The PADRECC Post

Department of Veterans Affairs
2015

THE PHILADELPHIA VA PARKINSON'S DISEASE RESEARCH, EDUCATION & CLINICAL CENTER

Nutrition and Parkinson's Disease

By: Dr. Shital Shah, PADRECC Fellow

Parkinson's disease (PD) is due to the loss of cells in a certain area of the brain that makes dopamine, which is a chemical that helps brain cells communicate with each other. At present, there are no medications proven to slow the progression of PD. However, many physicians and researchers believe that how you live your life may affect how you experience PD. For example, data that suggests that people who exercise often do better than people who don't. Further, nutrition may play a role in the symptoms of PD.

Dairy foods, mainly milk and cheese are linked to an increased risk of PD. On the other hand, plant-based foods such as fruits, vegetables, beans and whole grains have phytochemicals that are thought to have a number of health benefits. Phytochemicals are natural compounds contained in plant foods, of which the largest group are flavonoids. Flavonoids are substances that act as antioxidants stopping the buildup of harmful compounds and fight inflammation, two problems thought to be important in PD. Increased intake of a plant-based diet is associated with a lower risk of inflammation, and this may slow down the progression of PD or modify what symptoms you have.

Studies have found certain foods to be beneficial in PD. For example, drinking tea may help reduce the risk of PD. Caffeine may offer protection against PD, especially in men, by fighting against inflammation. Some initial research found that cinnamon may prevent inflammation. Curcumin, which is responsible for the yellow color of turmeric, is a common spice in Indian cooking and has long been used to fight a variety of diseases. It is thought to have antioxidant properties as well as antibacterial, antiviral, and anti-cancer properties. It may be helpful in the early stages of PD.

In addition to its effect on the disease itself, a plant based diet also helps with some of the non-motor symptoms of PD such as constipation. Due to the disease, as well as side effects from medications used to treat PD, constipation can be very troubling for some people living with PD. A diet rich in fruits and vegetables provides the fiber needed to help regulate the bowels and decrease constipation.

While much work still needs to be done about nutrients effect on the risk and progression of PD, it is obvious that what we eat impacts our health. The simplest way to take control of our future health is to increase the amount of fruits, vegetables, nuts, seeds and whole grains in our diet.

Standard recommendations are to eat at least 9 servings of fruits and vegetables a day, something that few people eating standard American diet do. For someone living with PD, we believe this is very good advice and we have clinicians ready to help you make this lifestyle change if you would like assistance. Taking control of an aspect of how you experience PD can also be very empowering, as you change from someone suffering with PD to someone managing life with PD.

Coping with Fatigue

By: Julia Wood, MOTR/L, BS

Fatigue is more than just being sleepy. It is often described as an overwhelming lack of energy and feeling of exhaustion that disrupts daily activities. Many people with Parkinson's disease (PD) experience fatigue, with up to one-third of PD patients interviewed rating it as their most disabling symptom. Little is known about the specific cause of fatigue in PD, but it is believed to be worsened by muscle stiffness, slowed movements, depression, medication side effects, and poor sleep. Fatigue is a personal and individual experience that can vary day to day and even change within the course of a single day. Because the experience of fatigue is unique to each person, it is important to try a variety of strategies to manage your fatigue and improve your overall quality of life.

Plan, Pace and Prioritize Your Day

It is important to create a balance of work tasks, self-care routines, and fun activities in your day. Many people with PD experience changes in their mobility throughout the day related to the dosing cycle of medications. Try to be flexible in planning your daily activities to create a balanced schedule that makes the most of your energy and mobility. Using a daily planner, smart phone, or another type of list can help you prioritize and space out your daily tasks and activities. Plan more difficult tasks during your times of optimal energy and mobility, but don't overdo it! Alternate heavy tasks with lighter activities, and pace your tasks with brief 15-30 minute rest breaks. Spend your energy wisely on the things you have to do and on what is most important to you.

The Importance of Rest

Rest can be used as a proactive, defensive strategy by resting ***before*** you typically become fatigued. Try keeping a daily journal of when you feel the greatest level of fatigue and plan to take your nap or rest break 1-2 hours before your period of increased fatigue. There are many ways to rest—listen to music, do quiet hobbies, meditate, sit quietly, or taking a nap. However, avoid long naps during the daytime if you experience trouble sleeping at night. Try different types of rest to see what works for you, and make it a daily habit!

Simplify Daily Tasks and Routines

It can be surprising how demanding our daily routines can be, especially when movement is difficult. Try to become aware of daily routines that are most challenging for you and attempt to change how you do them to reduce effort. Consider breaking up the routine of showering, grooming, and dressing before leaving for work or for a morning appointment by showering the night before. Another idea is to select your clothing for the next day before going to sleep. Try sitting to get dressed with all items placed within reach. Experiment with adaptive equipment, such as long- handled shoe horns, to decrease bending and stooping when putting on shoes. Consider ways to reduce the physical effort of daily activities—sit for tasks when possible, throw laundry down stairs in a bag, choose easy to wear clothing, utilize tools and technology, and ask for help when needed.

Nurture Your Body, Mind, and Spirit

Proper nutrition, activity/exercise, stress management, and forming a support network are crucial to your overall well-being and can help you cope with fatigue. Fueling your body with a balanced diet of fruits and vegetables, lean protein, healthy fats, and whole grains helps to maintain energy levels throughout the day. Try eating small, more frequent meals and snacks and avoid excess sugar and caffeine, which can cause fatigue. Discuss options for exercise/activity with your physician to see what is safe for you. Avoid boredom by actively engaging in fun leisure activities and enjoyable social events. Try mindfulness, meditation, or prayer to reduce stress, anxiety, or depression. Attend a local support group, talk with a friend, or participate in social activities to create an outlet for feelings and develop a sense of belonging. Talk to friends and family about your fatigue, and let them know how they can help you—they probably wish you would ask!

Julia Wood, MOTR/L, BS Exercise Science and Wellness is the Occupational Therapist at the Dan Aaron Parkinson's Rehabilitation Center in Philadelphia, PA.

Research Happenings at PVAMC PADRECC

Telehealth and Parkinson's Disease

Dr. Jayne Wilkinson has concluded a study evaluating the use of telehealth in treating Parkinson's disease. Telehealth allows a patient to be seen by a provider using a video connection either to their home, or to a closer, VAMC facility. The results of the study demonstrated promising findings. Dr. Wilkinson found that telehealth visits were associated with a high level of overall patient satisfaction, and improved patient satisfaction regarding convenience and accessibility, when compared with in-person visits. The study also demonstrated that telehealth results in savings related to travel and potentially impacts how patients utilize the healthcare system, in general. Clinical outcomes remained the same as in-person visits, demonstrating that telehealth is a viable way to deliver effective care. Findings were presented at the annual American Academy of Neurology Meeting in April 2014, and will be submitted for journal publication . The study was Dr. Wilkinson's thesis for her Masters in Clinical Epidemiology, which she will receive from Penn School of Medicine in May 2015.

Parkinson's Disease & Motor Symptoms

Dr. James Morley, Associate Research Director of the PADRECC, continues to study whether computerized movement tests can help identify early signs of PD and make the diagnosis of movement disorders more accurate. Data is being analyzed from patients who performed several movement tests using electronic monitoring devices. This included walking on a mat with sensors and moving their fingers and feet while wearing movement monitors.

Medication-Induced Parkinsonism

Dr. James Morley is conducting a study to understand how Parkinson's-like symptoms caused by medications are related to PD. Symptoms of PD can be mimicked by certain medicines (usually used for schizophrenia and some other psychiatric conditions) that block dopamine—the major brain chemical missing in PD. Not everyone's symptoms improve after the medicines are switched or stopped, so it is possible that the medicines uncover very early PD in some cases. Dr. Morley's team is comparing medication-exposed patients with and without Parkinson's symptoms using questionnaires, physical exam, blood tests and a brain scan in addition to following patients with symptoms after the medication is switched or stopped. Their goal is to determine whether any of these tests can predict which patients are at higher risk of developing PD.

Nutrition and Parkinson's Disease

Dr. Shital Shah, PADRECC Movement Disorders Fellow, Dr. John Duda, and Heidi Watson, RN, are conducting a study to determine the ease of following plant-based diet with the proper education and resources in addition to studying the effects of such a diet on the symptoms of Parkinson's disease. The study includes 3 months of bi-weekly sessions of education, food preparation and nutritional expertise. It is hoped that this study will allow patients to feel comfortable to change their diet to one that may improve the symptoms of PD.

Caregivers & Parkinson's Disease

Dr. Jayne Wilkinson, Gretchen Glenn, LCSW, and Eileen Hummel, RN, BSN conducted a study to examine a specific program that aims to help empower family caregivers to maintain their health, well-being and capacity to care. The telephone support group consisted of 8 weekly, 90 minute telephone conversations comprised of spouse caregivers of patients with Parkinson's disease. Caregivers found this support group helpful in taking care of a loved one with PD. The results of this study will be published in Geriatric Nursing.

Parkinson's Disease & Blood Pressure Medication

Dr. Shital Shah, PADRECC Movement Disorders Fellow, and Dr. James Morley are currently conducting a study to demonstrate the effects of a medication that increases blood pressure on symptoms of dizziness in patients with Parkinson's Disease. This study is based on a prior study conducted at the PADRECC by Dr. Amy Hellman using continuous non-invasive arterial pressure monitoring to show abnormal control of blood pressure responses in some PD patients. It is hoped that the results of this study will be able to provide additional options for the treatment of disabling dizziness to patients with Parkinson's Disease.

Traumatic Brain Injury

Dr. John Duda, PADRECC Director, and his colleagues, Drs. Kacy Cullen and John Wolf, from the Department of Neurosurgery at the University of Pennsylvania, continue studies funded by the Rehabilitation Research and Development Service of the Department of Veterans Affairs to develop animal models of Chronic Traumatic Encephalopathy (CTE) that sometimes develops years later in people such as football players and war fighters who have had traumatic brain injuries. The goal of these studies is to develop models of these changes in the brains of animals so that novel treatments and preventive strategies can be tested. It is hoped that these studies will lead to treatments to prevent the development of these neurodegenerative diseases in Veterans and others who have suffered head injuries.

Neurorestoration in Parkinson's Disease

Dr. John Duda and his colleagues Kacy Cullen, PhD, and James Harris, PhD from the recently established Center for Neurotrauma, Neurodegeneration, and Restoration (CNNR) at the Philadelphia VA Medical Center, were awarded a two-year grant from the Michael J. Fox Foundation for Parkinson's Research to investigate experimental reconstitution of the nigrostriatal pathway (the pathway that degenerates in PD and causes the motor symptoms) in animal models of PD in a grant entitled, 'Restoring the nigrostriatal pathway with living micro-tissue engineered axonal tracts'.

PADRECC Patient Spotlight: Tim Vallilee

By: Eileen Hummel, RN, BSN & Tim Valllilee

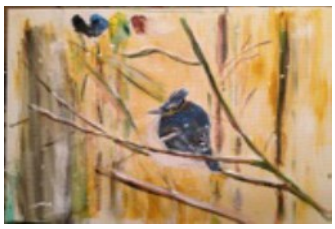
Tim Vallilee has been a patient at the Philadelphia VA PADRECC since 2010. After being diagnosed with Parkinson's disease, he discovered his creative side through painting. Tim's obvious talent has not gone unnoticed—his artwork was selected from over 300 artist submissions by the Parkinson's Disease Foundation (PDF), a leading national organization dedicated to Parkinson's disease research, education and public advocacy, for inclusion in their 2015 Creativity and Parkinson's Calendar. The annual calendar is a part of the organization's Creativity and Parkinson's Project, which highlights and supports creativity in the Parkinson's community. For more information and to see a gallery of work from other artists with Parkinson's disease, visit http://www.pdf.org/en/creativity.

How long have you had PD (when did symptoms start and when were you diagnosed)?

The first symptom I recall was while brushing my teeth in 2001 when I was about 48 years old. At age 52, I noticed a subtle tremor when taking a soup spoon away from my mouth. At first, I thought "too much coffee", but when it occurred every day, I suspected it was a Parkinson's symptom because my mother had PD. I went to a private neurologist who diagnosed familial or essential tremor. About 5 years later at age 56, my girlfriend at the time noticed a slight tremor while holding my hand. Dr. Hogg at the Wilkes-Barre VA Medical Center diagnosed PD in 2008.

When and why did you start painting?

Two years ago, a friend was visiting my girlfriend (now spouse) in Key West at Christmas. She brought along watercolor paints and suggested I give it a try. I scoffed and said, "I can't even draw a stick figure." She offered a brush and said, "Paint what you see." I've been painting nearly every day since and have produced over 500 paintings.



What is your preferred medium and why?

I used watercolor exclusively until recently, when I started experimenting with acrylics. I did four bird paintings in my first day with acrylics.

What is the best thing about being an artist for you?

Discovering myself and the world outside. Feeling the appreciation and enjoyment of others. It amazes me what resonates with people. All of my art is for sale for donations to causes we support. A surprising amount of money has been raised for helping others.

How has having PD influenced your artwork?

When I was first diagnosed I was scared. I thought the end was near because my mother died shortly after being diagnosed (from unrelated causes). I decided to open all the doors, let everything in and let everything out. Live each day like it is my last and fill it with love, beauty, gratitude, my best effort, and a contribution to others. PD has been a gentle blessing to me so far.

What message do you have for others with PD?

Paint what you see.

Tim moved to sunny Florida a few years ago, but is still followed by the Philadelphia VA PADRECC. He often alternates between home Telehealth and clinic visits when he is visiting the Philadelphia area. He recently married "the most beautiful woman in the world" and also has two grown children who he "admires and aspires to become more like." When he is not painting, he enjoys biking, running, swimming, fishing, playing guitar, singing, kayaking, and embarrassing his children regularly. He has raised thousands of dollars for charitable causes through donation of his artwork.

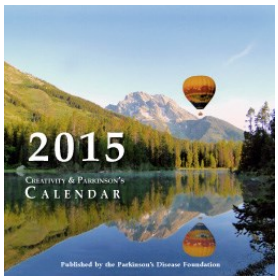
References: www.pdf.org

Creativity and PD

The PADRECC Post recently featured two Veterans who discovered their artistic abilities after being diagnosed with PD, coincidence…maybe not! There is growing interest in the possible relationship between enhanced creativity and dopaminergic therapy in PD, namely carbidopa/levodopa.

The Parkinson's Disease Foundation's ***Creativity and Parkinson's Project*** highlights and supports creativity in the Parkinson's community. This project develops a yearly calendar featuring artwork of those with PD and also has an online gallery sharing artists' personal stories. For more information and to view the online gallery, visit **www.pdf.org.en/creativity**.

The PADRECC will be hosting a **"Creativity Session"** on April 10, 2015 from 1pm-3pm. This program will give Veterans an opportunity to explore their "creative side" while experiencing how creativity can impact well-being. If interested in attending this program, please contact Gretchen Glenn at 215-823-5934.



PADRECC Telehealth: Exciting NEWS!

The PADRECC telehealth initiatives have successfully expanded to include home quantitative assessments of patients with Parkinson's disease.

Parkinson's disease is characterized by widely fluctuating symptoms; meaning in one day, a patient may experience periods of time with no/little symptoms, and conversely, periods of great disability/symptoms. It is widely recognized in the neurology community that seeing a patient in clinic is extremely limited, as this "snapshot" of ~30 minutes or so, may not accurately reflect their overall clinical status and treatment needs.

As such, we have worked over the last year to secure equipment and develop a clinical program that will allow us to monitor symptoms over the course of an entire day and/or multiple days. We believe this will enhance our ability to manage more difficult cases. We are also interested in how this equipment may allow us to continue to provide remote care to those veterans unable to travel to our center. We also believe it may someday provide a means to more easily include patients in interesting clinical trials and research activities.

We are excited to report that we just completed our first pilot patient, who underwent monitoring for 4 weeks. Mr. Howard Stein, a long-standing PADRECC patient and advocate for Parkinson's disease research and innovation, volunteered to participate in this pilot program. We are grateful for his service to our country, as well as his service to the Parkinson's disease community by participating in this program. It is solely due to the interest and willingness of patients like him to explore these newer innovations, that we continue to evolve and provide state-of-the-art care to our veterans afflicted with Parkinson's disease.

PADRECC Parkinson's Disease Education Group

Group meets the **1st Monday** of each month at **l:30 pm** in the 4th Floor PADRECC Conference Room and at the **VA Fort Dix & Horsham Clinics** via video connection. If you are interested in attending the education group at the **VA Ft. Dix or Horsham Clinics please contact Gretchen Glenn, 215-823-5934, as space is limited.**

**Topics and Speakers are subject to change*

April 6
Speaker: Dr. Shital Shah, PADRECC Fellow
Topic: Nutrition and PD

May 4
Speaker: Delores Iacovone, Occupational Therapist
Topic: Driving & PD: What is a Driving Evaluation

June 1
Speaker: Dr. Paul Moberg, Neuropsychologist
Dr. Laura Brennan, Neuropsychologist Fellow
Topic: Memory, Thinking & Other Non-Motor Symptoms in PD: Description & Coping Strategies

July 6 **NO GROUP**

August 3
Speaker: Maan Sukte, Speech Language Pathologist
Topic: Speech & Swallowing Issues in PD

September 7 **LABOR DAY NO GROUP**

October 5
Speaker: Erica Wiegand, Physical Therapist
Topic: Practical Pointers in PD: How to Manage Everyday Tasks

November 2
Speaker: Dr. James Morley, PADRECC Neurologist
Topic: Research Update: What's New

December 7
Speaker: PADRECC Fellow
Topic: TBA

VA Catastrophically Disabled Veterans Program

VA provides additional benefits for Veterans with a Catastrophic Disability. "Catastrophically Disabled" means that a specific medical condition, injury or disorder **severely** impacts your ability to perform routine, day-to-day activities (such as bathing, dressing, eating), and that you need assistance to do these tasks.

A Veteran who is determined by VA to be Catastrophically Disabled will be placed in Priority Group 4 and will be exempt from inpatient, outpatient and prescription copays. They are also exempt from copays associated with receipt of noninstitutional respite care, geriatric evaluation, adult day health care, home health aide, purchased skilled home care, and VA Home Based Primary Care. Copayments for other extended care services not mentioned still apply (ex. nursing home care).

If you are a patient registered with the Philadelphia VA Medical Center and followed for a condition at the PADRECC that impairs these activities, you may request a Catastrophic Disability Evaluation. Your Provider will determine if you meet this criteria and submit an application for further review to ultimately determine if you qualify for this program.

To request this review, please alert your PADRECC Provider at your next appointment or by calling **215-823-5934**, referencing this program. If you are registered at another VA Medical Center you should contact the Enrollment Coordinator at that facility and request a Catastrophic Disability Evaluation.

If you have additional questions about this program please feel free to ask your PADRECC Provider or Social Worker-Gretchen Glenn for more information.

Dr. John Duda

Dr. Jayne Wilkinson

Dr. James Morley

The Philadelphia PADRECC Team

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Tonya Belton, Program Support Associate
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To learn more about the Philadelphia PADRECC and the National PD Consortium, please call:
215-823-5934 or 1-888-959-2323
or check us out on the Internet at:
www.parkinsons.va.gov

PADRECC Resources

Patient Education Video Series

The PADRECCs developed the "My Parkinson's Story" Film Library Video Series. The videos provide information about common concerns related to PD. Each of segments explores a specific issue related to PD from the perspectives of the patient, his or her family and his or her healthcare team. All videos are available for viewing on the National PADRECC & VA PD Consortium website: **www.parkinson.va.gov** and on You Tube.

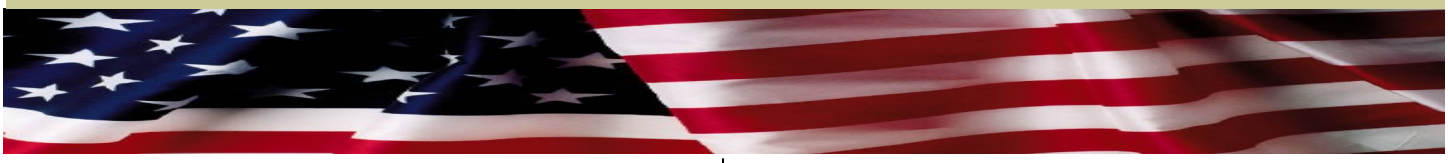
Parkinson's Disease Hospital Kits

According to the National Parkinson's Foundation (NPF), people with PD face greater risks and challenges when hospitalized. The best way to avoid complications while hospitalized is to be prepared. The **PADRECC Parkinson's Disease Hospital Kit** and the **NPF Aware in Care Kit** were developed to help you do this. If you are interested in obtaining a Parkinson's Disease Hospitalization Kit and/or the NPF Aware in Care Kit ask your PADRECC clinician or Social Worker.

Patient Education Brochures

Patient Education Brochures were developed to provide patients and families with information on the most common topics concerning Parkinson's disease: **Fall Prevention, Exercise and Physical Activity, Medications, Agent Orange, Motor and Non-Motor Symptoms of PD.**

The brochures are available in the Philadelphia VA PADRECC Clinic or can be downloaded from the National PADRECC & VA PD Consortium website: **www.parkinsons.va.gov**



PD Organizations

American Parkinson Disease Association (APDA)
www.apdaparkinson.org (800) 223-2732

National Parkinson Foundation (NPF)
www.parkinson.org (800) 327-4545

Parkinson Disease Foundation (PDF)
www.pdf.org (800) 457-6676

Michael J. Fox Foundation
www.michaeljfox.org 212-509-0995

Davis Phinney Foundation
www.davisphinneyfoundation.org (866) 358-0285

Related Movement Disorder Organizations

CurePSP
www.psp.org

Lewy Body Dementia Association
www.lbda.org

Association for Frontotemporal Degeneration
www.ftd-picks.org

Huntingdon's Disease Society of America
www.hdsa.org

International Essential Tremor Foundation
www.essentialtremor.org

Veterans Affairs

National PADRECC & VA PD Consortium
www.parkinsons.va.gov 1-888-959-2323

Agent Orange Website
www.publichealth.va.gov/exposures/agentorange

VA Health Care Eligibility
www.va.gov/healthbenefits 1-877-222-8387

Veterans Benefits Administration
www.benefits.va.gov/benefits/ 1-800-827-1000

VA and Department of Defense
www.ebenefits.va.gov

My Health*e*Vet
www.myhealth.va.gov

VA Caregiver Support
www.caregiver.va.gov 1-855-260-3274

State Veterans Affairs Offices
www.va.gov/statedva.htm

Veterans Crisis Line
1-800-273-8255 Press 1

With Sincere Thanks

The Philadelphia VA PADRECC would like to thank those who made charitable donations on behalf of loved ones followed in the clinic. The donations are used to support our education initiatives.

The PADRECC Post

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