

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
10AM, the first Saturday of each month
at the Central United Methodist Church,
4373 Galley Rd, Colo Spgs, 80915

(with exceptions to be noted
in this newsletter)

July Meeting: Saturday, **July 1st** – 10:00 am – 1:30 pm

We will be Zooming and recording this meeting

Location: Central United Methodist Church, 4373 Galley Road—just east of Murray Blvd.

9:30am – 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.

9:45am – Everyone else come 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 Central United Methodist Church.

July Program: Scam Prevention

Speaker: Scott Mathis, Colorado Springs Police Department

Scams are largely targeted to us, the older generation. Many scammers are very clever and have convincing approaches to get us to hand over money or our financial information. Older people lose millions of dollars to scammers each year. How do we know when a scammer is making a move on us? Come to the July meeting and find out. Officer Scott Mathis from the Colorado Springs Police Department's Scam Prevention section will teach us how to protect ourselves from these vicious and hard-core criminals.

The program will be followed by a potluck.

The July Potluck—Salads!

Such as pasta, potato, fruit and green salads

If you would like to sign up to be one of the providers of a main dish or a side dish/dessert for the July meeting, you can contact Bill Hicks at [REDACTED] or potluck@co-parkinson.org, no later than Wed. June 28th and tell him what you would like to bring.

Remember that bringing food for the potluck is voluntary.

We look forward to seeing you there!

SAVE THE DATE: SUMMER PICNIC - SATURDAY, AUGUST 5th 11am - 1pm



Our annual summer picnic will be August 5th at Venezia Park at the corner of Union Blvd and Briargate Parkway. Look for three large pavilions with green roofs. The BUNKHOUSE pavilion is the far left pavilion. There is a parking lot next to that pavilion (on the west side of the park) but you will have to climb a ramp because that parking lot is down a hill from the pavilion. The main parking lot next to the restrooms (east of the pavilions) is also available but you have to walk a little further past the first 2 pavilions to get to the BUNKHOUSE.

Directions to Venezia Park:

- From I-25 take the Briargate Parkway exit. Go east on Briargate Parkway where there will be the entrance on the right to the first parking lot that is next to the Bunkhouse Pavilion. A second entrance off of Briargate Parkway takes you to the parking lot that is east of the pavilions, or you can go all the way to Union, turn right and follow the "From Union Blvd.," directions.



- From Union Blvd., turn west at the light at Family Place into the park (across from the King Soopers). Wind around until you see the windmill and the large pavilions with the green roofs. The easiest parking lot is the one to the right (east, next to the HOUSE pavilion) – no inclines or ramps.

SEE MORE SUMMER PICNIC INFO ON PAGE 2 ⇨⇨⇨⇨

Summer Picnic – Saturday, August 5th, 11am – 1pm

There is another parking lot on the west side of the 3 large pavilions next to the BUNKHOUSE pavilion but you have to navigate an incline (ramp) to reach the pavilions. Main Dish – your choice of fried or baked chicken & water will be furnished. If you would like to drink something else, please bring your own.

In order to assure that we have a good variety of side dishes, Bill would like for you to let him know what you're bringing to the picnic by contacting him at [REDACTED] or potluck@co-parkinson.org.

Attire – if you own one, wear your 'safety green' (actually neon yellow) Parkinson's shirts so we stand out in the crowd by

'glowing'. If not, wear whatever Parkinson's Support Group apparel you might have, or wear something comfortable.

There are picnic tables with seats furnished but you're welcome to bring a lawn chair.

If you would like to help set up or clean up, please contact:

Carole Henrichsen
[REDACTED]

Janet Adams
[REDACTED]

The President's Corner

| Jill Reid - Acting President, CPF & CSPSG



As a reminder, starting with our June meeting, we will meet at the Fellowship Hall of Central United Methodist Church located at 4373 Galley Road, just east of Murray Blvd. The church is on the south side of Galley Road, between a strip mall to the west and an Ent Federal Credit Union building to the east. The parking lot and the front door are on the south side of the church. Fellowship Hall is the first room on the left when you walk through the main front door, making it a much shorter walk than we've had in recent times. There is a second big change starting

with the June meeting: we will have to meet on the FIRST Saturday of each month, rather than the second, since our new home is already fully booked on the second Saturday. Starting with our June meeting, we will meet in our new home and on a new Saturday: Central United Methodist Church at 10 am on the first Saturday of the month (July 1st for our next meeting). If you lose this newsletter, remember to check out our website, co-parkinson.org, for these same details.

And speaking of our new meeting place, I heard positive feedback from

those who attended our first meeting there. The shorter walk from the parking lot to Fellowship Hall got rave reviews. Brenda and Bill Hicks and the wonderful women who help them are very happy with the kitchen and its equipment. Except for reliable WIFI, this Fellowship Hall has everything we have come to need in a meeting place: large round tables that seat eight each; an electric-powered projection screen that drops with the flick of a switch; good acoustics for the room's sound system as well as for our portable sound system; plenty of side tables for check-in, displays, literature, and food; a flexible and helpful facilities manager, John Cox; nearby restrooms equipped with grab bars; a conveniently-located kitchen; and something we've never had before—a room that can expand in size, should we need it to. The initial impression is that we've found the perfect home for our monthly meetings. If you didn't attend the June meeting, be sure to join us on the first of July so that you can check out our very comfortable new home.

This month, I have **two** recommendations for comedy movies: Grumpy Old Men and Grumpier Old Men, both starring Walter Mathau and Jack Lemmon. Both movies also star Ann-Margret as the love interest while Grumpier Old Men adds Sophia Loren to the mix. Sequels don't always live up to their originals, but in this case, the sequel may be the better of the two! You be the judge. Enjoy!

HAPPY JULY BIRTHDAYS!

| | |
|---------------------|-------------------|
| Jyl Alexander | Brenda Jensen |
| Calvin Anderson | Gary Jensen |
| Tim Binkley | Heather Johnson |
| Gary Bradley | Louise Maestas |
| Brian Carlson | Vern McDonnell |
| Sally Clark | Patricia Meredith |
| Mala Cobey | Ruth Modaff |
| Andy de Naray | Debbie Nelson |
| Shelly Fly | Beverly Noe |
| Shirley Gloss-Soler | Julie Pfarrer |
| Rex Helmsing | Lorraine Scott |
| John Henricks | Steve Telatnik |
| Deloies Heyliger | |



Your birthday isn't listed?
Fill out the membership form and
check BD listed "YES".

HAPPY AUGUST BIRTHDAYS!

| | | |
|------------------------|--------------------|-----------------|
| Kathy Ader | Reva Epler | Lil Ray |
| Bethany Andreen-Bailey | June Essing | Catherine Reed |
| Randall Austin | Larry Grubaugh | Mark Ruport |
| Allen Beauchamp | Lorraine Helminski | Alfredo Serrano |
| Charles Bogues | Sonya Hero | Mary Taylor |
| Sharon Carlson | Roger Hill | Bruce Terrell |
| Barbara Carr | Andrea Joiner | MJ Thompson |
| James Coen | Lowell Kayser | Ron Thompson |
| Marc Collins | Michael Lippincott | Laura Torgerson |
| Larry Costello | Carl McKellip | Alice Wilson |
| Mike Davis | Jim Prior | Carol Zier |
| Jim Egolf | Frank Quidachay | Charlie Zinn |

Thank
You!

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

**September Newsletter
Input Deadline: August 9th**

Call or e-mail Julie at:
[REDACTED]
db_mgr@co-parkinson.org



Help 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 at [REDACTED]

July Executive Committee Meeting

July 11th at 1:00 p.m. at Mary and Rich Sauvain's house
Contact Jill at president@co-parkinson.org if you haven't been to an Executive Meeting so we will know that you're coming and to get the address. Leave your email address so Jill can contact you if anything changes.

Important Info on Getting Help after a Fall!

Did you know that if your loved one has a fall and you are unable to get him or her up, you can make a non-emergency call to the Colorado Springs Fire Department's "Lift Assist" at (719) 444-7000 to get help?

Two firefighters will come, minus sirens and lights.

Ask the Doctor!

| Dr. Brian Grabert, MD, a Parkinson's Specialist



Dr. Grabert has generously agreed to answer your questions pertaining to Parkinson's Disease each month in our new newsletter column called "Ask the Doctor!"

If you have questions you'd like to submit to Dr. Grabert, send them to our newsletter coordinator, Julie, at db_mgr@co-parkinson.org.

Answer: Individuals with Parkinson's Disease [PD] develop cognitive decline about twice the rate as age matched persons without PD. There are 5 general domains of cognition. Those with cognitive decline can have as little as one area impaired but more often two or more cognitive domains are impaired.

1. Attention & Processing speed [example: doing Months of the year backwards].
2. Executive function [example: Clock drawing test].
3. Language [example: picture naming]
4. Visuospatial: [example: drawing 3D complex figures such as a cube]
5. Memory [example: recalling a list of words after a short 1-2 minute delay. Three to five words is common on most screening tests].

All individuals with PD should have a yearly screening test for cognitive decline. I am not sure what "borderline" means as most tests have a "cutoff score" for normal/abnormal. The best screening test is probably the MOCA [**M**ontreal Cognitive Assessment]. A similar and newer screening test is the SLUMS [**S**aint Louis **U**niversity **M**ental **S**tatus] Exam. They both are non-proprietary and can be administered by a health professional with minimal training [usually an online video training]. One of oldest tests: the MMSE [**M**ini-**M**ental **S**tatus **E**xam] in my opinion is an inadequate screening test for cognitive decline in PD. All 3 tests have a maximum score of 30 and a cut off score of 25 or 26 [depending on years of education].

There are generally 3 Cognitive categories: Normal; Mild Cognitive Impairment called MCI [there are several sub-categories but the distinguishing characteristic is NO impairment in activities of daily living]; and Dementia [this requires recent impairment of activities of daily living in addition to cognitive impairment]. MCI is a risk factor for progression to dementia with or without a diagnosis of PD. ["borderline" is not a category!]. Cognitive stimulation programs and exercises have been shown to help normal individuals from progressing to MCI and slowing the conversion of individuals with MCI from progressing to dementia. There is a plethora of suggested cognitive stimulation activities by searching this topic on the internet. Cognitive Decline is usually slow and gradual. There are some cognitive disorders with more rapid pro-

Question 1: Is there a connection between PD and cognitive decline? My husband recently scored "borderline" on a cognitive test. Is cognitive decline slow and gradual? What should we expect for the future?

gression such as Creutzfeldt-Jakob disease, some cases of Dementia with Lewy Bodies, & other rare disorders.

Question 2: My spouse has periods when he can't open his eyes. Is this caused by Parkinson's? If so, is there any treatment for it?

Answer: There are 2 likely possibilities. This is isolated Blepharospasm or Blepharospasm associated with Apraxia of Eyelid Opening. There are several different causes, although this is exceedingly rare in Idiopathic Parkinson's Disease [$< 1\%$]. ("Clinical Analysis of Blepharospasm and Apraxia of Eyelid Opening in Patients with Parkinsonism" Won Tae Yoon, MD et. al. J Clin Neurol. 2005 Oct; 1(2): 159-165.) A remote possibility is an OFF phenomenon related to L-Dopa which should be discernable by history. Often this may be a sign of Atypical Parkinson's Disease. Your Neurologist may want to consult with an Ophthalmologist for help in the differential diagnosis and help with treatment. Botox may be helpful but to my knowledge would need to be administered by the Ophthalmologist.

Question 3: My son, who has Parkinson's and other health issues, is bed-ridden. Since pneumonia may be more prevalent in Parkinson's, what are the signs of pneumonia that I should watch for in him?

Answer: Before answering your question it may be important to divide pneumonia into at least 2 categories as it relates to individuals with Parkinson's Disease [PD]: Community acquired pneumonia and aspiration pneumonia. A good example of community acquired pneumonia is pneumonia due to COVID-19. A large Italian study did NOT find that PD patients had more COVID-19 pneumonia, although the severity of pneumonia if acquired was worse but may have been due to advanced age or more co-morbidities. Aspiration pneumonia, on the other hand, has an increased prevalence in the PD population. A risk factor for aspiration is swallowing dysfunction. Aspiration then leads to an elevated risk of aspiration pneumonia, which is a principal cause of mortality in Parkinson's disease patients. If aspiration is suspected then a video swallow should be strongly considered as a diagnostic test. To answer your question: Signs of pneumonia include cough, fever, difficulty breathing [dyspnea], rapid breathing [tachypnea] and low oxygen levels on pulse oximeter. If pneumonia is suspected, you should contact your primary care practitioner for advice. For more reading the following article details the follow up of over 2000 newly diagnosed patients with PD for an average of 6 years and reported the incidence of hospitalization with pneumonia. A take home message for me from this study is that a dental evaluation and treatment of decayed teeth [dental caries] was protective and decreased the incidence of hospitalization with pneumonia. [Neuropsychiatr Dis Treat. 2016; Vol.12:1037-1046 "Risk factors for pneumonia among patients with Parkinson's disease: a Taiwan nationwide population-based study" Yang-Pei Chang, et. al.](#)

Recipe of the Month: Marinated Salmon

Our low carb/good fat ketogenic study that was completed in 2021 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 caregivers who chose to change their diet along with their Parkinsonian). 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.

Ingredients

- ¾ tsp dill weed
- ½ tsp lemon pepper seasoning
- ½ t salt
- ¼ tsp garlic powder
- 1 to 1 ½ lb salmon fillets
- ¼ C low-carb brown sugar (Swerve)
- 3 Tbl chicken broth
- 3 Tbl olive oil
- 3 Tbl tamari
- 3 Tbl green onions, thinly sliced

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.

Directions

1. Place salmon in glass baking dish.
2. Sprinkle the dill, lemon pepper, salt and garlic powder over the salmon.
3. Combine brown sugar, broth, oil, soy sauce, and green onions and pour over salmon.
4. Cover and refrigerate at least 1 hour.
5. Oven method: Preheat to 500 degrees. Cook salmon in the glass dish 12 minutes for every inch in height as its thickest point. Remove from oven and cover with aluminum foil and let rest for 15 minutes and serve.
6. Grill method: Place salmon skin-side down on aluminum foil. Re-pour marinade over salmon, seal foil shut and liberally poke holes on the top of the foil. Place on grill, close lid, bake 15 to 20 minutes for moist, salmon or 30 minutes for well-done.

Other Local Support Groups:

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 6310 Gemstone Way, Colo Spgs, 80918.

Contact Brenda Hicks at

██████████ or ██████████
to let her know you are coming.

Ladies w/ Parkinson's Support Group

If you are a fun-idea person, please consider volunteering to lead this valuable group.

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

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 jimdjs22@gmail.com or 719-660-7275.

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 bhanenbu@hotmail.com or Syble Krafft at 719-488-2669.

Other Opportunities:

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

Cognitive-Linguistic Deficits

Aphasia following stroke

Swallowing

- Neuromuscular Electrical

Stimulation Therapy

- Respiratory Muscle Strength

Training

For more information, 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.

PD Exercise Classes:

Caregivers/Care-partners Exercise Class

This exercise class involves strength training and cardio circuits modifiable for any person!

When: Every Friday at 9:30am for 45 mins

Where: Movement Arts Community Studio 525 E. Fountain Blvd (GPS: 150 S. Royer St)

Price: \$20 Drop-in/\$10 a week (\$40 total monthly pay!). First class is FREE!

Limited space available so please contact Ashley Szekeres, NASM CPT at guardianfitllc@gmail.com or by calling (708) 846-0155 before coming.

Rock Steady Boxing – Boxing with Love

New Rock Steady Boxing for folks with Parkinson's Disease at the Boxing with Love Gym

When: Tuesdays @ noon

(please come 15 min early if your first time)

Where: 1710 Briargate Blvd. Suite 100 (Next to Dicks Sporting Goods at the Chapel Hills Mall). For more info contact Karen Bishop PT, DPT at love@rsbaffiliate.com

YMCA PD Exercise Classes

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

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

Falcon Exercise Group

Mon and Fri –11:00 – 12:00 noon, Grace Community Church. For more information contact Catherine Reed at ██████████

Colorado Springs Rocksteady Boxing

"Let's kick some PD BUTT!" Tues, Wed, & Thurs: 10am–11:15am & 11:45am–1:00pm
Location: Otis Park, 731 Iowa Ave. For more info, call Bill O'Donnell at 719-243-9422

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 11:00am 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. Contact Laura at laura.hymers@gmail.com or 719-640-8478

Max Capacity NeuroFitness

Free Boxing, PWR Bootcamp and Cardio Circuit for people with Parkinson's. Cognitive Cardio class available for \$10/class!

Physical therapist Emily Moncheski at Max Capacity, PLLC, offers individual Parkinson's physical therapy, most insurance accepted
Conveniently downtown

525 E. Fountain Blvd. Suite 150

Contact Emily at emily@maxcapacitypt.com or call: 719-213-3996, fax: 719-284-4624

PWR!Moves Class

Skyline Wellness & Aquatics Center has partnered 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. LOCATION: 2365 Patriot Heights (located within Brookdale Skyline, near Bear Creek Dog Park) Our classes are held every Tues and Thur from 12:30-1:30pm. For more info contact: Karisa Dreyer at (719) 867-4658

One-on-One Physical Therapy

For people with Parkinson's Disease and all movement disorders. Provided by Danielle (Spivey) Mulligan, PT, MSPT who is a Physical Therapist, Certified Vestibular Therapist, LSVT and PWR for Parkinson's.

Where: 5818 N. Nevada Avenue, Suite 325
Phone Number: 719-365-6871

LENDING LOCKER INVENTORY

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

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

| | |
|--|-------|
| 3-wheeled walker | 1 |
| Air mattress | 1 |
| Back brace | 1 |
| Bed cane | 4 |
| Bed pan | 1 |
| Bed rails | 1 |
| Bed risers (set) | 1 |
| Bedside toilets | 6 |
| Canes | 7 |
| Crutches (set) | 2 |
| Double floor exercise pedals | 1 |
| Exercise bike | 1 |
| Hospital bed | 2 |
| Lazercue for freezing help | 1 |
| Lift chairs | 3 |
| Lift-ware tremor compensating utensils | 1 set |
| Pick-up assist | 6 |
| Shower benches | 9 |
| Sock helper | 2 |
| Stair chair rail system | 1 |
| Standup Walker | 1 |
| Swivel seat | 1 |
| Toilet arm assist | 1 |
| Toilet seats | 3 |
| Transfer pole | 2 |
| Transport chairs | 4 |
| Tub rail | 2 |
| U-step | 3 |
| Walkers with wheels & seat | 13 |
| Wheelchairs | 6 |

Dental Care Often Irregular But Needed With Parkinson's: Study

By Andrea Lobo – Parkinson's News Today, 11/7/22

Dental care often is irregular in people with Parkinson's disease, who also require more dental treatments than those without this disease, a study from Denmark reported.

High-quality initiatives addressing basic care, from daily oral cleanings to regular checkups that could reduce cavities and tooth extractions, are needed for better oral health and to ease the economic burden that extensive dental treatments impose, its researchers noted.

"This knowledge can be used by clinicians and decision-makers to ensure the optimal dental care for persons with [Parkinson's disease]," the researchers wrote.

The study, "**Dental care utilization among persons with Parkinson's disease in Denmark**," was published in the journal *Community Dentistry and Oral Epidemiology*.

Ways of Better Ensuring Good Dental Care in Parkinson's Reviewed

Dental care a poorly studied area of Parkinson's overall care

The motor symptoms of Parkinson's can increase the difficulty of daily oral hygiene practices, while nonmotor symptoms like depression and cognitive changes can affect how well a person maintains good hygiene and makes regular dental appointments.

Disease treatments themselves, furthermore, often affect salivation.

"Controlled studies show a higher prevalence of caries, gingivitis, periodontitis and tooth loss" among Parkinson's patients, the study noted, which "can lead to pain, decreased quality of life and malnutrition," the scientists, all with the University of Copenhagen, wrote.

"Based on this, it is obvious that the need for both preventive dental care and dental treatment is high ... and necessary to control oral diseases and secure a sufficient oral function and a healthy life," they added, noting few studies have looked into dental care in this patient group.

Using the Danish National Prescription Registry, the researchers identified 6,874 patients with data covering their dental service use between 2015 and 2019. They then compared this information with data on 34,285 people without Parkinson's, serving as controls.

Both groups were similar in terms of median age (71) and sex distribution (60.7% male). People with Parkinson's had a higher educational and income level, were more likely to have a partner, and more likely to live in nursing homes and for longer periods than controls.

These people were further categorized by dental attendance over the study's five years: non-attenders (no evidence of any dental service use), irregular attenders (one to two examinations or dental treatments only), or regular attenders (three or more examinations). Dental care, generally private, is reimbursed in part under Denmark's national health policy once claims are filed, and partial reimbursement includes preventive care, tooth fillings or extractions, and periodontal treatments.

Irregular dental care, with need for fillings, more common with Parkinson's

Most people in both groups were regular visitors to dental care, although a smaller percentage of those with Parkinson's regularly went for care than did those

in the control group (57.5% vs. 59.5%). Patients, overall, were significantly more likely to have irregular dental visits than those without the disease (21% vs. 16.9%).

Adults without Parkinson's, however, were more likely to not use dental care services compared with patients (23.6% vs. 21.4%).

Among regular attenders, Parkinson's patients more likely to need services, with a 1.10 times higher rate of examinations and preventative services, 1.62 times higher rate of fillings, and 1.49 times higher rate of extractions than controls. This amounted to an incidence rate for overall dental service use among regular attenders that was 1.18 times greater for patients than controls, and 1.12 times higher among those classified as irregular attenders.

"The incidence rate of dental services in the overall PD [Parkinson's disease] population was significantly higher compared with the control population, especially for fillings and extractions," the researchers wrote.

Fillings given to treat small cavities or broken teeth had a 1.71 higher incidence rate among patients than controls, the study noted. And regular care attenders, whether patients or controls, had almost double the number of fillings (8.3 for patients and 5.1 for controls) over the study's years than did irregular attenders.

Absolute numbers of tooth extractions were small over these five years, the researchers wrote, with an estimated mean of 0.9 teeth extracted among all controls and 1.3 among all patients. By category, patients had an estimated mean of 1.3 extractions for regular attenders and 1.4 with irregular attendance; for controls, these estimated means were 0.9 for regular attenders and 1.2 for irregular attenders.

"The small but statistically significant higher extraction rate among cases during a five-year period may emphasize the pattern of more severe oral disease among persons with PD," the researchers wrote.

Regarding examinations and preventive treatments, the use rate was 1.1 times higher for Parkinson's persons than controls, regardless of whether they were regular or irregular attenders to dental care.

"Overall, people with [Parkinson's] received more dental services, especially treatments, than the control group, regardless of their attendance pattern," the researchers wrote.

This finding might be related to ineffective prevention approaches in dental care or a dentist's choice to offer treatment to a patient, they added.

Still, patients' "significantly higher usage of dental care services ... was most prominent for the treatment categories such as fillings and extractions, that is, for acute problems," while it was "low for preventive measures," the team wrote.

Given this high use rate and its associated economic burden, the researchers suggested that people with Parkinson's "should get higher reimbursements for their dental visits or possibly a special subsidy for dental care" under Denmark's health policy.

This study's findings should also raise awareness among dental health professionals of the need to better promote oral health practices, like the use of high fluoride toothpaste, and preventive care initiatives that are tailored to people with Parkinson's, like screening individuals for hyposalivation, the researchers concluded.

Virtual Music Therapy Benefits Parkinson's Patients and Caregivers

By Marisa Wexler, MS – Parkinson's News Today, 5/24/23

12-week program seen to ease apathy, depression in patients

A 12-week virtual music therapy program was found to reduce apathy and depression among people with Parkinson's disease — and to help ease feelings of burden for their caregivers, a new study reported.

"Group music therapy is an effective treatment for apathy in PD [Parkinson's disease] and may improve mood," the researchers wrote. Both patients and caregivers were invited to join in the weekly online music sessions.

"Subjectively, over one-third of people with PD reported increased interest in activities, and over half of the PD participants either restarted an old hobby or started a new one by the end of the study," the team wrote, adding that "the post-intervention satisfaction survey also revealed high levels of satisfaction among caregivers."

Additionally, the researchers highlighted the utility of the secure videoconferencing platform, noting that "the virtual format is a feasible alternative to in-person sessions with high adherence and satisfaction" among participants.

"Virtual Group Music Therapy for Apathy in Parkinson's Disease: A Pilot Study," was published in the *Journal of Geriatric Psychiatry and Neurology*.

Group Singing May Be Therapy for Walking Problems, Tremor

Patients give Parkinson's music therapy program a 9.5 of 10

Defined as a lack of motivation to one's achieve goals, apathy is a known emotional symptom of Parkinson's and is estimated to affect about 40% of people with the neurological disorder. Apathy has been linked to worse quality of life for patients and a poorer ability to manage day-to-day tasks.

It can be hard to manage, and there aren't any approved therapies to ease this symptom. Apathy in patients also has been linked to a greater sense of burden among caregivers.

Data suggest that participating in music therapy might be helpful for Parkinson's patients and caregivers struggling with apathy. To test this, a team of U.S. scientists investigated such a program's use in a small study designed to assess patient motivation.

Music therapy involves making and/or listening to music under the supervision of a trained therapist. This program consisted of hour-long sessions, held once weekly for 12 weeks, or about three months. Each session included five to six pairs of patients and caregivers. A session would start with a check-in, followed by vocalization exercises, drumming, and therapeutic group singing, then conclude with another check-in and a few minutes of deep breathing.

A total of 16 people with Parkinson's and their caregivers enrolled in the study. Most of the patients were men and most caregivers were women — almost all participants were husband-wife pairs. All of the participants were white individuals.

A kit including several musical instruments was given to everyone participating in the study.

All of the Parkinson's patients had notable apathy upon entering the trial. Half of them had depression, and about a third had anxiety.

At the start and end of the program, patients and caregivers completed a battery of standardized tests assessing their emotional wellbeing and quality of life.

The results showed that, at the end of the 12 weeks, there was a large and statistically significant decrease in apathy scores. Depression scores also decreased significantly.

Overall life quality scores tended to improve slightly after the program, but the change was not statistically significant — meaning there's a sizable mathematical probability the difference is due to random chance. The researchers noted that this study may have been too small to detect a statistically meaningful improvement.

When asked to rate their satisfaction with the music therapy program on a scale from 1 to 10, with higher numbers indicating greater satisfaction, most patients gave a rating of 9.5 or higher. Many patients reported subjectively feeling that the program had improved their mood and voice quality.

LSVT-BIG Therapy as Effective Online as in Clinic for Parkinson's

Separate music therapy sessions suggested for Parkinson's patients, caregivers

Data analyses from the 16 caregivers showed no significant effect on measures of caregiver burden. However, the researchers noted that two of these caregivers had only attended about half of the sessions. Analyses of the remaining 14 caregivers who went to the majority of sessions showed a statistically significant reduction in caregiver burden scores.

Caregivers and people with [Parkinson's] may need to participate in separate music therapy sessions so that goals of treatment are appropriately addressed and to allow caregivers to focus on themselves.

Most caregivers rated their satisfaction with the program as 9 of 10 or higher, and many reported that the program had inspired them to incorporate more music into their daily lives. However, many caregivers also reported feeling the program was more helpful for their loved one with Parkinson's disease than for the caregiver. This suggests having combined music therapy for both patients and caregivers might not be optimal.

"Caregivers and people with [Parkinson's] may need to participate in separate music therapy sessions so that goals of treatment are appropriately addressed and to allow caregivers to focus on themselves," the researchers wrote.

Several participants — both patients and caregivers — also reported that they did not like the music used in the program, which was determined based on decisions in each session group. Person-to-person variation in music tastes "remains a challenging aspect of providing music therapy in a group setting," the researchers said.

The team stressed that this was a small pilot study, so further research is needed to evaluate how music therapy might be used to optimally help patients. Still, they said this study suggests this type of treatment is worth exploring.

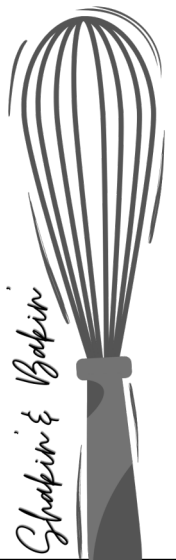
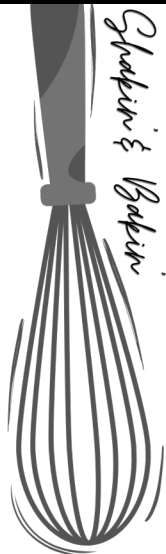
"Given the effectiveness of non-pharmacologic treatments and strong patient interest in these interventions, further research on the clinical uses of music and other complementary therapies in Parkinson's disease is warranted," the scientists concluded.

Potluck Favorites: Shakin' & Bakin' Cookbook!

Another reminder about a new CSPSG endeavor to add new recipes to the original cookbook the support group created years ago. Sherry Whitaker has volunteered to lead this effort to add your favorite recipes — old or new family recipes, newly discovered favorite recipes, etc.

We only want recipes that you have actually tried and liked — not ones that you think should be good but haven't tried or tasted. They don't have to be gluten-free or Keto. We will, however, indicate which ones fit those categories. We will also add a conversion table that will tell you how to convert ordinary recipes into gluten-free or Keto recipes if you would like to know how to do that.

All favorite recipes are welcome
Send them to Sherry at project@co-parkinson.org.



Aggression Aimed at Caregivers in Parkinson's Linked to Patients' Grief

By Andrea Lobo – Parkinson's News Today, 11/9/22

Aggression aimed at caregivers in Parkinson's disease and related disorders is associated with patients' grief in coping with disease progression and related losses, a new study suggests.

Fluctuations in cognition also play a role, researchers say.

But these behavioral disturbances have serious consequences for caregivers, according to investigators, who suggest that neurologists and movement specialists consider screening for aggression by incorporating the caregivers' perspectives. That will contribute to working with caregivers on strategies to cope with aggressive behavior by patients — “prioritizing caregiver education and wellbeing,” the researchers wrote.

“This is an issue that we think is very much underrecognized,” Zachary Macchi, MD, who led the study, said in a press release, adding that “this is a factor likely driving caregiver burden for some people.”

“I'm hoping to create more awareness toward it ... among clinicians who work directly with people living with Parkinson's disease,” said Macchi, an assistant professor of neurology at the University of Colorado School of Medicine.

Survey Shows Toll of ‘Off Times’ on Patients, Caregivers

Investigating aggressive behaviors among patients

Titled “**Aggression towards caregivers in Parkinson's disease and related disorders: A mixed methods study**,” the study was published in the journal *Movement Disorders*.

Aggression in advanced stages of Parkinson's disease and related disorders is common and relates to symptoms burden, according to researchers.

This includes verbal abuse, physical harm, or sexual advances. While previous studies have looked into behavioral disturbances and their impact on caregivers, the caregivers' perceptions of being the target of aggressive behaviors were not considered.

Now, a team of U.S. researchers identified factors associated with aggressive behavior in Parkinson's disease and other disorders. The study mixed quantitative data, obtained from a recent clinical trial, with a qualitative component of caregivers' perceptions, based on interviews.

The initial clinical trial enrolled 592 participants — dyads or related pairs of 296 patients and 296 caregivers — who were recruited from outpatient neurology care in California, Colorado, and Wyoming. The researchers collected the quantitative data every three months for 12 months, between March 2017 and December 2020.

At the beginning of the study, half of the patients (50.3%) had dementia, and two-thirds had idiopathic Parkinson's (66.6%). Idiopathic means the disease is of unknown origin. The average disease duration was nine years, with an average duration of caregiving of five years.

The majority of the caregivers were women (76.6%) who were highly educated — 50% had a college education. More than three-quarters (76.9%) were married to the patient and an even greater number (82.4%) lived in the same house.

Some type of aggression was reported by 22.3% of caregivers. This included physical aggression, experienced by 17.6%, and sexual aggressions, reported by 8.8%.

This is an issue that we think is very much underrecognized

At the study's start (baseline), patients' aggressive behaviors were correlated with lower annual income, longer disease duration, worse severity of motor symptoms, and reduced functional status. Grief and poorer quality of life also was associated with aggression.

A higher resistance to care correlated with physical aggression alone or with either type of aggression combined. Meanwhile, a higher severity of motor symptoms was associated with physical aggression alone.

An increase in aggressive behaviors also was associated with overall symptom burden, including motor and non-motor symptoms. Among the non-motor symptoms were nausea, depression, anxiety, confusion, and hallucinations.

Paranoia was related to sexual aggression alone.

When considering caregiver variables, greater baseline aggression correlated with depression, the overall burden for the caregiver, and the patient's quality of life as perceived by the caregiver.

Former Parkinson's Caregivers Could Help Those Now in That Role

Assessing the impact on caregivers

Following the collection of quantitative data, semi-structured interviews were conducted over 4 months, with 14 of the caregivers who reported aggression. These participants were predominantly spouses (nine caregivers) and shared a residence with the patients (12 caregivers).

“We did interviews with these caregivers, letting them share their experiences, and we were able to begin to understand the triggers, or what we call predecessors to aggression,” Macchi said. He noted these predecessors were “the things that were leading up to aggression, as well as the behaviors themselves.”

In the interviews, five themes were identified that exemplified aggressive behaviors and their effect on caregivers. These included:

- behaviors ranging from verbal abuse to threats of physical aggression.
- caregivers' beliefs that aggression was the result of patients' difficulties in coping with disease progression and the loss of abilities.
- a belief that aggressive behaviors worsen caregiver stress and mental health, and negatively impact the patient-caregiver relationship.
- caregivers' feelings that they were ill-prepared to cope with aggressive behaviors.

According to the researchers, several points converged between the identified themes and correlated variables. Grief is a contributor to aggression, mainly related to the patient's frustration with functional decline, the team concluded.

“Our study is the first to show a relationship between patients' grief and behavioral disturbances in [Parkinson's disease and related disorders],” the researchers wrote.

Grief counseling, they suggested, “is one possible strategy for preemptively mitigating interpersonal issues contributing to escalating behavioral disturbances.”

Also, cognitive fluctuations, associated with episodic confusion, were shown to contribute to aggression, independently of dementia or global cognitive impairment. According to the researchers, “education of caregivers and medications for cognition ... or mood disturbances ... may help.”

Aggression toward caregivers contributes to the overall burden for carers, with a negative impact on their physical and mental health, the study found.

During routine care, screening for aggressive behaviors allows patients and caregivers to access resources to “facilitate early intervention, provide guidance and education to families or loved ones” or “mobilization of protective services when caregivers' safety is threatened,” the researchers concluded.

“The next step would be to build what we call a psychoeducation intervention, where we work with caregivers on identifying these behaviors, and then identifying triggers — or potential precursors to these behaviors, and then understanding the consequences of them,” Macchi said.

“We want to give caregiver the tools and skillset to be able to manage those, and to foster an ongoing relationship between the caregiver and the clinician,” he said.

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PARKINSON'S PERSPECTIVE

**JULY & AUGUST
2023**

Coming Events

See inside for more information

July 1st - Reg Mtg at Central United Methodist Church — 10 am

Program: Scam Prevention; **Speaker:** Officer Scott Mathis, Colorado Springs Police Department

August 5th - Program: Picnic at John Venezia Park!!!! — 11 am

September 2nd - Reg Mtg at Central United Methodist Church — 10 am

Program: Deep Brain Stimulation; **Speakers:** Dr. David VanSickle and Dr. Abhijeet Gummadavelli

October 7th - Reg Mtg at Central United Methodist Church — 10 am; **Program:** TBD

November 4th - Reg Mtg at Central United Methodist Church — 10 am; **Program:** TBD

December 2nd - Reg Mtg at Central United Methodist Church — 10 am; **Program:** Holiday Party

More useful websites:

<https://parkinsonsnewstoday.com>; www.parkinsonrockies.org; www.parkinson.org; www.nwpf.org; michaeljfoxfoundation.org;
<http://caremap.parkinson.org>; <https://www.brainhq.com/world-class-science/published-research/active-study>;
www.davisphinneyfoundation.org/living-pd/webinar/videos/cognitive-nonmotor-symptoms-parkinsons; www.parkinsonheartland.org;
<https://www.pdself.org>; https://www.youtube.com/playlist?list=PLkPIhQnN7cN6dAJZ5K5zQzY84btUTLo_C; pmdalliance.org;