



THE PADRECC POST

Spring 2013

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

The Nose Knows, or Maybe Not

By: Dr. John Duda, PADRECC Director

When most people think about Parkinson's disease, they think about tremor, difficulty walking and slow movement. Many patients and caregivers know that these are certainly troubling symptoms, but also recognize that many other symptoms can be even more troublesome and disabling including problems with thinking, mood, constipation, sleep, and so on. Few people would immediately think of loss of sense of smell as an important symptom in Parkinson's disease, but in reality, it is very common, even more common than tremor. The loss of your sense of smell can affect your life in many ways including affecting your appetite and nutritional status, your quality of life and even your safety. In a study conducted by PADRECC collaborators at the University of Pennsylvania in 1991, patients with decreased sense of smell were questioned about the effect it had on their lives. Out of 750 patients, 68% reported altered quality of life, 46% reported changes in appetite or weight loss and 56% reported adverse influences on daily living or psychological well-being.

For many patients, loss of the sense of smell may not be as bothersome as some of the other numerous symptoms affecting them, but it is important for patients and caregivers to recognize whether this is a problem or not. To complicate matters, most patients with Parkinson's disease who can't smell aren't aware of their disability. Because of the gradual onset of smell loss, patients will often report that their sense of smell is fine

but when they are formally tested they are found to be functionally anosmic (having no functional smell ability). The only way to know for sure whether a patient has impaired olfaction (sense of smell) is to formally test it. Such testing is available at the PADRECC.

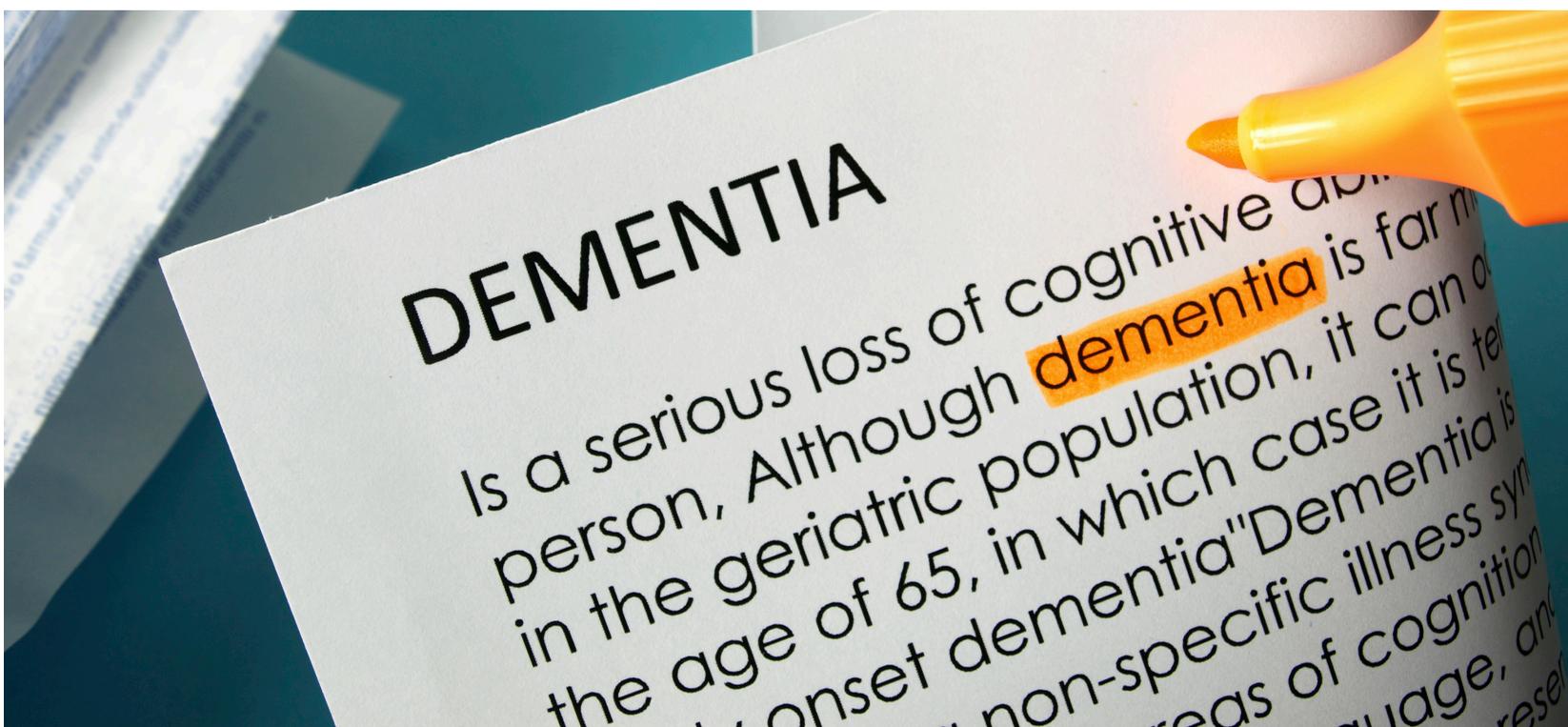
In fact, researchers at the Philadelphia PADRECC have been conducting studies for more than 10 years to try to use the loss of sense of smell as a tool to predict many things about Parkinson's disease, including who will eventually get it and the future progression of the illness.

Another common misperception about the sense of smell is that we don't use it for much anymore. In fact, the overwhelming majority of the sensations that we normally think of as taste, are actually brought to our attention by our olfactory system. To see for yourself, try eating something very flavorful with and without your nose pinched closed. If you can smell normally, you will notice a big difference. If you can't tell much of a difference with and without your nose closed, you may be having problems with your sense of smell. Because smell plays such a large part in our sense of taste, it also plays an important role in one of life's greatest pleasures: the enjoyment of fine food and drink. The decreased sensation of flavors causes many patients with Parkinson's disease to report less enjoyment in eating and drinking, and as a result, often lose weight because of a lack of desire to eat. To help overcome this problem, it is often helpful to make food that is more

flavorful by adding additional herbs and spices so that patients with decreased sense of smell can enjoy eating again. Experimenting with new foods and new ways of preparing foods, particularly whole grains, beans, seeds, nuts, fruits and vegetables, can also add some excitement to your meals and help maintain your overall health.

Finally, one more important reason to be aware of whether a patient with Parkinson's disease has impaired sense of smell is to know whether they would be likely to smell dangerous odors such as spoiled food, fire or natural gas. In one study from 2004, up to 45% of patients with no sense of smell reported at least one hazardous event, such as food poisoning or failure to detect fire or leaking natural gas. In those patients with decreased sense of smell, care should be taken to avoid these risks by making sure that foods are stored, handled and discarded appropriately. Additionally smoke and natural gas detectors should be installed throughout the house as necessary.

While losing your sense of smell may seem minor compared to having a disabling tremor or having problems walking, it is one symptom of Parkinson's disease that is important to keep in mind because it often goes unrecognized. While there are no known medical therapies to improve the sense of smell, simple lifestyle changes can certainly improve the quality of life and safety of someone with Parkinson's disease and impaired sense of smell.



Parkinson's Disease and Dementia

What You Should Know

By: Dr. Amy Hellman, PADRECC Fellow

Parkinson's disease (PD) affects many aspects of life in many ways. In addition to the effects it has on physical abilities, it can affect memory as well. Up to 40% of people with PD eventually develop dementia.

Dementia is a group of symptoms that may include loss of memory, judgment, language, and other mental functions.

Dementia in PD usually occurs in late stages of the disease, after having motor symptoms such as tremor, stiffness, and slowness for several years. Dementia in PD is different from the dementia we typically see in other diseases such as Alzheimer's disease. Memory problems are usually mild and less prominent.

Instead, people with PD dementia have more trouble making decisions or multi-tasking, judging distances, thinking clearly, paying attention, or remembering recent events. A person may get lost or have trouble doing normal daily activities.

Visual hallucinations may occur and can be made worse by the medications that treat PD. It is important to keep in mind that visual hallucinations can occur in PD without dementia as well, so having visual hallucinations does not mean you have dementia.



If you notice any of these signs, it is important to bring them up to your health care provider who can arrange further testing and, if necessary, treatment for the dementia. There

are medications that can provide some benefit. Although they are not able to restore memory function that has already been lost, they may be able to slow further decline.

A major issue for people with dementia as well as their caregivers is safety. Many people with dementia do not realize that they are impaired, so they try to continue their usual daily activities. In some cases, this can be dangerous. One such example is driving. As mentioned earlier, problems judging distance is commonly seen in PD dementia which can make driving unsafe. When your health care provider asks if you are still driving, be honest. They can refer you

for a driving test through the VA and, if needed, driving rehabilitation, so that you can continue driving safely as long as possible.

New Resources

Patient Education Brochures

The Patient Education Brochures listed below were developed by the PADRECCs to provide patients and families with information on the most common topics concerning Parkinson's disease. 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

- ◆ Fall Prevention
- ◆ Non-Motor Symptoms of Parkinson's Disease
- ◆ Motor Symptoms of Parkinson's Disease
- ◆ Exercise and Physical Activity
- ◆ Parkinson's Disease Medications
- ◆ Agent Orange and Parkinson's Disease



Patient Education Video Series

The PADRECCs in collaboration with the VHA Employee Education System (EES) developed the DVD, "My Parkinson's Story." The DVD provides information about common concerns related to PD. Each of the 8 segments on the disk explores a specific issue related to PD from the perspectives of the patient, his or her family, and his or her healthcare team. Topics include: DBS, depression, early PD, environmental exposures, falls, genetics, memory and thinking problems and sleep problems. To obtain a DVD, call the PVAMC PADRECC at 215-823-5934 or view from the National PADRECC & VA PD Consortium website: www.parkinsons.va.gov

National Parkinson's Foundation (NPF) "Aware in Care Kit"

This kit contains useful tools and information to help people with PD advocate for themselves during a hospital stay. The kit includes a bag for carrying medications, a hospital action plan, a medical alert ID bracelet and wallet card, forms to list medications, fact sheets about PD, and reminder slips to share with hospital staff stressing the importance of receiving PD medications on time. You can order the kit on line from the NPF: www.awareincare.org
 **Medical Alert ID Bracelets are also available at the VA- be sure to ask your PADRECC clinician or social worker to order you a personalized Medical Alert ID bracelet via Prosthetics Department. The bracelet will alert others about your DBS implant, Parkinson's disease, cognitive impairment, or other health conditions.

My HealthVet

My HealthVet is the VA's online Personal Health Record (PHR) that is secure and available online 24/7. Depending on the type of account, you will have access to following features:

Basic Account

- Self entered health information
- Food & activity journals
- Medical and drug libraries
- VA prescription refills

Upgraded Account

- VA Wellness Reminders
- Allergies & Adverse reactions
- VA Appointments
- VA Chemistry and Hematology Lab Results
- Secure Messaging with your health care team
- Access to your medical record

For more information or assistance with My HealthVet contact: My HealthVet Coordinator:
 (215) 823-5800 Ext:4758 or www.myhealth.va.gov



Research Happenings At PVAMC PADRECC

Telehealth

Dr. Jayne Wilkinson, Associate Clinical Director of the PADRECC, is conducting a study to evaluate the use of telehealth technology. Telehealth is a newer technology being used throughout the VA system and allows a patient to see a clinician by a video connection. Use of telehealth is thought to increase access to healthcare as well as reduce patient travel expenses. Recruitment for the study began in June 2011 and will end in February 2013. Dr. Wilkinson hopes to examine whether the use of telehealth improves accessibility to care offered by PADRECC clinicians and reduces cost and travel difficulties for Parkinson's patients, as well as maintaining customer satisfaction.

Parkinson's Disease and Overactive Bladder

Dr. Wilkinson is conducting a study to look at treating overactive bladder syndrome in patients with Parkinson's disease (PD). The study is examining the cognitive effects of medications used to treat overactive bladder (OAB) syndrome. OAB is common in patients with PD and characterized by symptoms such as feeling a sudden urge to urinate that's difficult to control, urinating frequently, and/or awakening often during the night to urinate. It is important to understand not only how well these medications work in PD, but to appreciate any side effects risks that may be present.

Parkinson's Disease & Motor Symptoms

Dr. Morley, Associate Research Director of the PADRECC, continues to enroll patients into a large study that looks at whether movement tests can help identify early signs of PD and make the diagnosis of movement disorders more accurate. Patients are asked to perform several movement tests using electronic monitoring devices. This includes walking on a mat with sensors and moving their fingers and feet while wearing movement monitors. Through the use of computers and other devices, Dr. Morley and his research

team record the results of these tests. Early results shows these studies to be promising for monitoring symptoms of PD and the findings will be presented at the annual American Academy of Neurology Meeting in March 2013.

Drug-Induced Parkinsonism

Dr. Morley is also conducting a study to understand how drug induced parkinsonism symptoms are related to PD symptoms. Symptoms of PD can sometimes be mimicked by certain drugs. Dr. Morley's team is performing a chart review to see what clinical features help tell the difference between drug induced parkinsonism patients and PD patients. The results of this study will also be used to help design future studies

Parkinson's Disease and Blood Pressure

Dr. Amy Hellman, PADRECC Movement Disorders Fellow, was awarded a PADRECC Pilot Grant to study blood pressure changes in Veterans with Parkinson's disease. Recruitment began in May 2012 and will end in May of 2013. Initial results will be presented at the annual American Academy of Neurology Meeting in San Diego in March 2013. Dr. Hellman hopes to show that blood pressure changes could potentially be used for early detection of PD.

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, were recently funded by the Rehabilitation Research and Development Service of the Department of Veterans Affairs to begin a 5-year research study of animal models of Traumatic Brain Injury (TBI). The goal of this study is to model the effects that TBI has on the later development of PD and Alzheimer's disease. It is hoped that these studies will lead to treatments to prevent the development of these neurodegenerative diseases in Veterans with TBI.

PADRECC Patient Rides Bicycle 100 miles on 10 Year Anniversary of DBS

By: Joe Cocalis, PADRECC Patient

I was once an avid bicyclist and had ridden several centuries (100 mile bike trips) in the early to mid 1980s. By the mid 1990s, my lack of coordination resulted in curtailment of my riding and in 1994 I was diagnosed with Parkinson's disease. In 2002, I had my first deep brain stimulation (DBS) surgery to control right-sided PD symptoms. The disease eventually progressed to my left side and in 2007 I had my second DBS surgery.

In 2009, the Morgantown, WV to Point Marion, PA segment of rail trail was completed. Dennis, my long time friend and colleague, challenged me in July 2010 to get my 1979 vintage trek bike out of hibernation and ride for 60 miles in September 2010; 60 miles on my 60th birthday. It seemed impossible but I trained hard for two months. The main issue I had was getting on and off the bike and sometimes falling when shifting gears. I completed the 60 miles. I felt great! Except for slurred speech and slowness, I felt like I didn't have PD and was off most of my medications.

Dennis then offered me another challenge: the Rogers Ride, a slow-paced century ride with 50-75 riders on flat terrain that starts in North East, PA, proceeds to Buffalo, NY and finishes in Niagara Falls, Canada. The ride occurred on June 2, 2012, the 10 year anniversary of my 1st DBS surgery. To train for the ride, I put in 1,000 miles of slow-paced flat trail riding with trips ranging in length up to 64 miles. Based on my training, I didn't know if I could complete the century because I often looked and felt like hell after 40 miles. What made the chances of completion difficult was for three weeks prior to the ride my right side weakened after about 20 miles, but I figured this would be my last good chance at completing a century ride.

The gods were with me on the day of the ride as there was a good tailwind and it was not too hot. After the first 10 miles I was last in the group. Not a good sign, because I was riding a faster pace than I was use to and falling further behind. Luckily, the riders regrouped after every 10-15 miles but my breaks were shorter than the rest of the group. After 40 miles, I phoned my wife and relayed to her that I

was exhausted and didn't know if I had it in me to complete the century, but I would not give up easily!

After 50 miles, the group had to traverse 5 miles of double lane highway, rather quickly under police escort. I was asked to ride the rest of the trip with the sag wagon so I would not hold up traffic. I grudgingly complied. Then after the 5 miles, I decided not to quit and got back on the bike. By that time, my right side was failing me and I was leaning to the right which caused my foot to occasionally come out of my pedal. The leaning made it difficult for me to get my foot back in the pedal. This happened once at a stoplight and to avoid crashing into several other bikers, I took the first of four falls.



At the next break area, I noticed my right foot dragging was pronounced. I was asked to go ahead of the group with the ride leader so I would not hold us up at customs. Then came my ride over the Peace Bridge into Canada. I was advised to walk my bike over the bridge because of the high cross-wind, low railing on the left, and sudden drop off from the narrow sidewalk but I rode my bike over it anyway. With the adrenaline rush, I forgot that I was tired.

After going through Canadian customs, I came out of my left pedal again and went into a curb and over the handlebars in front of a crowd of bikers. Some bikers rated my leap over the handlebars a "10" while asking if I needed help. I said "No" and told them that I was going to complete a century.

The last 20 miles were arduous. I had no power in my thighs and my feet hurt. Dennis stayed back to ride with me, while the rest of the crowd went on and completed the trip. I fell off the bike twice when stopping. Luckily, I have knowledge of how to fall safely from my training rides and paratrooper days. With a speed of about 6-8 miles per hour, the remaining miles seemed an eternity. At mile 97 the sag wagon came by to pick me up so I would not miss dinner, I said "No" and went on. At Niagara Falls, mile 99.9, I had to stop at a difficult crossing and could not get back on my bike. I walked my bike the last tenth mile to complete the century!

PADRECC Upcoming Events

Parkinson's Disease Patient & Caregiver Support Group

The group will meet the 1st Monday of each month at 1:30 pm starting April 1st. The group will be held in the 4th Floor PADRECC Conference Room and at the VA Fort Dix and Willow Grove Clinics via video connection. If you are interested in attending the support group at the VA Ft. Dix or Willow Grove Clinics please contact Gretchen Glenn, 215-823-5934, as space is limited.

**This group is for patients who are diagnosed with Parkinson's disease or parkinsonism, and their caregivers.*

April 1

Speaker: Dr. Alex Pantelyat, PADRECC Fellow

Topic: Dance and Music for PD

May 6

Speaker: Gretchen Glenn, PADRECC Social Worker

Topic: Traveling with PD: Practical Tips

June 3

Speaker: Dr. John Duda, PADRECC Director

Topic: Dietary Concerns in PD

July 1

Speaker: Heidi Watson, PADRECC RN

Topic: TBA

August 5

Speaker: Eileen Hummel, PADRECC RN

Topic: Driving and PD

September LABOR DAY NO GROUP

October 7

Speaker: Dr. Jayne Wilkinson, PADRECC Neurologist

Topic: Early PD

November 4

Speaker: Gretchen Glenn, PADRECC Social Worker

Topic: Hospitalization and Parkinson's Disease

December 2

Speaker: PADRECC Fellow

Topic: TBA

Essential Tremor Symposium

This is a joint education program with Pennsylvania Hospital's Movement Disorders Center and will be held on September 21, 2013, registration is required. If you would like additional information about this event please call Gretchen Glenn, 215-823-5934



Dr. John Duda,
Director



Dr. Jayne Wilkinson
Associate Clinical Director



Dr. James Morley
Associate Director of Research

Philadelphia PADRECC Staff

Dr. John Duda, Director

Dr. Jayne Wilkinson, Associate Clinical Director

Dr. James Morley, Associate Director of Research

Dr. Pratap Yagnik, Chief, Neurology Service

Dr. Alexander Pantelyat, 2nd year Fellow

Dr. Shital Shah, 1st year Fellow

Dr. Daniel Weintraub, Geriatric Psychiatrist

Dr. Paul Moberg, Neuropsychologist

Rebecca Martine, MSN, RN, PMHCNS, Nurse Coordinator

Heidi Watson, BSN, RN Nurse Coordinator

Eileen Hummel, BSN, RN Nurse Coordinator

Gretchen Glenn, LCSW Social Worker

Stephanie Pawlowski, Research Coordinator

Dawn McHale, Program Specialist

Tonya Belton, Program Support Associate

Yolanda Robinson, Patient Services Assistant

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



PHILADELPHIA
VA MEDICAL CENTER
Serving those who served.

Upcoming Community Events

World Parkinson Congress

The 3rd World Parkinson Congress will be held from **October 1-4, 2013** in Montreal, Canada. For additional information on this Congress see www.worldpdcongress.org

Stamp Out Parkinson's Disease

The 12th Annual Stamp Out Parkinson's Walk will be held on **October 12, 2013** at the Philadelphia Art Museum in MLK Drive. For more information visit The Parkinson Council website www.theparkinsoncouncil.org

THE **PADRECC** POST

Editors: Gretchen Glenn, LCSW & Rebecca Martine, MSN, RN, PMHCNS

Philadelphia VA Medical Center

PADRECC #127
3900 Woodland Ave.
Philadelphia, PA 19104
1-800-949-1001
www.philadelphia.va.gov

Phone: 215-823-5934 or 1-888-959-2323
Fax: 215-823-4603



PHILADELPHIA
VA MEDICAL CENTER
Serving those who served.



VA
HEALTH
CARE | Defining
EXCELLENCE
in the 21st Century