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INSIDE THE CIRCLE...

Lancaster County Parkinson's CIRCLE OF CARE Alliance

Issue #6



GREETINGS FROM THE BOARD:

Another holiday season has rolled around!! We would like to wish you all the blessings of good health, peace and happiness for you and your families.

We were so very sorry we had to cancel our 2019 CIRCLE OF CARE Symposium in November! We hope to have an even greater event to offer you in 2020!!

It is our mission that the information and resources we provide through the Lancaster County Parkinson's CIRCLE OF CARE Alliance will indeed equip you to enhance your quality of life and enjoyment of your everyday activities!!

We are currently looking to expand our Board of Directors!!! If you have a passion to support the PD Community in Lancaster County, check out our website at parkinsonscca.org or contact us at 717-568-8448 to express your interest.

In "Marriage Story", Alan Alda Lets His Parkinson's Show

In an industry where actors are aware of their every camera angle—they fight pretty, cry pretty, even die pretty—Alan Alda does something unusual in "Marriage Story": He lets his tremor show.

The 83-year-old actor, who announced last year that he is living with Parkinson's disease, plays a scattered but principled lawyer in the movie about a scorched-earth divorce starring Adam Driver and Scarlett Johansson. The film from director Noah Baumbach doesn't mask Mr. Alda's shaking hands but keeps them in the frame, a visual contrast to the slick moves of the sharklike lawyers elsewhere in the movie.

Hurray for Mr. Alda!!

(Re-printed from Wall Street Journal, November 9, 2019)

OUR MISSION:

"To give those with Parkinson's Disorder and their caretakers hope in awareness, education, encouragement, and action to take control of and responsibility for their future."

OUR VISION:

"To improve the lives of those with Parkinson's Disorder and their caretakers."

PARKINSON'S CIRCLE OF CARE ALLIANCE

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STUDENT/INTERN RESOURCE CENTER:

Welcome to the first article in our Student/Intern Resource Center! Each season, we will tap into the wonderful in-training clinicians who are studying Parkinson's and potential treatments, studies, research and more!! Thank you, Madelyn, for being our first contributor!!

What is occupational therapy (OT) and how does it help individuals with Parkinson's Disease?: A student's perspective

"But I don't need an occupational therapist, I already have a job." This is a phrase many occupational therapy practitioners and students hear all the time! No, we don't help you find a job; rather occupational therapy is a health profession that helps individuals gain independence in their desired daily tasks, which are referred to as "occupations." Occupational therapy practitioners can help individuals across the lifespan with a variety of different needs. Some common areas of occupation which practitioners address include activities of daily living (ADLs) such as bathing and hygiene, instrumental activities of daily living (IADLs) such as cooking and cleaning, rest and sleep, education, work, play, leisure, and social participation (American Occupational Therapy Association, 2014). Some settings in which occupational therapy practitioners commonly practice are acute care hospitals, rehabilitation hospitals, schools, outpatient settings, etc. When working with individuals with Parkinson's Disease (PD), occupational therapy practitioners' main role is to help clients maximize independence in the occupations which they want or need to return to. This may involve adapting the environment or task to maximize participation (Almeida, n.d.). Occupational therapists may work with individuals with PD on safety and fall prevention. To do so they may teach individuals with PD to concentrate on walking and avoid unnecessary speech. They may also make home safety recommendations such as removing rugs or bulky furniture to maximize safety within their home environment. Occupational therapy practitioners may teach strategies such as visual cues to target the area of handwriting, as individuals with PD tend to have small sloping handwriting (Almeida, n.d.). Occupational therapy practitioners may also teach strategies or recommend equipment to maximize independence with self-care and self-feeding routines. To complete all desired areas of occupations, individuals with PD may benefit from energy conservation strategies, which an occupational therapy practitioner can assist in developing and implementing (Almeida, n.d.). As a client-centered profession, occupational therapy practitioners develop unique interventions to meet their client's and their client's families goals. These are general recommendations of ways in which occupational therapy practitioners can assist individuals with PD, the best source for more information is consulting with a licensed and certified occupational therapy practitioner.

Madelyn Baker
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References

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INSIDE THE CIRCLE RESEARCH & RESOURCES

**TIPS FOR THE WINTER WEATHER AHEAD...

The weather turned pretty cold pretty quickly, here in Lancaster County. If the cold temps are getting you down, here are some tips from the Michael J. Fox Foundation.

- ☐ Don't go outside if you can avoid it. Make sure your pantry and medicine cabinet are stocked.
- ☐ If you must go outside, take precautions. Go out during daylight, when it's relatively warmer and busier (more people around to help in case of emergency). Wear layers, and cover all exposed skin, even your nose and mouth. (Breathing cold air can be harsh.)
- ☐ Keep warm while inside. Once you get a chill, it can be hard to warm up. Dress in layers, use blankets or space heaters (follow safety tips and never leave heaters unattended), set the thermostat to a comfortable level, and eat warm foods (soups and tea, for example).
- ☐ Maintain your exercise routine. Moving less can lead to stiff muscles and pain. Even though you can't get to the gym or outside for your daily walk, you can still work out. Look to online videos, DVDs, or exercise handouts from your doctor or physical therapist.

Get more tips at <https://www.michaeljfox.org/news/ask-md-cold-weather-and-parkinsons?fbclid=IwAR27ieLA8cerm91QeJZOqWH2tcPOksTwWZDgS188UUPB1uYEN1Sb41tjig0>.

**KIT AVAILABLE THROUGH PARKINSON'S FOUNDATION FOR NEWLY DIAGNOSED WITH PD



Here's an initiative that's exactly aligned with our mission to help those living with Parkinson's Disease get the support they need. *
The Parkinson's Foundation "announced the launch of Newly Diagnosed: Building a Better Life with Parkinson's Disease," a new campaign designed to arm people who are newly diagnosed with the knowledge, tools and resources they need to navigate life with Parkinson's disease (PD).

Newly Diagnosed with Parkinson's
by the numbers

60,000 Americans diagnosed with Parkinson's disease (PD) every year

1 Million people in the U.S. living with Parkinson's

Nearly 50% of people with PD do not receive educational materials upon diagnosis

5 steps to living well with Parkinson's

1. Think about what is most important to you
2. Find someone you can talk to
3. Create healthy habits
4. Be active in whatever way works best for you
5. Find a doctor who is a Parkinson's expert

Top questions after a diagnosis:
1. How can I live my best possible life?
2. At what rate does PD progress?
3. What does the future hold?

Most helpful to someone newly diagnosed:
Social Support
Healthy + Active Lifestyle
Medical Support

Information + Support are the most important resources for someone newly diagnosed.

We are here to help.
Parkinson.org/NewlyDiagnosed

Data according to a Parkinson's Foundation survey.

Parkinson's Foundation

"In an effort to help provide better outcomes from the beginning of their journey, the Parkinson's Foundation is wholeheartedly committed to connecting sooner with those facing a life-changing diagnosis," said John L. Lehr, President and Chief Executive Officer of the Parkinson's Foundation. "Our goal is to empower everyone new to our community to build a better life with Parkinson's from day one while addressing their unmet needs."

Close to 50 percent¹ of people of people with Parkinson's and their care partners leave the doctor's office following a diagnosis without educational resources or information on what the future holds. The Parkinson's Foundation aims to connect with this group earlier and more frequently to provide ongoing support to the newly diagnosed person throughout their entire journey with PD.

Get your own kit and read more about it at <https://www.multivu.com/players/English/8624451-parkinsons-foundation-launches-national-program-newly-diagnosed/?fbclid=IwAR2uOYBwHktwSuMrctFokf5-MnLN3jhYQwXRUOY18IZJZWTvFctJf6k893A> Also see this edition's BOOK CORNER review of THE PARKINSON'S PLAYBOOK for lots of helpful information!!

Meet Dr. Laurie K Mischley, ND, MPH, PhD

Dr. Laurie Mischley is a pioneer in the field of Parkinson's treatment and daily living! She has studied naturopathic medicine at Bastyr University and epidermiology/nutritional science at University of Washington. The focus of her work is on describing conditionally essential nutrients in PD, attempting to describe the nutritional status and requirements unique to individuals with neurodegenerative diseases. Dr. Mischley is on staff at the Seattle Integrative Medicine, as well as being a clinical research assistant professor at Bastyr University, where she is principal investigator of PD studies. She has been treating patients with PD for almost a decade and does not believe the disease need be either progressive or irreversible. It is her medical opinion that PD progression can be halted, and possibly reversed, with proper nutrition and optimization of biochemical function. Both her clinical experience and her understanding of the literature support this perspective. Her book, *NATURAL THERAPIES FOR PARKINSON'S DISEASE*, is groundbreaking!

NATURAL THERAPIES FOR PARKINSON'S DISEASE is a science-based reference manual...inspirational and empowering for PD clients...educational for both PD clients and neurologists...and it is even entertaining!! Here is a taste of Dr. Mischley's advise:

GUIDELINES FOR EATING WITH PARKINSONISM

- Choose nutrition-dense foods! If the food you are about to eat is not a rich source of nutrients, don't eat it!
- No dairy
- Lots of water
- High antioxidants: bright colored fruits/vegetables, green and black tea, beans/legumes
- Fish---5 servings per week
- Fava beans
- Moderate protein consumption, mostly from beans and poultry
- Spices—turmeric, cinnamon, cloves
- Egg yolks (choline source)—6/week

This is but a snippet of the wealth of information Dr. Mischley has to offer! You can learn more about her work at her website: <https://educationismedicine.com>.



**BOOK CORNER:****THE PARKINSON'S PLAYBOOK: A GAMEPLAN
TO PUT YOUR PD ON THE DEFENSE**

by
Robert W Smith

The Parkinson's Playbook puts the power in your hands, giving you the knowledge you need to proactively defend yourself against the progression of Parkinson's disease with energy, vitality, and confidence.

The diagnosis of Parkinson's disease is not an easy one. In *The Parkinson's Playbook*, author Robert Smith has prepared an enlightening and engaging "playbook" to help you tackle Parkinson's head on, including a pro-active offense of lifestyle improvements and defensive measures including cutting-edge medications and natural healing techniques.

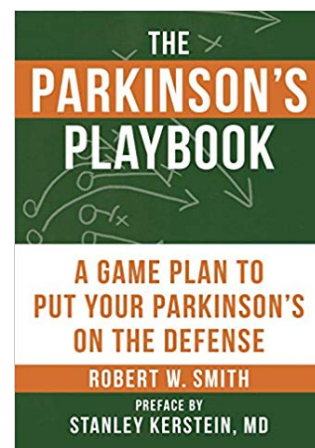
The Parkinson's Playbook makes you the MVP of your life—so get out there and win!

Also featured in *The Parkinson's Playbook*:

- How to assemble a line-up of medical and emotional support systems
- Learn the importance of exercise to boost strength and relieve stress
- Effective, easy-to-implement diet changes for well-being

...and so much more, all with the unique patient's perspective of the author's personal experiences fighting—and winning—against his disease. (Review by Amazon)

About the Author: **Robert Smith** is a Parkinson's disease advocate. His own diagnosis with Parkinson's disease has inspired him to be a mentor to those suffering from the same debilitating condition. Professionally, Robert has enjoyed a successful career as a landscape architect, and is a Fellow in the American Society of Landscape Architects. He currently lives in Denver, CO.



QUOTE OF THE SEASON:

“It’s about overcoming! If you can’t crawl over an obstacle, push it down or go around it. But never give up.”

Allison Toepperwein—Ninja Warrior & Marathoner

