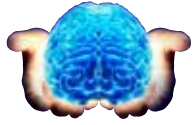




Ruby's Big Move

..... P2



Making a Deposit at Your Local Brain Bank

..... P4



The Creative Spirit: Victoria Tane

.....P12



Parkinson's companion

 Dartmouth-Hitchcock

A publication of the Parkinson's Information & Referral Center at Dartmouth-Hitchcock

SPRING 2018

Maureen Chamberlain, a Volunteer and Advocate for Parkinson's

BY GAY PALAZZO

YOU MAY HAVE seen Maureen Chamberlain as she introduced a lecturer at a workshop for those affected by Parkinson's disease (PD) or with her husband Fred, pulling together a Parkinson's Walk-A-Thon, organizing a support group meeting, or masquerading as elves in the local Polar Express Train Ride! For many years, Maureen and Fred have been volunteers in their hometown as well as in the PD community.

Maureen and Fred raised their three children in the Derry, NH area. For more than 25 years Maureen was a busy elementary school teacher. Then she began experiencing symptoms and was diagnosed with PD. She eventually gave up her teaching career and

became devoted to helping others living with this disease.

In 2008, Maureen contacted Diane Sherman, Coordinator of the Parkinson's Disease and Movement Disorders Center at Dartmouth-Hitchcock Medical Center (DHMC), and became part of Diane's team. Maureen stated her interest in reviving the long-dormant NH Chapter of the American Parkinson's Disease Association (APDA), which is devoted to raising funds for research to find a cure and providing information and support to the Parkinson's community. Maureen leapt in as the new Chapter President, recruiting others to serve as Vice-President, Secretary, Treasurer and

Board Members...and doubling up on those positions whenever someone was no longer able to serve. With Fred's help and support, she organized several fundraisers in southern NH including candlelight vigils and an annual Walk in the Park.

Maureen has been ever-present at Parkinson's educational events in NH, providing Chapter information at both the podium and exhibit tables. She has contributed several articles to the *Parkinson's Companion* newsletter published by the DHMC Parkinson's Center. She campaigns for caregivers, who are often under-recognized and in need of a break and some time and care for themselves. And if she

Continued on Page 2



Ruby's Big Move

BY B. ELWIN SHERMAN

WE'RE HAVING one more conversation with Ruby before she makes "The Big Move."

Ruby has Parkinson's disease. She has just reached her seventy-fifth birthday, and tomorrow she's leaving her home and husband of fifty-one years for a new life.

Ruby, tomorrow is a big day for you, when you will leave here and move into a nursing home. What are you thinking right now?

The line that keeps coming into my mind is "Here I sit, surrounded by boxes."

What's in the boxes?

A lifetime of collecting.

Collecting ... what?

Art. My paintings have taken me into new places, and I now must figure out how to

display them. It's important to me that they find the right places on the right walls. I suppose I'm just a big variation of that.

Could you share what it is that scares you?

I don't know if my friends will remember me. What more does this old body have in store for me? Lately, it has let me down. Will I fit in there? Will they like me? Will it work—living without my husband? They'll think I'm a widow. Will I have to eat my broccoli? What if I don't? I want my old life back.

What have you done to prepare for this change in your life?

I've planted in my mind: places where this lamp should go, or where that painting will hang, or where I'll put my doodads. Maybe if I do what I've always done— just let those things find their own way—it will turn out alright.

How do you think your new home will be different from this one?

Smaller. I may have to share special places that have always been private, and that will be hard for me. There will be more traffic outside my window. Someone else will weed the gardens. I'm losing my beautiful view. There will be people to help me do a variety of things that I would like to do myself.

Like what?

Giving up spontaneity. Everything will be planned, scheduled, according to someone else's idea of who I should be ... and when I should be.

So... you like doing things when you like to do them?

Is that your stupid question of the day?

Continued from Page 1

hears of a person who needs support, she is on the phone immediately to say, "You are not alone!" Her positive attitude is infectious and her own program of physical exercise is a model for us all.

A few years ago, Maureen and Fred relocated to northern NH to start a new adventure in their lives. (Typical Maureen!) They were eager to meet others in the area who were affected by PD but were very

surprised at the lack of organized services available. As you can imagine, they have taken on Parkinson's awareness and support in the White Mountains as their new project, providing leadership at the local support group and reaching out to others in need of information and a warm and friendly voice of recognition.

Thank you Maureen and Fred for all you have done and continue to do!



COVER PHOTO: Maureen Chamberlain advocating for people with Parkinson's and for the American Parkinson Disease Association at an educational event at DHMC.

Sorry.

I have a question for you: How will I know what to keep and what to leave behind? This house has nine rooms. I'm moving into three. You're good at math, aren't you? How do I leave behind the precious things I've had for fifty years? What goes? What stays? How do I wrap up the warmth I have here in these nine rooms, and unpack it in three?

What are your expectations?

I hope I can grow into this life. I hope I can take advantage of what it has to offer. I hope it will fit. I hope I will fit.

Did you ever imagine your life coming to this?

Never. Now I see myself as outside of myself, because of my Parkinson's. I thought I would grow old with my family. I never thought I would be among the excluded. I feel removed. I feel like a stranger to myself.

What do you think you'll miss most about the way your life has been?

I'll miss the enjoyment of watching my grandson discover the beauty of where he is in his years. I'll miss sharing his journey, the book of his life. Yes, I'll still see him, but much less than now. Now, I might miss a chapter or two.

Do you have any advice for anyone facing what you're facing?

Hang on tight. Hold on to your memories, even the ones you've forgotten (that's an inside Parkinson's joke). Try to find the joy in what's around you, not way out there, but right here, close to you. Never forget that tomorrow is a new day.

What if you could only take one thing with you from this place into your new life? One thing, at the expense of all others. What would it be?

Big Red. She's over there hanging on the wall above the amaryllis plant.

The painting of the young girl?

Yes. My daughter dubbed her 'Big Red' because of her flaming red hair. It's by a Dutch artist who I know, but it's of a girl I don't know, which I think is a perfect match for me right now.

Is she your metaphor for the big move?

Yes. Yes. Yes! Look there. Do you see the mystery in her eyes? I always have. She's always drawn me into the unknown. She's my Mona Lisa. She's the unknown girl facing an unknown future. Do you see that?

And, she's going with you?

No. I'm going with her.

For more reading on Ruby, please visit the Dartmouth-Hitchcock *Parkinson's Companion* web page and follow the links to the Fall 2015 and Fall 2016 issues. You'll find "Ruby and the Not People," and "Ruby Now and Then."

Senior Wire News Service Syndicated Columnist B. Elwin Sherman writes from Bethlehem, NH. He is an author, poet, humorist and long-time eldercare and hospice nurse. His latest book is "The Dioecians—His and Her Love." You may contact him via his website at Witbones.com. Copyright 2018. All rights reserved. Used here with permission.



A Note from the Coordinator: Diane L. Sherman, PhD

Dear friends,

It is with great sadness that I announce that this is the final edition of the *Parkinson's Companion*. The newsletter has been published twice a year since spring 2008. It has provided a platform for the community to share insights into life with PD, and timely information on symptoms, treatments and research, and announcements of events, support groups and clinical studies. Unfortunately, the cost involved in producing, printing and mailing the newsletter has led to the decision to discontinue publication.

In this, our swan song edition, we feature a tribute to Maureen Chamberlain in our "Voices of Parkinson's," the conclusion of a trilogy about "Ruby," and some most-requested articles from past newsletters.

I will continue to send a weekly newsletter via email, and am available by phone, email and in person to assist you in any way I can.

Best wishes,

PARKINSON'S COMPANION IS A PUBLICATION OF THE PARKINSON'S DISEASE AND MOVEMENT DISORDERS CENTER AT DARTMOUTH-HITCHCOCK

Dartmouth-Hitchcock
Department of Neurology
One Medical Center Drive
Lebanon, NH 03756
603.653.6672

Diane.L.Sherman@hitchcock.org
www.dartmouth-hitchcock.org/parkinsons

Coordinator/Editor:
Diane L. Sherman, PhD

Medical Directors:
Stephen L. Lee, MD, PhD
Rebecca J. Thompson, MD

This newsletter is intended solely to provide you with information on Parkinson's disease. You should not make any changes in your treatment without first discussing them with your health care provider.

also in this issue:

P4
Making a Deposit at
Your Local Brain Bank

P6
Get Up and Go???

P7
Balanced Nutrition for
Balanced Lives

P8
Driving Safely with
Parkinson's Disease

P10
Hospitalization and
the Person with
Parkinson's

P14
Oral Health...
What's Parkinson's
Got to Do With It?



Making a Deposit at Your Local Brain Bank: **The Ultimate Investment in Neuroscience Research**

BY DIANE L. SHERMAN

Brain donation is a unique and valuable gift to the neuroscience research community. Moreover, it is the ultimate gift to future generations who will benefit from new tests, treatments, preventative measures and cures developed by researchers studying the donated brain tissue.

Did you know?

- Only a tiny amount of tissue is used in most research studies. So one donated brain provides a large amount of tissue that can be used at institutions throughout the US and even the world!
- There is a critical need for brain tissue from persons who are normal as well as those with neurological disorders such as Parkinson's. Normal control brain tissue is needed for comparison, to determine the differences between what is normal and what is not.
- Approximately 300 brains are donated to the Harvard Brain Tissue Resource Center (aka the "Harvard Brain Bank") each year. Only 10%, or 30, of these are "normal."

Information in this article was used with permission from the Harvard Brain Tissue Resource Center, and adapted from their "Brain Donation Information for Neurodegenerative Disease" (brochure) and from their website: <http://www.brainbank.mclean.org/>. Contact information for Brain Banks in the northeast is provided at the end of the article.

Types of tissue donation

There are three distinct categories of tissue donation:

- The "body donor" donates the entire body for medical education; however, the brain must remain with the body and cannot be used for research.
- The "organ donor" donates organs for transplantation; however, the brain begins to decay immediately at death, and brain donation is generally not compatible with organ donation. However, each case is assessed individually at death.
- The "brain donor" donates the brain for medical research and, if interested, also has the option of donating eyes, skin, blood, or bone tissue.

At the time of death

To initiate the process of brain donation, call the Harvard Brain Bank at the time of impending death or immediately after the death of the donor. The Brain Bank representative will need the donor's name, time of death, neurological diagnosis, and location.

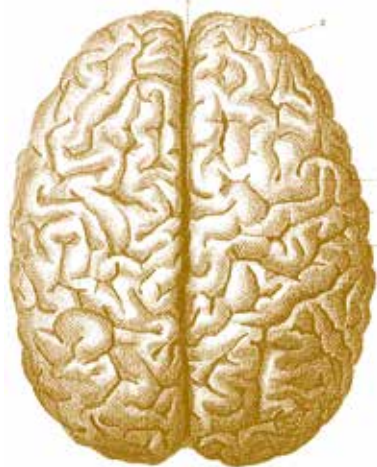
The Brain Bank will work directly with the Pathology Department at your local hospital to make arrangements for brain removal and provide donation instructions.

It is essential that the donation procedure occur within 24 hours from the time of death of the donor. Only the donor's brain will be sent to the Brain Bank; the donor's body will not be transported away from your local area.

Things you should know

The identity of each donor will remain strictly confidential.

- Religious groups including Protestant, Catholic, Jewish and other faiths support organ and tissue donation as a charitable gift of life consistent with the basic tenets of these faiths.
- The donation process involves a careful surgical procedure in which the body is not disfigured in any way. This procedure does not interfere with any funeral or burial arrangements – including an open casket.
- No fee is charged by the Harvard Brain Bank for transportation of the brain, neuropathological evaluation or other processing undertaken at our facility. However, the hospital pathology department where the brain is actually removed may charge a fee to the donor's family for this service.



Steps for a successful brain donation

If you are interested in brain donation the Harvard Brain Tissue Resource Center recommends the following steps:

1) Have a family discussion about brain donation. Be sure your family members understand clearly your intention to donate.

2) To register a potential donor, contact us at 1-800-Brain Bank (1-800-272-4622) to obtain a “Brain Donation Registration” form.

3) Make preliminary arrangements for brain removal through your physician or social worker. Send us the name and phone number of the hospital or pathologist that has agreed to perform the brain removal.

4) When death is impending or at the time of death, call 1-800-Brain Bank (1-800-272-4622) and provide the following information:

- Complete name and age of donor
- Current location of donor
- Time and cause of death (if known)
- Neurological diagnosis
- Name, address, and phone number of

legal next-of-kin (“Legal next-of-kin” is the spouse, or, if there is no spouse, then the adult children or parent of the deceased.)

5) The legal next-of-kin will be required to sign a “Consent for Donation” following the death of the donor, which authorizes the donation of the brain to the Harvard Brain Tissue Resource Center for use in neurological research.

Some examples of Parkinson’s research findings from donated brain tissue:

Early 1900s: Various researchers described the pathological physiology of the Parkinson’s brain. In 1912, Friedrich Heinrich Lewy described brain cell loss and the inclusion bodies that now bear his name. In his doctoral thesis of 1919, Konstantin Tretiakoff linked the reduced number of pigmented cells in that substantia nigra with PD. He also coined the term, “Lewy bodies,” and noted their presence in the remaining cells of the substantia nigra.

Late 1950s: Using donated brain tissue, Arvid Carlsson discovered that dopamine is concentrated in parts of the brain that control movement. He then demonstrated that dopamine is an important neurotransmitter: When immobile dopamine-depleted animals were treated with L-DOPA (or “levodopa,” which the brain converts to dopamine), they were quickly restored to full movement! Carlsson’s ground-breaking research led to the eventual approval of levodopa for treatment of Parkinson’s disease. He shared the 2000 Nobel Prize for Medicine for his discovery that lack of available dopamine in the human brain causes the symptoms of Parkinson’s disease.

Late 1990s: Alpha-synuclein, a protein, was found to be an abundant component of Lewy bodies found in degenerating neurons in Parkinson’s brain tissue. (Note that some familial cases of PD are associated with alpha-synuclein mutations, making the protein a “prime suspect” in the development of PD.) Why does alpha-synuclein accumulate and clump in Lewy bodies? Do Lewy bodies cause the death of brain cells or do they protect

the nerve cells against something else? Each new research finding raises more questions.

Fast forward to current research: In 2017, Matthew Havrda’s research team at the Geisel School of Medicine at Dartmouth published results of studies on the Nlrp3 inflammasome. This regulatory complex is required for neuroinflammation and brain cell death in a mouse model in which PD-like changes result from exposure to an environmental toxin. Identification of biomarkers and targets for anti-inflammatory strategies will allow better diagnosis, monitoring and treatment of PD.

Dr. Havrda and colleagues seek to develop a sensitive test for inflammasome activation through clinical studies and analysis of tissues donated to brain banks.

REFERENCES:

1. Lewandowsky M and Lewy FH, 1912, and Tretiakoff, C, 1919, *Thèse de Paris*, No. 293. Cited in: Holdorff, B, 2006, *J Neurol*, Vol 253, p. 677-678 and Bak TH and Lennox GG, in: *Dementia with Lewy Bodies and Parkinson’s Disease Dementia*, ed. O’Brien et al, 2006, p 1-7
2. Carlsson A, et al., 1958, *Science*, Vol. 127, No. 3296, p. 471
3. Carlsson A, et al., 1957, *Nature*, Vol. 180, p. 1200
4. Carlsson A, 2001, *Science*, Vol. 294, No. 5544, p. 1021-1024
5. Spillantani MG, et al., 1997, *Nature*, Vol. 388, p. 839-840
6. Mezey E, et al., 1998, *Molecular Psychiatry*, Vol. 3, p. 493-499
7. Martinez, E.M et al, 2017, *Toxicol. Sci.*, Vol. 159, p. 64-75
8. *The Network, Fall 2015, The Wisconsin Parkinson Association*, p. 5. https://www.wiparkinson.org/wp-content/uploads/2016/12/2015_Fall_Local_Research-NationalImpact.pdf

Brain Banks in the Northeast:

■ **Harvard Brain Tissue Resource Center, McLean Hospital**
(800) BRAIN BANK (1-800-272-4622)
www.brainbank.mclean.org

■ **Columbia University Center for Parkinson’s and Other Movement Disorders**
(212) 305-5779
columbianeurology.org/patient-care/movement-disorders/movement-disorders-brain-bank



Get Up and Go???

By Gay Palazzo

IT'S 8:03 IN THE MORNING. I pop a Sinemet pill into my mouth. I have an hour before I can have breakfast so I check my computer for messages. The day stretches ahead and the phone rings. It is a friend who says "I am going to exercise class, want me to pick you up?" I respond that I am all set and will see her there. I eat breakfast and turn to my book "Cleopatra". The next time I look up I am clearly not going to make class.

The following week, I missed class as well. I had a legitimate excuse, but after that, it was all downhill. I found reasons not to go to many activities that I had always looked forward to.

I cancelled exercising with my personal trainer and I called in sick for my usual shifts at the Food Pantry. I kept saying that it was summer and I'd go hiking, biking, etc., but I didn't do those either. Even gentle nudging by my husband didn't spur me to action. And the tennis racket that I bought at the local thrift shop has gone unused.

You might have noted that I got myself to the thrift shop with no problems. And I just walked to the refrigerator for a snack too.

What to do. How can I get out of this funk? I keep thinking I need one of those fancy wrist

things that tells me how many steps I have taken, etc., but I know that I haven't taken enough steps and a wrist thing isn't going to make me change.

My membership at the gym was going unused and guilt is a powerful motivator. When I had finally run out of excuses, I headed off to an aerobics class. There, several in the class greeted me with a "welcome back" and the pre-class chatter filled me in on everyone's summer trips and family happenings. I looked for my usual spot in the middle of the second row and slipped right in. The instructor welcomed us all to class, and the warm up music was "There's a hero." The date was Sept 11th and she told us that it was the anniversary of her 14th year at the gym and also the anniversary of the World Trade Center collapse. While we warmed up, we shared brief stories of what we were doing that long sad day.

After class, I approached the instructor. She told me that I am not alone and many others that she usually sees in class are also "no shows" in the summer, near a holiday, etc. I left the gym feeling glad that I had gone, both for the exercise and the comradeship.

I have a personal trainer to help me work on specific "deficiencies." She is quite vigilant

and showed me no mercy. She looked at me with her dark brown eyes, and nodded as she said "I have you in my schedule for Monday at noon." I know I will be there.

The Food Pantry called to confirm that I will be at my shift on Thursday. When I arrive, I get a hardy hello from my shift mates. I feel welcomed and am glad to be back. The shelves were empty that morning, and we filled them with deliveries from area produce companies, grocery stores, bakeries, and an organization called "Willing Hands."

When I leave later in the day, I am once again humbled by the generosity of those in our community and by the gratitude of the shoppers who range from veterans to grandmothers who are feeding three generations of families.

Gradually, I am getting back in the groove. This is made easier by the support I get from those around me. I remind myself that I can help others as well. Although there is no quick, easy way, the road points ahead and together we take one step and then another.

There are many reasons to "get up and go" and they are all good. Oops, here I go again. It is late and I am not dressed for class. Got to run! ●

Balanced Nutrition for Balanced Lives

— BY DIANE L. SHERMAN —

Dieticians and neurologists agree: good nutrition is essential for good health, and nutritional awareness is especially important for people with Parkinson's disease (PD). Thanks to those living with Parkinson's who submitted many of the following tips to help keep your life in balance! Parkinson's patients may need to put extra effort into ensuring adequate nutrition to avoid weight loss and malnutrition.

Has diminished sense of smell or taste reduced your appetite?

Treat yourself to frequent small portions of colorful foods with textures that you enjoy.

Are you less hungry due to nausea or because your digestive tract is emptying slowly?

Eat smaller meals and snack throughout the day to feel more comfortable. Exercise also helps stimulate the intestine.

Is constipation a problem?

Drink plenty of fluids and eat foods rich in fiber, such as vegetables, fruits, cooked dried beans, seeds, nuts, and whole grain breads and cereals. Or, try the "anticonstipation recipe": mix together and refrigerate for up to one week 1/2 cup applesauce, 2-4 Tbsp miller's bran (or wheat germ or bran cereal), and 4-6 oz prune juice; take 1 Tbsp per day, adding more gradually until you find the right amount for you.

Are you eating less because you need more time for your meal?

Set aside plenty of time for relaxed and re-energizing meals and snacks. Dishes with raised edges and utensils with builtup handles make it easier to maneuver food on the plate. Raising your plate to mouth-level by placing it atop a box on the dinner table can reduce the amount of effort needed to eat your meal. Ask your doctor to refer you to an occupational therapist for more tips.

Do you have swallowing or choking difficulties?

Softer foods and those of a single consistency may be easier to swallow. For further help, ask your doctor to refer you to a speech-language pathologist.



Are you eating enough protein, but ensuring that it doesn't interfere with your medications?

- According to Registered Dietician Kathrynne Holden*, people with PD need a daily intake of about 1/2 gram of protein per pound of body weight. To calculate this, divide your weight in pounds by two to get the grams of protein you need each day. Foods rich in protein include milk, yogurt, cheese, eggs, fish, meats, cooked dried beans, nuts, and seeds.
- Unfortunately, protein interferes with the body's absorption of levodopa, the dopaminergic placement drug found in Sinemet®, Parcopa®, and Stalevo®. Holden* recommends dividing your protein intake equally between breakfast, lunch, and dinner, and taking levodopa 30-60 minutes before these meals.
- Low-protein snacks (bread, crackers, fruits, and vegetables) eaten between meals allow your body to absorb levodopa and may reduce nausea, a side effect of many PD medications.

* Reference: Kathrynne Holden, MS RD, is a dietician specializing in Parkinson's. Her books are available at our lending library and at www.nutritioncanlivewith.com.

Driving Safely with Parkinson's Disease

Peggy P. Barco, MS, BSW, OTR/L, Driving Rehabilitation Specialist, Program in Occupational Therapy, Washington University Medical Center in St. Louis, and **David Carr, MD**, Professor of Medicine and Neurology and Clinical Director for the Division of Geriatrics and Nutritional Science, Washington University Medical Center in St. Louis, Medical Director of the Rehabilitation Institute of St. Louis



DRIVING IS ONE OF those important activities that provide independence and the ability to stay connected within the community. But driving is also a public-safety issue – especially when one has a medical condition like Parkinson's.

PD is commonly known as a disease that affects movement and motor function. But there can also be vision, cognitive, and perceptual changes—especially as the disease progresses. Being aware of the changes that can occur with Parkinson's, how these changes can impact driving safety, and using good judgment regarding one's own driving ability are important in determining who is fit behind the wheel.

The following non-motor PD symptoms have the potential to greatly decrease driving safety in the following ways:

1) Decreased contrast sensitivity affects the ability of an individual to detect objects in low contrast environments—such as pedestrians in crosswalks at dusk or on a foggy day. A recent study of drivers in low contrast light conditions confirmed that those with PD displayed less control over their vehicles, had slower responses to hazards, and committed more safety errors than those without PD.

2) Decreased proprioception occurs with PD and in aging, resulting in a reduced sense of spatial orientation. Inability to sense the relative positions of one's arms and legs in space leads to clumsiness and falls as well as difficulties in coordinating movements. Although the specific risks of decreased proprioception for Parkinson's drivers have

not been studied, an example might be difficulty with positioning one's foot correctly on the gas or brake pedal.

3) Difficulties with cognitive functioning as PD progresses include decreases in attention, memory, problem solving, planning, visual-spatial abilities, and decision making. Studies indicate that individuals with PD, and especially those with cognitive changes, are less safe drivers.

While many persons with PD (especially those in the early stages) remain safe drivers, it is very important to be aware of the cognitive and perceptual changes that can occur as the disease progresses and to adapt one's driving accordingly. Appropriate changes in one's driving habits might include driving only during daylight and avoiding venturing out on foggy days, driving only in familiar areas, and driving only at times when fewer cars are on the road and in areas with lower traffic density.

The Driving Assessment Process

Often families and individuals have difficulty assessing driving safety objectively. Indications of driving difficulties can include a recent history of accidents/tickets, difficulties maintaining good lane positioning, delayed responses to traffic lights or planning lane changes, difficulty deciding when it is safe to make a turn, relying on non-drivers in the car

to help with decision-making, and getting lost while driving.

If you, your family member, or physician are concerned about your driving safety, it is advisable to seek a driving assessment, which is provided by an occupational therapist who is also a driving specialist. These assessments usually take a few hours and include in-depth clinical testing of vision, sensory, motor, and cognitive functions. In addition, the assessments involve an on-road driving assessment to judge how well an individual's driving ability is in real traffic conditions. These on-road assessments are done in a driving evaluation car (with a passenger side brake for safety). The road assessment usually begins in a parking lot and progresses to higher levels of traffic. The on-road driving assessment looks at how well the individual manages the car in traffic, visually attends to and scans the surroundings, maintains good lane positioning, follows the rules of the roads, yields to oncoming vehicles, and plans and makes everyday driving decisions. Once both the clinical and on-road driving assessment are completed, the occupational therapist can provide recommendations back to the individual, family, and physician regarding driving safety.

Adapted from an article that first appeared in St. Louis APDA LiNK, Newsletter of the American Parkinson Disease Association, St. Louis (MO) Chapter, August 2012: Volume 26, Issue 3. Used with permission from Peggy P. Barco, MS BSW OTR/L, Author, and Deborah D. Guyer, Editor.

BEAT THE FREEZE IN PARKINSON'S DISEASE

“When I ‘freeze,’ I feel like my feet are glued to the ground! It’s frustrating and scary, especially if I am in a crowded place or crossing a parking lot or road. And sometimes my words and thoughts get frozen, too.”

- Adrienne, 72, person with Parkinson's

About one third of people with Parkinson's disease experience freezing episodes. Freezing episodes are sudden, short, transient blocks of movement that occur primarily with initiating walking, turning, navigating through narrow spaces or approaching obstacles. Freezing can last just a few seconds or up to several minutes. Freezing can limit household and community mobility, increase risk of falling and contributes to reduced socialization and quality of life.

Ten Tips to Put the Freeze on Freezing!

- 1) **Try another movement** – raise an arm, touch your head, point to the ceiling; then re-start
- 2) **Change direction:** if you can't move forward, try stepping sideways and then go forward
- 3) **Carry a laser pointer in your pocket;** when you freeze – shine the laser in front of your foot and step on the light – this cue can help you re-start
- 4) **Visualize an object** on the ground in front of you and try to step over it
- 5) **Wear a metronome on your belt or carry a small one in your pocket** – turn it on and the external beat can help you re-start
- 6) **Try humming a song** and time your re-start with the beat of the music
- 7) **Count “1-2-3-go”** and then step forward
- 8) **Shift weight side to side** to help initiate taking a step
- 9) **March in place a few times** and then step forward
- 10) **Don't fight the freeze by trying harder to step forward** – shift your attention from moving the legs to moving the arms – then resume walking forward

USED WITH PERMISSION FROM:

Terry Ellis, PhD, PT, NCS, Director; Tami DeAngelis, PT, GCS, Coordinator
APDA National Rehab Resource Center at Boston University
www.bu.edu/neurorehab/resource-center/
Toll Free Exercise Hotline (to speak with a physical therapist): (888) 606-1688
Email: rehab@bu.edu

Caregiver's Perspective: Tips for Handling Anger & Frustration

by Shirley Bennette

How caregivers cope with PD is as individual as the disease itself.

To handle anger and frustration:

- Get your feelings out without feeling guilty if possible.
- Leave the room and have a good cry.
- Write down what is bothering you.
- Sound off to family or friends. Get professional help if that is not adequate.
- Join a support group (or start one) where caregiver sessions allow a chance to vent your feelings.
- Subscribe to PD publications and read what other caregivers think and feel.
- Try to see the humor in a bad situation. As my husband George said, “PD is such a complicated disease that it's almost a privilege to have it!”
- Remember that having PD is harder than being a caregiver.
- Tell the person with Parkinson's: “It's the disease I'm angry at, not you,” and, “This is a statement of fact, not a complaint against you.”
- All things considered, when you have done your best, accept your limitations and learn to forgive yourself.



Hospitalization and the Person with Parkinson's

— BY DIANE L. SHERMAN —

When a person with Parkinson's must be hospitalized, it is typically NOT for PD symptoms but to deal with infections, injuries suffered in a fall, or elective surgeries. But whatever the reason for one's visit to the emergency room or hospital, PD patients are at increased risk of complications. You may need to educate yourself, your family members and friends, and the medical staff about PD symptom fluctuations, the complex timing of PD medication schedules, and drugs to be avoided by PD patients. And it is always best if a trusted family member or friend can stay with the hospitalized person with Parkinson's.

You can order a free "Aware in Care" Patient Safety Kit from the Parkinson's Foundation to help get the best care possible during a hospital stay. <http://parkinson.org>, (800) 473-4636

Several organ systems are affected by Parkinson's

The attending physician or hospitalist (a medical doctor who handles your care while you are in the hospital) must assess the following prior to treatment and/or surgery to understand your "baseline status". The following may result from PD, and need to be considered:

- Impaired lung function
- Swallowing difficulties/drooling
- Slow digestion and bowel function
- Difficulty with various types of movements
- Difficulty speaking
- Difficulty opening the eyelids

Common complications and how to assist the hospital staff

Many complications can be avoided by minimizing interruptions in the patient's PD drug regimen during the hospital stay.

- Dr. Friedman advises, "**Be sure that the drug schedule, with time and dose, is understood and copied into the hospital orders.**" An example of why this is important: For the Parkinson's patient, taking a medication three times daily

("TID") may mean 30 minutes before each meal. But for the medical staff, TID typically translates to "every 8 hours", and the medication may be given, inappropriately, at 8 a.m., 4 p.m. and midnight.

- If you are undergoing planned surgery, the surgical team will likely want you to be optimally medicated for your PD prior to surgery, and standard admission advice, "absolutely nothing by mouth after midnight", may not be in your best interest. Schedule a pre-admission appointment with your anesthesiologist and surgeon to discuss how soon before and after surgery you can take PD drugs.
- You may be taking medications not available in the hospital pharmacy (eg if you are participating in a clinical trial). Be sure to bring your medications to the hospital in their original bottles with instructions so that you do not miss any doses.
- Medical personnel frequently do not understand the sudden "ons" and "offs" and dyskinesias that the person with Parkinson's may experience. Provide a written summary of Parkinson's symptoms that will likely occur if you are over- or under-medicated. The hospital staff will need to know, for example, that your ability to swallow food and drink, or to get yourself to the restroom, will be impaired if you do not receive your Parkinson's medications at the appropriate time.

Dr. Friedman writes that confusion, caused by anesthesia, pain medication, and/or the stress of surgery, "...is so common that it is to be expected. I tell my patients and their families that this problem may occur and not to worry."

- Mental changes, if they do occur, are almost always temporary.
- Comforting the patient often gives the best result
- If the confusion causes difficult/dangerous behaviors, antipsychotic medications may be used: quetiapine (Seroquel®) or clozapine (Clozaril®). These are the only antipsychotic drugs that do not worsen Parkinson's symptoms.
- ANTIPSYCHOTIC DRUGS TO BE AVOIDED because they worsen PD symptoms: haldol, olanzeipine (Zyprexa®) risperidone (Risperdal®), and aripiprazole (Abilify®)



Other medications to be avoided by PD patients:

- For gut mobility and nausea:
 - Avoid metoclopramide (Reglan®) and prochlorperazine (Compazine®)
 - Substitute: ondansetron (Zofran®)
- For pain: Meperidine (Demerol®) should not be given to patients taking selegiline (Eldepryl®) due to potential drug interaction.

Parkinsonism hyperpyrexia syndrome: rare but potentially fatal

“The message should be clear: complete and abrupt cessation of established antiparkinson medication in a PD patient should almost always be avoided.” (Newman et al.)

Parkinsonism-hyperpyrexia syndrome (PHS) is a rare but potentially fatal complication observed in PD patients. PHS

is characterized by rigidity, extremely high fever, and reduced consciousness, ranging from confusion to coma.

Causes of PHS:

- Sudden withdrawal of antiparkinson medications (especially levodopa)
- Infection
- Dehydration
- Inactivity of the bowel

PHS develops between 18 hours and 7 days following the trigger. It is important that PHS be prevented if possible, and that PHS is considered if a PD patient deteriorates rapidly. Early diagnosis and prompt treatment of PHS (by re-starting PD medications; treatment with antibiotics; and/or rehydration) and resulting complications (such as kidney failure, aspiration pneumonia, and disrupted regulation of blood coagulation and inflammation) are essential.

References:

Friedman, JH, “Hospitalization of a Parkinson Patient”, Educational Supplement #5 (2009), The American Parkinson Disease Association

Leader, G and L Leader, “Undergoing Anaesthesia: Nutritional Considerations”, in: Parkinson’s Disease: Reducing Symptoms with Nutrition & Drugs (2009), p. 126-128

Newman, EJ, DG Grosset, and PGE Kennedy, “The Parkinsonism-Hyperpyrexia Syndrome”, Neurocritical Care (2009) Vol 10: p. 136-140 <http://www.springerlink.com/content/g51ou6x3q1257k51/>

Patel, SG, CR Stickrath, M Anderson, and O Klepitskaya, “How should Parkinson’s disease be managed perioperatively?” June 2010, The Hospitalist



Artist Victoria Tane layers colorful pieces of metal and plastic to make a link in a necklace in her studio at her Nashua home Tuesday, February 12, 2013. She said she often accompanies her husband to building supply stores for tiny interesting jewelry parts.

PHOTO BY BOB HAMMERSTROM

The worktable in Victoria Tane's home studio could easily be mistaken for a vendor's table at a flea market.

Plastic ziplock bags hold beads of various shapes and sizes, bits of broken costume jewelry and metal pencil tops. Wine collar wrappers and cardstock paint swatches are carefully stored in multi-compartment boxes.

From these disparate, cast-off items, the 61-year-old Nashua artist creates beautiful upcycled jewelry, which she sells through her website, www.victoriatane.com. No two pieces are exactly alike. "I call what I do 'ten thousand decisions,'" Tane said. Though she has limited amounts of some supplies, she sees no need to panic when the contents of a bag or box start to dwindle. "Running out of something is the best thing that can happen to me as an artist, because it forces me to come up with the next iteration," Tane said.

The Crea

Her approach to her art has influenced her approach to Parkinson's disease. She began experiencing the symptoms 10 or more years ago, but was only diagnosed with the movement disorder within the past three or four years. "I run out of something and I have to replace it," Tane said, referring to her jewelry supplies. "Well, it turns out I've run out of dopamine and I have to replace it."

According to the Parkinson's Disease Foundation, Parkinson's involves the malfunction and death of nerve cells, or neurons, in the substantia nigra, the part of the brain that handles movement and coordination. Some of these neurons produce dopamine, a neurotransmitter that helps control movement. As Parkinson's progresses and more neurons are destroyed, less dopamine is produced, leaving the individual increasingly less able to control movement normally. At this time, there is no cure for Parkinson's. Though experts are unsure as to the cause of the movement disorder, some believe genetics and environmental factors may play a role.

The path to Tane's diagnosis began when she scheduled a doctor's appointment to address a nagging pain in her shoulder. "I had this feeling inside, like I was shaking," she said. She later followed up with her doctor about a tremor that had developed in her right hand, which is also her dominant hand. Though tremors are a classic symptom of Parkinson's, they can have a number of other causes. "My husband has a tremor, but he doesn't have Parkinson's," Tane said.

Her doctor did not think Tane had the movement disorder, but Tane felt differently. "I know my own body. I know things before they're diagnosed," she said, adding that her father passed away from complications due to Parkinson's about two years ago.

tive Spirit: Victoria Tane

by Teresa Santoski

Tane arranged for a consultation with a neurologist, who said she might be in the early stages of the movement disorder. Over the next year, her symptoms progressed, cementing the diagnosis. As she learned more about Parkinson's, Tane realized she may have been experiencing symptoms of the movement disorder long before the tremor manifested itself. As far back as the '90s, "I had had a hard time with smell," she said.

Many researchers believe the loss or impairment of the sense of smell—as well as other symptoms like sleep or mood disorders or low blood pressure when standing up—can precede movement-related symptoms of Parkinson's by years. Tane said she can smell very high notes and very low notes when it comes to aromas, but that she's "lost the mid-range of the keyboard." Her deteriorating sense of smell has in turn affected her sense of taste. Once again, flavors at the ends of the spectrum are easier to taste than those in the middle. "I kind of have to interpret via texture," Tane said. "Sometimes, I don't know if I'm tasting something or remembering tasting something."

In spite of having struggled with Parkinson's for several years, she resisted taking medication for her movement-related symptoms until just a few months ago. "I was trying to be a hero and tough it out about not taking medication, but it was ridiculous," Tane said, noting that people who have seen her before and after medication say there has been a definite improvement. Regular exercise has also helped her movement-related symptoms. "It's kind of a cocktail disease," she said of Parkinson's. "You have to establish a regimen that works for you."

Tane continues to create and sell jewelry, though the movement disorder

means it takes her longer to finish a piece. "My hands shake," she said. "But I'm still able to design, and I still have my sense of humor, which I think comes through in my art." Making jewelry, Tane has found, also makes her hand less apt to tremor. "Busy hands are happy hands, so the idea is to keep those hands engaged as much as possible," she said.



“My hands shake, but I’m still able to design, and I still have my sense of humor, which I think comes through in my art.”

One of Tane's bracelets is featured in the 2013 Creativity & Parkinson's Calendar, published by the Parkinson's Disease Foundation, as the art for February. Tane had been looking for artists with Parkinson's to blog about for Parkinson's Awareness Month. Her assistant came across the Parkinson's

Disease Foundation's website, www.pdf.org, with its gallery of 300 such artists. At her assistant's suggestion, Tane submitted photos of her own work for the online gallery. The next thing Tane knew, the foundation contacted her and told her she was a finalist to be in the calendar for February. "It was really an honor. I was thrilled," she said.

Like many people with Parkinson's, Tane has battled her share of depression and anxiety in connection with the movement disorder. "You struggle with the disease. It's personal," she said. "You're not always up to seeing other people." She does feel, however, that she has made peace with her condition. "I call it the squatter in my apartment building. It's here to stay, and it's not going to leave," Tane said.

Though Parkinson's has impacted the way she lives her life, she refuses to give in to concerns as to how the movement disorder will progress. "My biggest fear is where my next idea is going to come from, as a creative person," Tane said. Instead of allowing Parkinson's to define her, she has chosen to define Parkinson's. In addition to participating in a study for a new medication and contributing financially to research efforts, she has designed a line of jewelry inspired by the tulip, the symbol for Parkinson's.

"I do feel very fortunate to still have the creative spirit," Tane said.

First published February 26, 2013, and reprinted with permission of The Telegraph, Nashua, NH.

Oral Health...

What's Parkinson's Got to Do With It?

— BY DIANE L. SHERMAN —

Oral and dental health is often neglected in those with Parkinson's disease (PD).

The symptoms of PD and side-effects of medications make flossing and brushing more difficult and trips to the dentist a real chore. However, it is very important that this critical aspect of one's overall health not be overlooked. Poor dental hygiene contributes to painful oral conditions, increased

risk of aspiration pneumonia, and inadequate intake of food leading to malnutrition, unintended weight loss and frailty.

Remember to discuss oral and dental hygiene with your dentist and doctor, and to enlist your family members and care partners to help you maintain good home care and regular dental visits.

| | 1 | 2 |
|---|--|--|
| Five "problem areas" of concern for those with PD: | Poor oral hygiene | Involuntary face, tongue, & jaw movements |
| Causes | <ul style="list-style-type: none"> Inadequate brushing & flossing caused by tremor, slowness of movement, muscle rigidity and dyskinesias Behavioral/cognitive symptoms: Apathy, forgetfulness, lack of awareness, missed or hampered visits to the dentist's office | <ul style="list-style-type: none"> Tremor Rigidity & cramping of facial muscles Dyskinesia |
| Complications | <ul style="list-style-type: none"> Tooth decay and loss Gum disease Aspiration of food debris, dental plaque, and/or broken tooth that can lead to pneumonia | <ul style="list-style-type: none"> Tooth grinding & jaw clenching Mouth, jaw & facial pain Worn, cracked, sensitive teeth/loss of teeth Difficulties in wearing dentures |
| Recommendations | <ul style="list-style-type: none"> Mechanical aids: toothbrush with large handle, electric toothbrush, flossing aids, Water-Pik® Chemical aids: fluoride toothpaste, rinses, & varnishes Caregiver assistance as needed, with written instructions from dentist More frequent visits with dental hygienist/dentist | <ul style="list-style-type: none"> Medication review by neurologist Tooth guards Replace dentures with tooth implants |

References:

- Bakke M et al., Orofacial function and oral health in patients with Parkinson's disease. *European Journal of Oral Sciences* 2011; 119: 27-32.
- Friedlander AH et al., Parkinson disease: Systemic and orofacial manifestations, medical and dental management. *Journal of the American Dental Association* 2009; 140: 658-669.
- Holden K, Oral Health Issues, in *Parkinson's Disease: Guidelines for Medical Nutrition Therapy for Use By Nutrition Professionals*, 2003.



3

4

5

Drooling of saliva from corners of mouth
(occurs in 75% of people with PD)

Xerostomia (dry mouth)
“The most devastating oral complication from a dental point of view.”
- Elaine Neal, DMD, PA

“Burning mouth syndrome”
(occurs in 25% of people with PD)

- Inefficient & infrequent swallowing
- Inability to close mouth fully
- Forward-leaning posture

- Symptom of Parkinson’s
- Side-effect of most Parkinson’s medications

Cause usually unknown, but possible medical causes include...

- Dry mouth
- Nutritional deficiencies
- Hormonal imbalances (in females)

- Social discomfort
- Choking sensation
- Aspiration of excess saliva into the lungs, increasing risk of pneumonia
- “Angular cheilosis” = redness & cracking at corners of mouth due to persistent moisture/yeast infection or Vitamin B deficiency

- Increased risk of oral infection
- Tooth decay
- Periodontal disease
- Ill-fitting dentures
- Difficulty speaking and swallowing

- Depression
- Difficulty sleeping
- Difficulty eating possibly leading to nutritional deficiencies
- Difficulty caring out oral hygiene

- Speech therapy to improve swallowing and control of facial muscles
- Suck on sugar-free candy to increase frequency of swallowing
- Try to maintain upright posture
- Botox injections to reduce production of saliva
- For angular cheilosis: attempt to keep corners of mouth dry. Apply topical antifungal product. Request nutritional deficiency assessment.

- Stay well-hydrated: sip water frequently
- Avoid tobacco and alcohol
- Avoid mouthwashes containing alcohol, and toothpastes containing peroxide
- Use mouth moisturizing products
- Request a medication review from your neurologist

- Request that doctor rule out possible medical causes
- See recommendations for dry mouth

4. Cicerone, BR, RDH and CR Carter, DMD, Oral Health and Parkinson’s Disease, APDA, 2010.

5. Neal, Elaine, DMD, PA; personal communication, Upper Valley Parkinson’s Disease Support Group, Hanover, NH, 11/9/2012.

6. Mayo Clinic: Burning Mouth Syndrome <http://www.mayoclinic.com/health/burning-mouth-syndrome/DS00462>, accessed 2/6/2013.