

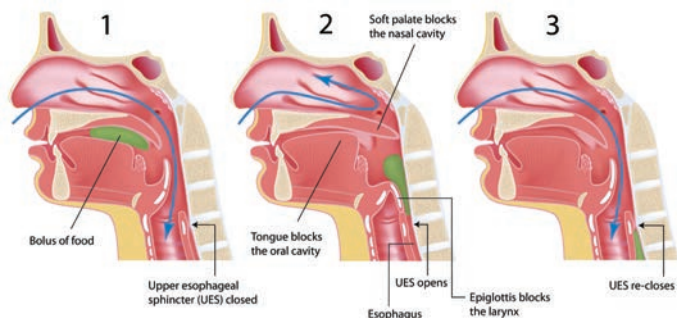
SWALLOWING DIFFICULTIES in Parkinson's Disease

The act of swallowing involves a complex series of activities that begin in the mouth, continue in the pharynx (or the throat) and end in the esophagus. These include chewing, using the tongue to move the bolus of food to the back of the throat and then coordinating the muscles that both propel the food into the esophagus and protect the airway or trachea from food penetration. Swallowing dysfunction (also called dysphagia) can be considered both a motor and a non-motor symptom of PD. Loss of dopamine neurons in the substantia nigra area of the brain can cause the motor dysfunction that impairs swallowing. However, loss of neurons in other areas of the brain, such as the cortex and lower brain stem can also affect the overall control and coordination of swallowing, and can be thought of as a non-motor symptom of PD. Swallowing issues are very important to diagnose. Impacts on your daily life and your health can range from difficulties with meals to more extreme (but less common) cases where it could lead to choking and aspiration which can be very serious or even fatal.

How do you know if you or your loved one has a problem with swallowing?

Swallowing difficulties can start very subtly and initially not be obvious to either the person with PD or their loved ones. There are signs to look out for before swallowing difficulty becomes overt (i.e. choking on food). Some of the signs you should pay attention to include:

- Slow rate of eating – people with difficulty swallowing may slow down their eating to avoid coughing or choking
- Fatigue during eating or decreased enjoyment of food
- A sensation that food is “sticking” in the throat
- Coughing or excessive throat clearing during eating
- Difficulty in swallowing pills
- Unexplained weight loss – people with difficulty swallowing may reduce their consumption in an attempt to eat without coughing or choking
- Change in dietary habits – people with difficult swallowing may alter their diet to avoid foods that cause difficulty. This may not be a choice made consciously
- Diagnosis of a pneumonia – this could be caused by aspiration, or entry of a foreign substance (i.e. food) into the airway



[continued on next page]



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If you think there might be a swallowing issue, it is important to speak with your doctor about it. There are steps you can take to properly assess the situation (i.e., a swallowing evaluation) and improve your swallowing function. This can in turn reduce your risk of choking, make eating more enjoyable, and lessen the chances of unwanted weight loss and/or other discomforts.

What is a swallowing evaluation?

If because of the above signs there is concern that swallowing difficulties exist, your doctor may recommend a swallow evaluation, which can be performed by a speech and language pathologist.

There are two main ways to evaluate someone's swallow:

- Modified barium swallow study – This is the most common test that is performed. The person is asked to ingest different consistencies of barium and moving x-rays are taken that follow the barium as it is swallowed. This x-ray video pinpoints the areas of the swallow that are problematic and helps to determine the correct exercises to address the problem.
- Fiberoptic endoscopic evaluation of swallowing (FEES) is another type of test that can be performed to evaluate swallow. During this procedure, a very thin flexible fiberoptic tube which is hooked up to a camera and light source, is passed through the nasal passage. The tube does not go down the throat, but allows swallowing to be observed. This procedure is painless and well-tolerated by most individuals.

If you have swallowing difficulty, what can be done?

In some cases, swallowing function varies in response to dopamine medication doses, much like other aspects of motor function. Therefore, if swallowing becomes problematic, an increase in dopaminergic medications can be tried. In addition, make sure you undergo a swallow evaluation when you are in the ON state.

Even before a formal swallow study, you can take steps to increase the efficiency of your swallow. These include:

- Sit upright during all eating and drinking, even when taking pills
- Tilt the head slightly forward, not backward, as you swallow
- Take small bites of food, chew thoroughly, and do not add any more food until everything from the first bite has been swallowed

- Take small sips of liquid
- Concentrate while moving the food backward in the mouth with the tongue
- “Double swallow” (swallow a second time) if the food did not go down completely with the first swallow
- Sometimes taking a sip of liquid between bites can help to wash the food down
- If eating is very tiring, try several smaller meals spaced out during the day instead of three large meals.

Swallowing exercises can be very helpful to improve your swallowing

After a formal swallow assessment, swallowing therapy sessions can be designed for you, involving exercises tailored to the specific parts of your mouth and throat that are causing the swallowing problem. Sessions may involve practicing compensatory swallowing strategies with various types of foods in order to maximize safety and efficiency while swallowing.

During swallow therapy, recommendations may include:

- Best feeding techniques
- Exercises to strengthen oral and throat muscles
- Compensatory techniques to assist in safe swallowing
- Oral and mouth care techniques
- Appropriate food selection and ways to modify food texture
- Safe positioning strategies
- Patient/family education

Choosing foods for successful eating

Part of formal swallow therapy will be to make appropriate food suggestions that you can eat safely. Good food choices include:

- Foods that don't require vigorous chewing. Avoid dry and crumbly foods.
- Moderately textured wheat breads instead of very coarse, nutty breads or very soft, white breads.
- Oatmeal, cream of wheat or moistened dry cereals instead of coarse, dry cereals.
- Well-cooked, tender chicken/turkey,

well-cooked fish without bones, chopped and ground meats, instead of stringy, tough meats that require a lot of chewing.

- Soft casseroles and poached or scrambled eggs
- Mashed potatoes or rice, moistened with gravy or margarine, instead of wild rice or French-fried potatoes.
- Soft, cooked pasta elbows, instead of long spaghetti.
- Soft, well-cooked vegetables cut up or creamed, instead of raw vegetables or those with a hard texture.
- Pureed or mashed fruits, fruit juices and fruit sauces, instead of fruits with seeds or hard outer skins. Avoid nuts, seeds or coconut.
- Custard, yogurt, ice cream or other soft desserts

Tips and Takeaways

- Swallow impairment is common symptom of oral dysfunction in Parkinson's disease.
- Subtle signs of swallow dysfunction can include slow eating, coughing with eating and weight loss.
- If swallow dysfunction is suspected, a swallow evaluation can pinpoint the problem and swallow therapy can help improve it.
- Do not suffer silently or wait until the problem is very advanced before seeking help. Talk to your doctor as soon as you notice any issues or potential difficulties so proactive steps can be taken to lessen the impact of swallowing issues to keep you safe and comfortable.



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We will be known forever by the tracks we leave....

4th ANNUAL MIDWEST PARKINSON CONGRESS

April 8th - 9th



The 4th annual Midwest Parkinson Congress presented by the APDA-Greater St. Louis Chapter, APDA Midwest Chapter, and APDA Oklahoma Chapter will take place **virtually** on April 8th and 9th from 10:00am – 1:00pm CST. Participants will have the opportunity to hear from an esteemed panel of industry leading professionals discussing the latest in Parkinson’s research, depression, nutrition, caregiving, speech, financial planning, and adaptive technologies. This year, The Elliot and Mary Ann Stein Keynote address will be presented by Heather Kennedy. Heather is the founder of Kathleen Kiddo, an advocacy site

offering PD resources and connections through social media. She is a motivational speaker, writer, blogger, visual artist, and mother of two. Diagnosed with PD in 2012, after many years of misdiagnosis, she works to raise awareness about the disease, and especially the challenges that living with Parkinson’s presents. Since her diagnosis, she has collaborated with organizations such as the Davis Phinney Foundation, The Cure Parkinson’s Trust, and The World Parkinson’s Congress.

Online Registration for this event is required: Visit www.apdaparkinson.org/greaterstlouis

Interested in becoming a sponsor? There’s still time!

For more information on how to become a sponsor, **contact Melissa Skrivan, Director of Development, at 636.778.3377 or mskrivan@apdaparkinson.org.**

APDA VIRTUAL PRESS™

Parkinson’s Roadmap for Education and Support Services™



Beginning in late January, the APDA – Greater St. Louis Chapter will host a virtual APDA Parkinson Roadmap for Education and Support Services™ (PRESS™) Program. This free, 8-week program is open to any adult who has been diagnosed with Parkinson’s disease (PD) within the last 5 years and their care partners. The purpose of PRESS™ is to meet with others facing a similar experience and share coping strategies regarding day-to-day issues related to living with Parkinson’s. For many people with PD, the support group is a gateway into the world of PD advocacy, education, and services available in their community. It is a place to share their feelings in a safe, caring environment and gather information and resources. This group is led by a healthcare professional experienced with psychosocial group facilitation. The healthcare professional who leads the group will offer insights and engage the participants so they can meet personal and emotional goals as they move through the educational curriculum.

Weekly Topics:

1. What’s Next After Diagnosis
2. Medication Management of Parkinson’s
3. Importance of Exercise in PD
4. Dealing with Physical Symptoms of PD
5. Impact of Parkinson’s on Daily Coping and Relationships
6. Tips for Daily Living
7. Caring for Others, Caring for Yourself
8. Building your Healthcare Team

Space is limited and registration is required.

Participants will undergo a screening to ensure they meet the criteria for the group.

To register or for additional information please contact Angela Weaver at aweaver@apdaparkinson.org or 636.778.3377.

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LIVE STREAM EXERCISE CLASS SCHEDULE

Please visit: bit.ly/APDAYoutube for exercise classes

DAY	TIME	CLASS	LEVEL	INSTRUCTOR
MONDAY	10:00am	Strength & Cardio	Level 2	Marina Clements
MONDAY	1:00pm	Interval Training	Level 2	Jen Berger
TUESDAY	1:00pm	Seated Exercise	Level 1	Michelle Kinnett
TUESDAY (not live streamed)	posted weekly	Yoga & Meditation	All Levels	Ulrikke Malik
WEDNESDAY	1:00pm	Interval Training	Level 2	Michelle Kinnett
THURSDAY	1:00pm	Seated Exercise	Level 1	Jen Berger
FRIDAY	10:00am	Tai Chi	Level 1	Craig Miller
FRIDAY	11:15am	Tai Chi	Level 2	Craig Miller

ZOOM EXERCISE CLASS SCHEDULE

Please contact Angela Weaver at aweaver@apdaparkinson.org for Zoom link.

DAY	TIME	CLASS	LEVEL	INSTRUCTOR
TUESDAY	9:00am	Seated Exercise	Level 1	Jen Berger
TUESDAY	10:00am	Strength & Cardio	Level 2	Jen Berger
THURSDAY	10:00am	Strength & Cardio	Level 2	Rachel Lehman
FRIDAY	11:00am	Seated Exercise	Level 1	Rachel Lehman
FRIDAY	10:00am	Strength & Cardio	Level 2	Michelle Valenti
FRIDAY	11:00am	Seated Exercise	Level 1	Michelle Valenti

Calling all exercisers and exercise instructors!

Tell us how COVID-19 has impacted your participation in exercise.

- ▶ If you have Parkinson's disease and were participating in any type of exercise class at least once per week before the pandemic, please visit - **Participant survey link:** <https://redcap.link/covidchanges.pdexercise>
- ▶ If you were teaching any type of exercise class for people with Parkinson's prior to the pandemic, please visit - **Instructor survey link:** <https://redcap.link/pd.covidchanges.instructor>

This study is being conducted by the Program in Physical Therapy at Washington University in St. Louis. The goal of these surveys is to learn the best ways to support exercise for people with PD during the current pandemic and in the future. For questions about the study please contact Gammon Earhart at earhart@wustl.edu.

VIRTUAL SUPPORT GROUP SCHEDULE

For more information, please contact Angela Weaver
at aweaver@apdaparkinson.org

MISSOURI SUPPORT GROUPS

LOCATION	DAY	TIME	SUPPORT GROUP LEADER
Chesterfield	Third Tuesday	11:00am	Carrie Burgraff
Chesterfield Caregivers	Second Monday	11:00am	Lynda Wiens & Jay Bender
Carthage	First Friday	2:00pm	Tericia Mixon
Kirkwood	Fourth Tuesday	6:00pm	Terri Hosto
Online	Third Wednesday	1:00pm	Angela Weaver
South County	Second Wednesday	10:30am	Caitlin Jones
St. Peters	First Tuesday	1:00pm	Jodi Peterson
St. Louis Caregivers	Second Monday	1:00pm	Kathy Schroeder
Webster Groves	Fourth Thursday	1:00pm	Laurel Willis
YOPD	Every Wednesday	6:00pm	Karen Frank & Mike Mylenbusch

ILLINOIS SUPPORT GROUPS

LOCATION	DAY	TIME	SUPPORT GROUP LEADER
Carbondale	First Wednesday	1:00pm	Gala Lockwood
Charleston	Fourth Tuesday	1:00pm	Jean Shobe & Jean Penrod
Highland	Fourth Tuesday	2:00pm	Kayla Deerhake
Online	Third Wednesday	1:00pm	Angela Weaver
Quincy	Saturdays	10:00am	Dave & Terri May

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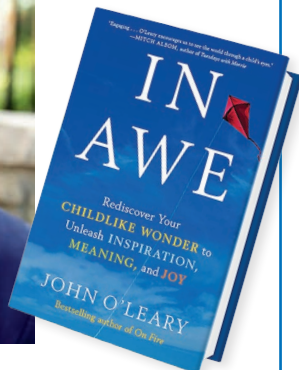
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SAVE THIS DATE IN 2021!

August 1st

Elliot and Mary Ann Stein Speaker Series featuring JOHN O'LEARY, author of *On Fire*, who will celebrate and share his new book *IN AWE: Rediscover Your Childlike Wonder to Unleash Inspiration, Meaning, and Joy*.



In the fall of 2020, the American Parkinson Disease Association – Greater St. Louis Chapter established the Optimism Society to honor those who provide annual support of \$1,000 or more. Optimism Society members are a vital component of the APDA – Greater St. Louis Chapter, and each year we extend our gratitude to those who support us with a special Optimism Society celebration.

To join the Optimism Society, contact Director of Development, Melissa Skrivan at mkskrivan@apdaparkinson.org or 636-778-3377.

APDA Community Resource Center

1415 Elbridge Payne Rd, Ste 150 | Chesterfield, MO 63017

Hours: 8:00 a.m. - 4:00 p.m. M-F

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