may find yourself on your own when you need help the most. Don't shorten your caregiver's life by letting him or her do everything for you, by refusing to participate in the things you both enjoyed before Parkinson's, by isolating yourself from the world, by refusing to do the things that have been proven to slow significantly the progression of Parkinson's and keep you in the earlier stages (aerobic exercise), and by allowing apathy to rule your and your caregiver's lives. Choose to embrace **all** the things that will help your caregiver and yourself in your Parkinson's journey because you love unselfishly.

As the Proverb says, guard your thoughts, emotions, and attitudes against all things negative; choose instead life and life abundant.

Getting To Know You: Mike and Linda Koloski

My name is Mike Koloski and I have Parkinsons Disease. Linda, through fifty-six years of acquaintance, is my friend, confidante, wife, co-parent, and caregiver. We are newcomers to both the Colorado Springs area and this support group. The next few paragraphs are intended to let **you know** us.



In September of 2020 Linda and I relocated our home from Northeastern Oregon to Colorado Springs. In the ensuing months we have been caught up in the process of selling a home, packing, moving, buying, building, and establishing a new, functional household against the backdrop of "the pandemic". As you might imagine, this has been challenging! Only now, nearly a year and a half later, do they feel free from enough "must do" tasks, appointments, and time commitments to allow them to rejoin the Parkinson's Support Family.

Mike explains that since his diagnosis in 2008, "we have been involved in regional and local support groups in the Pacific Northwest. We attended the 2016 World Congress in Portland,

Oregon. We served as co-facilitators of our local support group in NE Oregon. We have participated in several monthly meetings of the CSPS Group, and feel very comfortable with people we have met. We look forward to **knowing** them better. To that end, I volunteered my time and services to Jill Reid and Julie Pfarer to revive the helpful practice of publishing short biographical articles that identify and introduce both new and established group members to their colleagues. Who better to begin with than the newcomers we **know** best. Ourselves.

Mike was born and raised in a very small town in Ohio. Linda was born and raised in a small town in Maine. Linda was the firstborn of seven. Mike has four siblings, three brothers and a sister. Both were successful through high school; graduating with valedictory/salutatorian honors. Mike was a four-year letterman in football. Moving on to college, Linda studied at Bates College in Lewiston, Maine, Mike entered the U. S. Coast Guard Academy in New London, Connecticut. Fate brought them together on a "blind date" at a Bates College Spring Weekend. In less than a year they married and began their life together.

That life turned out to be a challenging, yet enjoyable, series of adventures as they moved from coast to coast pursuing Mike's career as a Coast Guard Officer. All told, their 56-year acquaintance has embraced nine different locations, while living in fifteen individual homes. They have resided in Maine, Illinois, New Jersey, Alaska, Maryland, Virginia, Oregon, and Colorado. Their varied experiences include Home Economics, US Forest service, County administration, "Barbershop" singing, quilting, gardening for Linda. Mike was well occupied hunting, fishing, building, repairing,

fine art painting, and teaching.

Of all these adventures, parenthood is the one of which they are most proud. They were blessed with two sons who lead very successful lives. Andrew is a graduate of West Point and served our country over twenty-two years as a US Army officer. Thomas is a graduate of the US Naval Academy and retired as a Major in the US Marine Corps. Each chose an intelligent, capable, and resourceful woman to marry as a wife. Their union presented us with a total of four wonderful grandchildren! What more could anyone wish in a family?

Mr. Parkinson joined the "party" as a formally diagnosed ailment in 2008; Mike had just celebrated his 65th birthday. Initially a tremor and loss of olfactory sensation seemed more of a nuisance than genuine impairment. Gradually, however, over ensuing years, Parkinson's symptoms presented more and greater disabling challenges demanding attention and treatment. A process of disappointment, denial, anger, and finally acceptance became the routine as each new symptom asserted its presence. Mike and Linda responded with exercise, changes in work and leisure routines, and use of helpful medical appliances. They owe much to the many helpful, caring PWP's who have generously shared advice and guidance each step along the way. Their support ensured that although Mike has PD, PD does not have Mike and Linda. Mike and Linda encourage fellow PWP's to allow them to do for you as others have done for them.

Mike and Linda reside in an Accessory Dwelling Unit to Andrew and Kimberli Koloski's home at 580 Struthers Loop near the town of Monument. They welcome visitors there.

A CPF Charitable Giving Opportunity!

Another reminder about an easy and painless way for you to help CPF. An ongoing charitable giving opportunity each time you order merchandise from Amazon. It's called **Amazon Smile**. Colorado Parkinson Foundation (which includes CSPSG and all its other support groups) is listed with Amazon Smile as a charity that you can generate donations for. Rather than starting your Amazon shopping by pulling up **Amazon.com**, type in **SMILE.AMAZON.COM** instead.

The first time you do that you will have to designate Colorado Parkinson Foundation, Inc. as the recipient of charitable donations based on your purchases. From then on 0.5% of the eligible purchase prices you place through Amazon Smile will automatically generate donations from Amazon to CPF – at no cost to you!

(January 8th, 2022: Program Review)

Parkinson's 101

Presented by: Jill Reid, Educational Outreach

Jill Reid introduced herself as Acting Chairman of the Board of Directors of the Colorado Parkinson Foundation, Acting President of the Colorado Springs Parkinson's Support Group, Program Director for the support group and Education Outreach Coordinator. She helped take care of her mother, who was diagnosed with Parkinson's disease (PD) in 1993 and who went through all 5 stages of PD before her death. She also correctly diagnosed her mother-in-law with PD before any doctor did, and she helped with her caregiving as well. She has been an officer in the support group since 1995.

The goals of the presentation are to train the listeners on the do's and don'ts of caregiving for people with Parkinson's disease (PWWs), retrain listeners annually to update their knowledge as the disorder progresses, give information that the listeners can share with others, and give specific things that the listeners can do that will improve the quality of life of PWWs. At the end of the presentation, listeners will know more about Parkinson's disease than most doctors.

There are "new" things in PD: 1) a true diagnostic tool for PD that is available in Colorado Springs; called the DAT scan, it is usually used only when a neurologist has some doubts about whether a patient has PD. The classic ways of diagnosing are still used today most of the time. One of those ways is to try PD medication; if the patient's symptoms improve, he has PD; if they don't, he may still have PD but the medication doesn't work well for him. 2) Duopa. This is a new PD medication delivery system similar to an insulin pump. It does require surgery to insert a tube into the intestines and some hospital time to get the dosages right. There are three huge advantages to Duopa: the medication bypasses the stomach and goes directly into the intestines, so protein competition is no longer a problem (more on protein later) AND the medication is loaded only once a day AND there are no medication "on's" and "off's" because the PWP is getting a steady stream of PD meds (more on on's and off's later), which means the medication works all the time. However, we mention Duopa with major reservations because it has been fraught with infections. 3) Sleep Deep Brain Stimulus surgery. Until recent years, DBS surgery was done while the PWP was awake, a grueling 18-hour ordeal in some cases. Now, the surgery can be done in as little as 1 1/2 hours while the PWP is asleep. The new version is much more accurate as well, so the results are much better. DBS only helps the symptoms that the medication helps—it essentially replaces the need for the medications. It has helped with freezing, to some extent. Some people have experienced reduced vocalization after the surgery, but this reduction can be overcome by the wonderful voice therapies available for PD. 4) Free "Aware in Care" hospital kits. These are available, one to a family, through the National Parkinson Foundation (1-800-4PD-INFO or www.parkinson.org). The kit contains helpful information for hospital doctors, including the need for a PWP to get his medications on time, and an alert bracelet.

There are also helpful technologies available. Voice recognition software helps PWWs whose tremors make it difficult, if not impossible, to use a computer keyboard. Tremor-compensating eating utensils help the PWP use a fork or spoon without throwing food around the dining room. Modern cell phones have movement-compensating camera software enabling PWWs to take beautiful, blur-free photos. Lane Assist cars keep PWP drivers from straying out of their lane and from running up on the rear

bumper of the car in front; you don't have to buy a high-end car to get this feature. Lane Assist cars give the PWP and the spouse their freedom back! Theracycles provide forced exercise, which improves motor functions. Check out the report published by the Cleveland Clinic and entitled Forced, Not Voluntary, Exercise Improves Motor Function in Parkinson's Disease Patients, dated July 2009.

Many of the above items are relatively expensive, but there are some great inexpensive tools out there as well. These are plate rings, Hot Straws, and nosey cups. Plate rings fit around dinner plates and enable the PWP to push his food onto his fork or spoon. Hot Straws fit into the openings of Starbucks-type coffee cup lids, enabling the PWP to have a full drink without sloshing out the contents; they are made of thick silicone so they can be used with hot fluids as well as cold. The advantage to using a straw is it is a much safer way for a PWP to take liquids. The same can be said of nosey cups that we associate with toddlers; a PWP can drink fluids safely from these cups, minimizing the chance of the liquid's going into his lungs and causing aspiration pneumonia.

PD is a progressive neurological disorder caused by the loss of dopamine-producing cells in the substantia nigra deep within the brain. Dopamine allows the smooth, coordinated function of muscles and movement, and its loss adversely impacts movement and other roles of muscles in the body (e.g., intestines, bladders). By the time the first PD symptoms appear, 80% of a PWWs dopamine-producing cells have already died.

Dr. Brian Grabert (one of the best PD neurologists in Colorado) likens treating PD to treating diabetes (including self-medicating). Diabetics don't inject insulin on a schedule; they inject insulin when they need it. The same applies to PWWs; they need to give themselves permission to take their PD meds when they need them, not necessarily when a doctor says they should. Pill management is **KEY** to managing PD well and maximizing a patient's quality of life and longevity. More on medication management later.

The primary PD medication is carbidopa-levodopa (carbevo for short or Sinemet until it went generic as few years ago). PWWs need to be treated by a neurologist, PA, or Nurse Practitioner who specializes in Parkinson's. Those who don't specialize in PD don't have enough in-depth knowledge and experience, especially in medication management, to provide good treatment. Good medication management involves intervals between doses as opposed to scheduled pill times. More on intervals later. Providers who specialize in Parkinson's in Colorado Springs include PA Beth Harmon, NP Melinda McClendon (both of whom also do DBS programming), Dr. Adams, and Dr. Andrea Manhart.

[At this point was shown a video presentation by Dr. Melissa J. Nirenberg, MD, PhD, Associate Professor of Neurology and Neuroscience at Weill Cornell Medical College and Associate Director of the Parkinson's Disease and Movement Disorders Institute at Weill Cornell Medical College presentation to a Partners in Care conference. You can view this video by clicking on 'Resources' at the top of the main page of our website, select 'Meeting Videos' from the drop-down menu. Under 'Our Latest Video', click the play button on the bottom left corner of Dr. Nirenberg's video.]

PD's most common symptoms are stiffness, lack of facial expression, dystonia, resting tremor, slowness, difficulty with small movements, flexing of the

posture (exercise helps), and shuffling. The symptoms are asymmetric and are often mistaken for strokes when the time course is not known: stroke symptoms come on immediately while PD symptoms come on very slowly. There is a tendency for the medical field to fixate on the movement problems of PD, but in fact the non-motor symptoms may be more troublesome. These include sensory (pain and tingling), sleep disorders (REM sleep disorder which can start 20 years before any other symptom shows up, sleepiness, inability to sleep, sleep apnea), cognition (difficulty multi-tasking—PWWs should never try to do two things at once, including conversing and eating simultaneously—and dementia), autonomic symptoms (constipation is almost universal and can start years before other symptoms), hypotension, bladder problems, sexual dysfunction, mood (severe anxiety, panic attacks when meds wear off, apathy, depression; there are meds for all these except apathy), and fatigue. What you see is not all that is going on. The non-motor symptoms are treatable, some without medications (e.g., physical therapy).

Later on in the disorder, not early on, PWWs will look great when they go see their doctors but they aren't great. That's because PD fluctuates with "on's" and "off's." When the medications are working, PWWs look great, even to the extent of not looking like they have PD at all. But when the medications are not working well, they can be severely, severely disabled. So when they are getting ready to go to the doctors, they tend to make sure they've optimized their meds so that they can get out the door. PWWs need to be forthright with their doctors and tell them all the symptoms they experience when their meds are not working well; otherwise, the doctors have no way of knowing because the doctors are only seeing them at their best. The medication (carbidopa-levodopa) works differently from person to person and within a person from year to year so no doctor will know what a PWP needs unless the PWP tells him how the carbevo is working. For a week or two before all periodic appointments with a PD specialist, every PWP should keep a diary of when he takes his meds and how long they last until they start wearing off and take the diary to the appointment so the doctor will know how much carbevo to prescribe.

A myth of PD is that patients should wait until the last dose wears off before taking the next dose because "less is more." There is a fear of the medication. But in fact, if they wait until it wears off, it may not work very well for the rest of the day. They need to take the pill to anticipate the wearing off. The meds don't work very well if they miss a dose or take a dose late; if they crash completely, they will have difficulty getting back "on." Good timers are available on Amazon; they go off every, say, hour and a half all day long. Adherence without a timer is very difficult when a patient has to take his medications every hour.

Abnormal movements are not always from PD but from the medications. When patients have been on the medications for some time, particularly young onset patients, they get these abnormal, flowing movements as a side effect of the medication. These extra movements are called dyskinesia. If they have dyskinesia, they may need less levodopa or a longer interval between doses OR they don't have a happy medium and need to have the dyskinesia in order to be "on." Dyskinesia is usually not disabling unless it adversely affects balance.

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Recipe of the Month: Keto Pesto Deviled Eggs

Our low carb/good fat ketogenic study that was completed this past year showed incredible results. Not only was there remarkable improvement in the symptoms of Parkinson's but also with overall health in general (including the health of the caregivers who chose to change their diet along with their Parkinsonians). Since it seems clear that everyone's health would improve exponentially if we all changed our diet to eat this way and since we have potlucks, we thought we would feature an easy low carb/good fat recipe or two in the newsletter each month to promote healthy eating at our potlucks.

If you have a favorite low carb/good fat recipe you'd like to share, please send it to Julie at db_mgr@co-parkinson.org.

- Ingredients:
- 2 lightly packed cups fresh basil
 - 2 Tbl chopped macadamia nuts
 - 1 medium garlic clove, roughly chopped
 - Sea salt and pepper
 - ½ C olive oil, divided
 - ¼ C grated parmesan cheese
 - ¼ C grated pecorino cheese
 - 8 large eggs (makes enough filling for 12 eggs)
 - 1/3 C mayonnaise
 - 4 grape tomatoes, quartered (of 6 if 12 eggs)

Pesto: in food processor, combine basil, nuts, garlic, 1/8 tsp salt and ¼ C olive oil. Pulse until smooth. With machine slowly running, add remaining ¼ C olive oil and process until smooth. Add cheese, then pulse a few times to incorporate.

Hard boil the eggs. Steaming the eggs for 20 minutes rather than boiling them allows for easier egg peeling. Peel eggs and slice them in half lengthwise than remove yolks into medium bowl. Set egg whites aside. Mash egg yolks with a fork, then add mayonnaise, 6 Tbl of pesto, ¼ tsp salt and 1/8 tsp pepper and stir into a smooth paste.

Put into pastry bag or sandwich bag (snip off an end). Pipe into egg whites.

Garnish each egg with ¼ grape tomato and serve.

Other Local Support Groups:
Due to Coronavirus concerns, check ahead to see if canceled

Ladies w/ Parkinson's Support Group

The leader of this support group, Carla, is stepping down. The group meets once a month to do various fun activities such as lunch, crafting, baking, etc. If you are a fun-idea person and would like to make sure that this group that has been so valuable to its members continues, please consider volunteering to lead the group.

If you're interested please notify Julie Pfarrer at db_mgr@co-parkinson.org or [redacted].

Tri-Lakes Parkinson's Support Group

Meets the 3rd Saturday of every month at 10 am at the Monument Community Presbyterian Church, 238 3rd Street, Monument. For more information contact Barry Hanenburg at [redacted] or

Syble Krafft at [redacted].

Parkinson's Caregivers Support Group

All family caregivers of persons with Parkinson's are invited to come and participate in our discussion meetings.

We meet the 3rd Thursday of each month from 10:00 to 12:00 at New Life Church Midtown 3985 N. Academy Blvd., Suite 103, Academy & Austin Bluffs. Contact Brenda Hicks at [redacted] or [redacted].

to let her know you are coming.

Essential Tremor Support Group

Meeting Location: ENT Conference Room Pikes Peak Library District, Colorado Springs Library 21c, 1175 Chapel Hills Drive.

For meeting dates/times or for questions, contact Jim Sanchez at [redacted].

Other Opportunities:

Due to Coronavirus concerns, check ahead to see if canceled

Adult Speech Therapy at Home

Outpatient speech therapy services conducted in the comfort of the patient's home. Personalized speech therapy for restoration of function due to illness or injury.

Treating:

- Parkinson's: Voice & Swallowing*
- SPEAK OUT!
 - LSVT, an evidenced based voice treatment program designed for Parkinson's patients

Swallowing

- Neuromuscular Electrical Stimulation Therapy
- Respiratory Muscle Strength Training
- Aphasia following stroke
- Cognitive-Linguistic Deficits

For more info, contact Jana Hothan, MA, CCC-SLP at slp@janahothan.com or by phone at (719) 338-8165.

Parkinson's Sing-a-Long Group

No music experience necessary!

Join board certified music therapist, Heather Johnson, every Monday at 1 pm as we participate in group singing focused on improving breath control, strengthening of the throat muscles, and improving voice control, volume, and quality!

Parkinson's Sing-a-Long is held at Square Music Co located at 2332 Vickers Drive in Colorado Springs.

An online participation option is available as well.

Square Music Co also offers individual music therapy to work towards motor movement goals along with the voice qualities listed above.

For more information or to sign up, please email heather@squaremusic.co or call/text 719-345-2887.

Thank You!

Thanks to ALL who brought food and to those that helped set up & clean-up at the last meeting!



Jan Atha
Amy Carrico
Elaine Ceagne
Jerry Donley
Laura Hallas
Deborah Herrman
Gene Ireland

Ann Jaeger
Linda Koloski
Dale Kraiss
Cindy Page
Ann Ringler
Timothy Stuehmeyer
Jessica Useman

February Executive Committee Meetings

February 15th at 11:00 a.m. | Location: Place to be determined (you will be notified by email)

Contact Jill at president@co-parkinson.org if you haven't been to an Executive Meeting so we will know that you're coming. Leave your email address so Jill can contact you if anything changes.

March Newsletter Input Deadline: February 16th

Call or e-mail Julie at:

db_mgr@co-parkinson.org.

LENDING LOCKER INVENTORY

Note: a stair chair lift system has been donated to us. It's a seat on a rail that takes you up & down a staircase. This one is for a 14 step or less straight staircase with no turns.

If you would like to borrow any of the equipment listed here, please contact: Rich Sauvain at [redacted].

| | | | | | | | |
|----------------------------|---|--|---|-------------------------|---|------------------------------|---|
| 3 Wheeled Walker | 1 | Black Back Brace | 1 | Knee Splint | 1 | Suction Cup Hand Rail | 1 |
| Arm Assist for Wheelchairs | 1 | Canes | 5 | Lift Chair | 1 | Tub Rail | 1 |
| Arm Splint | 1 | Chair/Sofa Cane | 1 | Lumbar Traction Belt | 1 | Transport Chairs | 4 |
| Bed Cane | 3 | Crutches | 2 | Pickup Assist | 5 | U-Step | 2 |
| Bedpan | 1 | Exercise Bike | 1 | Raised Toilet Seats | 4 | Voice Amplifier | 2 |
| Bed Rails | 1 | Hospital Bed | 2 | Shower Benches/ Chairs | 9 | Walkers with Wheels and Seat | 9 |
| Bedside Toilet | 5 | Ice Man - therapeutic for knee replacement surgery | 1 | Stair Chair Lift System | 1 | Wheelchairs | 6 |
| | | | | Stand-up Walker | 1 | | |

PD Exercise Classes: Due to Coronavirus concerns, check ahead to see if canceled

Dance for Parkinson's

Moving with joy, creativity, and community to support people living with Parkinson's.

All are welcome and care partners are encouraged to move with us!

Classes meet in person every Friday at 11:00 am at Ormao Dance Company, 10 S. Spruce Street \$5/class. Free for care partners.

You can also join us for this class online. Visit our website www.ormaodance.org and click on "Dance for Parkinson's" under the "Outreach" tab to get the Zoom link.

Questions: Contact Laura at laura.hymers@gmail.com or 719-640-8478.

Max Capacity NeuroFitness

is offering PWR Boot Camp classes, donation based Power Punch Boxing, pole walking classes and individual PD specific fitness training.

NEW LOCATION: 525 E. Fountain Blvd. Suite 150. Park on the S. Royer side of the building.

Boxing: Tues/Thur – 4:00 to 5:00pm and Sat – 9:00am to 10:00am

PWR Boot Camp: Mon/Wed – 3:30pm to 4:30pm

Boxing is free of charge, Boot Camp packages available! Contact Emily Moncheski at (719) 213-3996 or emily@maxcapacitypt.com for info.

YMCA PD Exercise Classes

We utilize exercise as medicine to increase quality of life so that you can get better and stay better.

NOTE: All classes have been suspended except the following:

Tri-Lakes YMCA: PWR!Moves Tuesday & Thursday, 1:30-2:30 PM

Briargate YMCA: PWR!Moves Monday, Wednesday & Friday, 1:30-2:30 PM

For more information contact Jamie Clayton at jclayton@ppymca.org

UCCS Center for Active Living - at the Lane Center

Power Moves group exercise and Balance & Agility classes.

For more information call (719) 255-8004 or email CAL@uccs.edu.

PWR!Moves Class

Skyline Wellness & Aquatics Center is partnering with the YMCA to help the PWR! Moves class be more available to everyone. We are reaching out to help individuals who may be located on the south side of town and need a closer location to their home.

We are located within Brookdale Skyline at 2365 Patriot Heights near Bear Creek Dog Park. Our classes are held every Tuesday and Thursday from 12:30-1:30 pm.

If you have any questions, please contact the Fitness Coordinator Karisa Dreyer at (719) 867-4658

PWP: Parkinson's With Poles

Come join Emily Moncheski and Eileen O'Reilly for a great exercise workout at Monument Valley Park.

Every Friday, 9 am at the north parking entrance of Fontanero and Culebra streets. Poles are provided.

Everyone is welcome.

NIA Class

Moving to Heal – the art of feeling better; slower movements with joy and purpose. NIA works with balance, breath, cognitive mind/body function, mobility and stability. You can go at your own pace. Stop if you want, sit down and dance while sitting in a chair for a while. All while dancing to music from all genres; Jane, the instructor, often asks what we need that day and works her routine around what can help. She has done a wonderful job making the routines fit our Parkinson's needs.

When: Every Friday at 10:30

Location: 525 East Fountain Blvd.

MACS–corner of Fountain & Royer

Cost: \$10.00 a class.

Falcon Exercise Group

Mon and Fri –11:00 – 12:00 noon, Grace Community Church.

For more information contact Catherine Reed at [REDACTED]

Coronavirus and Parkinson's Disease

For information on coronavirus and Parkinson's Disease go to: www.parkinson.org/CoronaVirus.

NeuroRehab Project at ORA Water and Movement Classes

Note: We were told that these classes have been discontinued, check ahead to see if canceled.

Improve your mobility in the water:

We offer warm water (92 degrees) pool classes for people with movement disorders. Mondays and Wednesdays from 1:30-2:30. \$10.

Parkinson's Wellness Recovery Exercise Class:

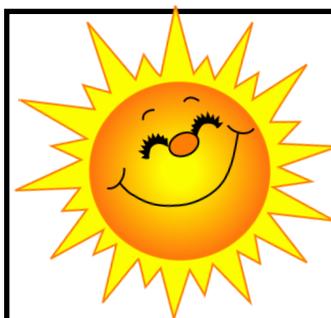
Power Moderate level. Fri at 1:30. \$10

Parkinson's Wellness Recovery Exercise Class:

Power Advanced level. Wed at 1:30. \$10.

Danielle Spivey, PT and Rachel Johnson, SLP have created these opportunities to augment skilled Physical and Speech Therapy.

Location: Pikes Peak Athletics, 602 Elkton Drive in Rockrimmon. Please call us at (719) 559-0680 for information and to get signed up.



Help us spread some sunshine to our members!

If you know of a Parkinsonian or PD caregiver that is having a tough time (illness, surgery) or one of our members has passed away, please let our Sunshine Chairman, Sharon Carlson, know.

Sharon can be reached by calling [REDACTED]

Many patients aren't aware that they are dyskinetic. These are not tremors and should not be mistaken for the rhythmic shaking that is a classic symptom of PD.

Another major problem is that everyone ascribes every problem that a PWP has to Parkinson's. You always have to apply common sense and consider what else may be the cause of the problem. One example is sudden severe back pain and leg weakness; PD is slow moving and does not cause weakness. The sudden appearance of a problem means that something else is wrong, even if the only symptoms appearing are the sudden worsening of the patient's PD symptoms. PD is NEVER fast. If it's fast, something else is going on. One of the most common culprits is urinary tract infections.

Another myth of PD is that carblevo stops working after five years. There is no truth to this whatsoever. The stuff is good stuff. As PD progresses and symptoms worsen and new ones that don't respond to carblevo appear, it may look like the carblevo has stopped working, but it has not stopped and will not stop working. It has no expiration date, and it improves the quality of life.

Another myth of PD is that it is predictable. The truth is that it is a different disease in each patient, and every patient progresses differently. PD progression is highly variable. But there are many things that you can do to change that course; and that's where physical therapists and occupational therapists can make a tremendous difference.

Walker myths. Most walkers, including rollators with standard brakes and the light-weight aluminum walkers you see in hospitals, are no good for PWP's. Only rollator walkers that have reverse braking systems are safe for PWP's. These walkers require the user to squeeze the brake handles in order for the walker to move; releasing the brake handles applies the brakes. When a PWP is about to fall, it is unlikely he will think to squeeze the brake handles on standard braking systems; however, if he is falling and without thinking lets go of the reverse brake handles, the walker stops. There are two companies that make the reverse-brake walkers specifically for Parkinson's. U-Step is one of the companies, and their walkers can also be weighted properly to prevent backwards and sideways falls. [end of Dr. Nirenberg's presentation]

There are 5 classic stages of PD. Listeners may need to be able to distinguish Stage 1 from the other stages and may also be able to spot someone who has PD and doesn't know it. Pill management becomes critical starting in Stage 2. **The later stages of PD can be avoided!!!**

Stage 1: Most newly diagnosed PWP's are in Stage 1 and may or not be prescribed carblevo. Adhering to a hard and fast carblevo schedule is not as important as it is later because PWP's in Stage 1 don't experience the swings between "on" and "off." Still, it's best to keep as close as possible to a medication schedule that works for them because it makes the Activities of Daily Living (e.g., dressing, brushing teeth) easier.

Stage 1 symptoms appear on only one side of the body. Some or possibly all of the following could appear: greatly reduced eye blinks (8-12 per minute), tired arm or leg muscle, one arm that doesn't swing, stiffness, difficulty getting out of a chair, slight stooping, tremors, reduced fine motor skills (e.g., handwriting gets smaller), slightly dragging foot. They can still turn and pivot well, have a normal stride, and rarely, if ever, fall. Why is getting out of a chair a problem? That's because PWP's place their feet well out in front when they are seated and they don't move them back when they try to stand up. More on how to counter this problem later.

Stage 2: The symptoms that were seen in Stage 1 will now be on both sides of the body, and they will

be worse than before on the original side. In addition, there could be some additional symptoms, such as shorter gait, balance problems with occasional falls, choking, difficulty pivoting, reduced motor skills, cognitive issues. Good medication management is **critical** now. The goal of good medication management is to have one big "on" period that lasts all day, with no "off" periods. To achieve this goal, PWP's should take the next dose of carblevo before the previous one wears off. Time between pills is more important than scheduled times. For example, if a PWP normally takes his first dose at 7 a.m. and his second one at 10 a.m. but he sleeps in one day and takes his first dose at 8 a.m., he should take his next dose at 11 a.m., not at 10 a.m. (Hint: Run quickly from any PD "specialist" who insists that carblevo has to be taken at specific times and find a PD specialist who understands intervals and good medication management!) If PD symptoms appear regularly between doses, the schedule needs to be adjusted; keep a log as recommended in Dr. Nirenberg's presentation. PWP's can adjust the schedule themselves and inform the PD specialist later for a new prescription but in any case, take the log to the next appointment with the PD specialist.

Stage 3. **This stage can be avoided!** The symptoms from Stage 2 will be worse and there will likely be new ones, such as shuffling, festination, more slowness and stiffness, less stability with more frequent falls, difficulty pivoting without help or coaching, and freezing. The PWP may need a walker in this stage.

Festination is the tendency for a PWP to start taking short, fast steps on their toes. Left unstopped, festination can end in a fall. Caregivers can nip a festination episode in the bud by physically stopping the forward motion and getting the PWP to get off their toes and onto their heels. Then coach the PWP to "walk on your heels."

Freezing occurs when the feet won't start from a standstill or they stop moving without warning. In both cases, the brain is telling the feet to walk but the message is not getting through. When the feet stop moving without warning, the brain thinks the feet are walking and the rest of the body keeps moving forward, which of course ends in a fall. This often happens in narrow areas like doorways. There is no medication for freezing because it is actually a psychological phenomenon, not a physical one. It can be overcome by changing the PWP's mindset, for example getting the PWP to pick up his knees instead of his feet, to step up like he's climbing stairs, to step over an imaginary log, to follow a flashlight beam on the floor. Marching music helps as well, as do strips of colored tape across narrow areas; the strips of tape and the flashlight beam give the PWP something to aim for. There are also exercises that can help (more on that later). Freezing can also result from fear, which is why going up stairs is easy for PWP's but going down stairs is very difficult. **Never** pull or push a PWP who is freezing—support him and coach him to change his mindset to get him moving. Also, if he is using a walker, make sure he keeps the walker close to his body and not pushed out in front of him.

Stage 4. **This stage can be avoided!** Stage 3 symptoms will be worse. The PWP will likely not be able to walk with a walker. Pivoting will be extremely difficult if not impossible. He will freeze a lot and probably won't be able to get out of chairs without help. There will be lots of falls and lots of choking.

Stage 5. **This stage can be avoided!** PWP's in Stage 5 will be wheel-chair bound and/or bedridden. They cannot swallow safely so they will have to take all food, fluids, and medications through feeding tubes.

Medication management. Good medication management gets more critical as PD progresses because the brain produces less and less dopa-

mine. It is most critical in Stage 5, even though use of the limbs is practically non-existent. **Other muscles are critical to survival:** diaphragms and chest walls for breathing and coughing, throat muscles for swallowing saliva safely, intestines, and bladders. Most PWP's die from aspirations pneumonia and bowel blockages resulting from poor pill management. Medication schedule will most likely be dependent on observations by others for a PWP in Stage 5 because he won't be able to speak for himself.

Self-medicating. No one knows why, but the normal carblevo dose isn't always sufficient. It's OK for PWP's to take extra carblevo (say ½ or 1 pill) if needed. Like diabetics with insulin, they can take what they need when they need it.

Protein vs carblevo. Protein and carblevo compete for absorption and uptake into the brain, and protein wins out every time. The solution to this problem is to avoid eating protein within one hour of taking carblevo OR to take extra carblevo if the hour interval can't be met. Another solution is to avoid all proteins until dinner time since the need to be "on" and mobile is less critical at night. Generally, PWP's don't need carblevo during sleep because PD symptoms go away. Beware! Protein is in a lot of foods and drinks!

On the other hand, protein can be a useful tool for those times when a PWP has too much levodopa in his system. Excessive levodopa causes excessive, unwanted movements or talking; these are known as dyskinesia (if you've seen Michael J. Fox doing interviews in recent years, you will have seen dyskinesia). A few bites of cheese or some meat, milk, or ice cream will "kill off" excess levodopa and get the dyskinesia under control. If a PWP experiences dyskinesia regularly, he probably needs to cut back on his carblevo dose or extend the time between pills. Unfortunately, some people need to be dyskinetic in order to be "on."

Carblevo and nausea. Nausea is a fairly common side effect of levodopa. The levodopa portion of carblevo is the dopamine replacement while the carbidopa portion is an anti-nausea drug. The amount of carbidopa in carblevo is not enough for some people. Carbidopa can be prescribed separately. If separate carbidopa is not available, eating saltines or other non-protein foods before taking carblevo helps.

Constipation. Per Dr. Nirenberg, constipation is almost universal in PD. This is not a trivial matter; bowel blockages are the second leading cause of death in PWP's. High-fiber food, good hydration, Miralax (it works well and has no addictive side effects), vigorous aerobic exercise, and Metamucil wafers all help. Our own Greg Ritscher's book, [Rising Above Parkinson's](#), has a recipe for a fruit paste that works well for him; see page 183.

PD and choking. Choking effects all PWP's sooner or later. The throat muscles react too slowly to direct food or liquid into the esophagus; they end up going down the windpipe and into the lungs instead. This can lead to aspiration pneumonia, the leading cause of death for PWP's. There are several solutions. Tucking the chin against the neck when swallowing directs the food or liquids to the right place. Add thickening to fluids, especially water, the thinnest and therefore the most dangerous of all fluids. Suck on ice cubes to get hydrated; the cold ice triggers the throat muscles to work quickly. Grind up pills and put in apple sauce, apple butter, honey, or jam. Be sure NOT to grind an Extended Release or Continuous Release carblevo.

Effects of PD on vision. PD can effect vision in a number of ways, including dry eyes, double vision, fatigue, and difficulty reading. Neuro-ophthalmologists and optometrists such as the ones at the UHealth Eye Center Anschutz in Aurora can treat the effects of PD on vision. Proper

diagnosis of the precise vision problems can lead to the restoration of normal vision.

Helpful Hints

Hospitals. Hospitals are very dangerous places for PWP's. Our website currently lists two safe hospitals in Colorado Springs. Even if a PWP goes to one of those, he MUST have a strong advocate to fight for him while in the hospital's care. Every PWP should name a person or persons you trust your Medical Durable Power of Attorney so that they can protect you if you can't speak for yourself. An MDPOA comes into effect when you can no longer communicate for yourself and has all the same medical rights on your behalf that you have for yourself. Going to a hospital without an MDPOA in place is putting your very life at risk. Also be aware that if you're released from a hospital but come back for a second visit for the same (unresolved) issue, the hospital will get penalized and will try to avoid penalties by getting you to sign a form consenting to observation only; DON'T SIGN IT or you'll get billed for the second visit. They may even leave you in the waiting room, even if you're in severe pain, to avoid the penalties of a second visit.

Attitude and activities. Humor is huge for PWP's. Laughter releases dopamine as well as endorphins and boosts mood. Watch funny shows and movies instead of serious ones. PWP's in all stages benefit from activities such as exercise, socialization, and participation in life-long interests. One of our members took up oil painting and found that his tremors completely disappeared while he painted; as an extra plus, his works were beautiful and art-gallery worthy.

PD and exercise. Exercise that involves vigorous movement is VITAL and is the only thing proven in double-blind studies to slow and even reverse the progression of the disease. A former member, Barbara, was a professional ballerina before she was diagnosed with PD. By the time she joined our group, she was in Stage 3 of PD and used a hot pink walker. Many years after she had stopped dancing because of PD, she saw herself in a plate glass window and was shocked at how stiff she looked; so she took up dancing again and went from Stage 3 to Stage 1! She even donated us her walker that she no longer needed! Here are some other movement exercises that can slow the progression of PD: walking, hiking, stationary biking, water aerobics, ping pong, moving to music (dancing), rowing, movement exercises in a chair (for safety), boxing, Power Moves. Be sure to get your heart rate up for 30 minutes 3-5 times a week. Resistance exercises (e.g., weight lifting) improves fine motor skills. Wii Sports is exercise that's fun; it even includes balance exercises and games. The old adage, "Use it or lose it," applies to balance. Stretching and tai chi are also helpful.

Walkers. In addition to the U-Step that Dr. Nirenberg advocates, another interesting walker to think about is an upright walker. The advantage it offers is that the user is completely upright and not bent over as he would be on all other walkers. Bending over and leaning forward on lower walkers often results in festination (walking on toes while taking small, quick steps), which needs to be avoided at all costs. Here are pictures of both the U-Step walker specially designed for PWP's and an upright walker.



U-Step Walker



Upright Walker

Exercises that reduce freezing. Bicycling of any sort reduces freezing. Floor-mounted pedals that have no resistance even work because it's the cycling motion that reduces the freezing. If freezing is an issue, you should do this exercise daily. Below are two other exercise that help:

- Stand on right leg
- Lift left foot and raise right arm
- Lower both
- Do 5-10 times
- Repeat with other leg
- Alternate legs 5-10 times



- Stand on left leg
- Put right leg back
- Swing right leg forward
- Touch ground
- Swing right leg back
- Repeat with other leg
- Alternate legs 5-10 times



Touch therapy. Anecdotal evidence about touch therapy (for example, deep tissue massage) has shown that it doesn't raise dopamine levels but can relieve some PD symptoms; improves blood circulation, flexibility, and range of motion; reduces tremors and eases cramping of fingers and toes; and helps PWP's walk better, farther, and more often.

Additional therapies to consider. Treating PD takes a team, so consider adding alternate therapies to your arsenal in addition to medication, PT, OT, LSVT Big and Loud, and exercise. Here are some complementary therapies: massage, vitamins, acupuncture, chiropractic, and the Alexander Technique.

Socialization. Encourage PWP's to socialize. PWP's tend to isolate themselves to avoid the discomforts and embarrassment of being in public with their symptoms showing. PWP's can avoid this discomfort by optimizing their medications and being well-exercised. Studies have shown that a shrinking social network has the same negative impact on health and longevity as taking up a two-pack a day smoking habit. Involve PWP's in as many activities as possible. Cooking meals with the help of Blue Apron or Hello Fresh stimulates the mind and uses fine motor skills. Card games and other board games also exercise the mind and dexterity. Parties and other get-togethers can be non-threatening with a little creativity, like not serving thin liquids and difficult foods and offering finger foods. Sing-alongs with friends provide wonderful vocal exercise; PWP's tend to speak softly and singing is actually excellent therapy to overcome soft voices that no one can hear. The Colorado Springs Senior Center offers excellent programs and activities. Time activities and exercise according to when the PWP is at his best, usually in the afternoons.

Safety. In-home safety is key. Remove trip hazards like throw rugs. Widen narrow openings between pieces of furniture, if possible. Some companies have received grants to add safety features like grab bars and to widen doorways for little or no cost.

Low blood pressure. Hypotension is common amongst PWP's. Taking salt pills is a good solution if there are no other health issues that would make the salt pills dangerous. Eating something salty also helps. There are blood pressure-boosting medications if these non-medical interventions aren't sufficient. Florinef is very effective but requires doctor-supervised potassium supplementation.

Creative solutions. Observe what things cause

problems and find creative solutions for them. For example, stuff your change into pockets rather than your wallet after purchases. Serve mashed potatoes with peas or corn; this keeps the peas or corn from flying around the room. Drink soup through a Hot Straw. Effective solutions to problems take the stress out of the situation, decrease embarrassment, and keep PD medications working (stress kills off carbrlevo).

Coddling. Don't coddle a PWP. Let him do for himself all that he can. Many PWP's have apathy and will let you do everything if you offer to step in—if you do, you will only accelerate his inability to do things for himself. It's very tempting to step in because it's so much faster but RESIST RESIST RESIST! If necessary, have him start getting ready for appointments and outings two or three hours early so you don't have to step in in order to get out the door on time.

Rushing. Help PWP's avoid rushing at all costs. Rushing is a form of stress and will actually cause the medications to stop working, the symptoms to get worse, and frustration to mount. Rushing brings on the exact opposite of what you're trying to accomplish—it slows him down!

Apathy. There is no medical treatment available. Use inspiration or persuasion. I advocate using brow beating and guilt! I know that sounds terrible, but you caregivers need your PWP's out there doing everything they can to slow the progression of the disease for YOUR sake if not for theirs. So if it's effective, lay on the guilt trips so that you as a caregiver don't burn out!

Timing. Exercise and participate in activities when your meds are working well. That varies from person to person and from day to day.

Getting out of chairs. Scoot to the edge of the chair. Put both feet as far under you as the chair allows and keep them shoulder-width apart. One foot can be slightly in front of the other. Bend at the hips until your nose is "over your toes." Place both hands on the chair seat or arms. Push with your hands and stand up. Caregivers, you may need to coach your PWP each time he tries to get out of a chair.

Constipation. In addition to the hints already given, a Squatty Potty is an inexpensive tool to help overcome constipation. It helps straighten the intestines to ease the passage of the BM without straining. Straining can dangerously raise blood pressure.

Support groups. Caregivers, encourage your PWP's to attend our support group meeting, where they will be with other PWP's who completely understand their PD issues. They can learn from others how they have solved PD problems and can be inspired and encouraged to see others who are living well with PD, even decades after diagnosis.

PWP's, encourage your family members and other caregivers to come to our support group meetings—the more they know, the better for everyone!

The Colorado Springs Parkinson's Support Group is an all-volunteer organization striving to improve the quality of life of our members through socializing, sharing knowledge and information, giving each other emotional support, and training professional caregivers. The group provides reimbursement for transportation to our meetings if needed. We meet currently in Fellowship Hall of the First United Methodist Church 420 N Nevada Ave on the second Saturday of each month from 10 am to around noon. Meetings include guest speakers and great potluck lunches. In August, we have a picnic in lieu of a meeting. The support group also provides an extremely informative free monthly newsletter.

See our website, www.co-parkinson.org, for links to other helpful websites and youtube presentations.

One last thought: positive attitudes and humor help everyone!

Colorado Parkinson Foundation, Inc.

1155 Kelly Johnson Blvd.

Suite # 111

Colorado Springs, CO 80920

Parkinson's Perspective

FEBRUARY 2022

Coming Events

See Inside for More Information

(Current location for all meetings listed below is the First United Methodist Church with the exception of the August Picnic)

February 12th: Reg Mtg – 10 am; **Program:** Results of the 24 week CPF Study on the effects of a low-carb/healthy fat diet on PD, biomarkers, depression, anxiety & quality of life; **Speaker:** Melanie Tidman DHSc, M.A., OTR/L, MHP

March 12th: Reg Mtg–10 am; **Program:** Breakout Sessions

Moderators: Steve Locke–Parkinsonians; Jill Reid & Julie Pfarrer–Caregivers

April 9th: Reg Mtg–10 am; **Program:** Wealth Preservation & Planning for Long Term Care

Speaker: Kim Searles, Beneficent - LTC Consulting Group

May 14th: Reg Mtg–10 am; **Program:** Results of the CPF Phenomenological Study of Wives Caring for their Husbands with Parkinson's Disease. **Speaker:** Dawn White, PhD, RT (R)

June 11th: Reg Mtg – 10 am; **Program:** TBD

July 9th: Reg Mtg–10 am; **Program:** Breakout Sessions;

Moderators: Steve Locke–Parkinsonians; Jill Reid & Julie Pfarrer–Caregivers

August 13th: 11 am; Picnic at John Venezia Park!!!!!!

More useful websites: <https://parkinsonsnewstoday.com>; www.parkinsonrockies.org; www.parkinson.org; www.nwpcf.org; michaeljfoxfoundation.org; www.parkinsonheartland.org; <https://www.pdself.org>; <https://www.brainhq.com/world-class-science/published-research/active-study>; www.davisphinneyfoundation.org/living-pd/webinar/videos/cognitive-nonmotor-symptoms-parkinsons; <http://caremap.parkinson.org>; https://www.youtube.com/playlist?list=PLkPIhQnN7cN6dAJZ5K5zQzY84btUTLo_C; <https://www.michaeljfox.org/foundation/news-detail.php?self-care-tips-for-parkinson-disease-caregivers>; pmdalliance.org