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Parkinson's companion

 Dartmouth-Hitchcock

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

SPRING 2015

Voices of Parkinson's: A Spirituality of Parkinson's

BY THOMAS TEICHMANN, PASTOR
MESSIAH LUTHERAN CHURCH
AMHERST, NH

A three strand thread...

It's been more than ten years since I was diagnosed with Parkinson's disease. It was devastating, and I told no one except my spouse. After five years of leading a covert life, I came to a point where I could finally admit PD's existence in my life—to myself, as well as to those around me. A big part of that initial denial and subsequent recognition of the condition was an ongoing inner dialog concerning the spiritual dimension of chronic illness. The "why's" and "why me's" and the search for meaning in a life dramatically altered by a disease I did

not cause, challenged my spirituality, in which a benevolent and almighty God traded me his protection for my belief. I emerged from that process with a changed sense of the spiritual, and a way of being that works with that and not against it.

I began to see my relationship with this condition as "living with Parkinson's." Accent on the *with*. Accepting its presence as a part of my life—then stretching its limitations, adapting to its progression, and not allowing it to define my life—provided a means through which I could interact with others in a world that is largely uninformed about PD. Living with

Parkinson's is integrating the hard reality of the disease into the ever-changing story that I, and all of us, tell about ourselves. It becomes a thread that runs through our lives. A thread made up of three strands—the physical, the mental, and the spiritual.

Two of the strands are easy to spot. The wise use of an ever-evolving vanguard of Parkinson's medications, joined with taking care of oneself through diet, exercise, and supplements, makes up the familiar physical routine of "living with." Staying connected to the world, treating depression, and actively engaging the

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

Dear friends,

I am still ironing out the details but am happy to announce three educational events for the Parkinson's community: A Question and Answer session in April plus conferences in June and September. Please see "Announcements and Events" on page 7 for more information.

What else is new for 2015? We have many new items in our lending library, including new books and DVDs from the Parkinson's Fitness Series ("Daily Exercise" and "Gentle Yoga") and from "FallStop...Move Strong"™ (Fall Prevention and Strengthening, Level 1 and 2). We have also added some titles dealing with Lewy Body Dementia. Please see the listings at www.d-h.org/parkinsons/lending_library.html or drop by the Aging Resource Center to browse the shelves.

And for those who have wondered about my name change: I have a new husband and a new last name!

I wish you all well and hope to speak with you soon.

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brain in exercises designed to promote healthy cognition, all work towards the mental goals of living with Parkinson's.

But when it comes to the spiritual thread, the prescription for living with Parkinson's becomes fairly illegible. Partly because spirituality is such a nebulous concept—not measureable like miles on the treadmill, or a dose of L-dopa. And partly because many feel that there is no universal truth anymore—that what you see is what you get—and that there is no such thing as the spiritual.

And that is unfortunate. I understand a human being, not as three separable, stand-alone segments (*mind, body, spirit*), but rather as a whole—undivided. Now imagine human beings as navel oranges, which look beautiful and taste great but have no seed, no "spirit"—so there is no growth, no future for them. The spirit is important.

Your spiritual self...

You may shy away from your spiritual self. Although you may not consider yourself to be "religious," there is a spiritual part of you. A part that seeks meaning in life; a part that recognizes you can discover order even in a chaotic world; a part that hopes, even when there seems to be no hope. You are a spiritual being. And just as "use it or lose it" is your slogan for both physical and cognitive training—so, too, your spirit can be exercised, nourished, and used to promote the wellness of the whole body.

Spiritual "practices," of which there are many, provide a way to invite into our consciousness the awareness of the ebb and flow of life. It is a way to step back and see what, unbeknownst to us, was obscured by the stress of life in general, not to mention existing with the uncertainty of a progressive neurological disease.

Practicing spirituality opens us to the possibility that there is possibility, even for Parkinson's patients. The future is still there, waiting for us, evolving with us, adapting to us. We are not navel oranges. We are still full and complete. We have the "seeds" of the future. Seeds that contain what's needed to produce whole and perfect fruit. So, too, we will bear fruit in our lives as we progress through a life that includes a resident condition like PD.

Living with...

Where to start to get a grip on the spiritual side of things? There are two schools of thought. One – you ignore PD and never surrender to it. Or two, you lament, crying out for justice in a world that denies and isolates the infirm. The one is not better than the other. In fact I would say they equally miss the mark.

I would venture this—somewhere along the line you are going to accept this Parkinson's as yours. Unique to you, neither good nor bad—it just is. Like a hand. An eye. A birthmark. PD is like a visitor who stays in your guest room and eats every meal with you and has no thought for leaving. But he is not a foreign intruder. He was always there. It is like your hair going gray. Something to manage, adjust to, admit to, negotiate with, subjugate at times, but always acknowledge.

A spirituality of Parkinson's starts with that co-existence. Where it goes from there is up to you. You are spiritual. You'll find many books on spiritual disciplines you can follow. But really anything that reaches out from your existence, reminds you that there is meaning in even the most fractured of lives, and offers you hope, will open wide the door to spiritual well-being. May attending to your spiritual journey give you peace! ●

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You get what you get...resilience in Parkinson's BY GAY PALAZZO

“You get what you get...and you don't get upset.” This is a great phrase that my grandchildren have learned, probably at school. It would be even greater if they applied it to themselves instead of their siblings though!

For adults, this phrase could be summed up as resilience. As we who have PD worry about our tomorrows, we also know that resilience is our ally.

In PD-speak, I am going to politely suggest, no I am going to demand, that you reach down and find a way to make your life what you want it to be. In exercise class this would be the equivalent of a trainer asking you to try one more push-up, in school the teacher coaxing you to focus, and at work your

supervisor urging you to go the extra mile.

Look at the faces of the men and women that you see at conferences, at support groups, and in the waiting rooms of their doctor's offices. These are people who are fighting to maintain strength and courage. Here are a couple of examples of resilience in action:

A friend with PD recently moved away. Not because she wanted to leave the area, but because she knew it was best for her. Moving into an assisted living facility would enable her grown children to know that she was comfortable and safe. It would relieve her of the need to shovel snow or maintain the house, and that is important as she lives alone, really alone since her faithful dog passed on. Like most families in rural NH and VT, she did not have access to public transportation. Driving (especially at night) brought on many anxious moments. Resilient? You bet, but come this summer I will

very much miss our trips to the ice cream store for a cone with sprinkles.

I have another friend with PD who has cared for her husband, her kids, her home, and her clients. Being “cared for” by family is not an option...her husband has health issues of his own and her children live far away. But her friends are nothing short of amazing! They stop by her house and ask if she needs a ride or wants to accompany them to get groceries. They go to PD workshops with her and learn about this disease and what a person afflicted by it is experiencing. And they ask me, a stranger to them, to call them if I need something! I might just do that as they make me feel like we are all on a team and working together.

Our bodies may feel the effects of rigidity and there are times our spirits feel defeated, but with so many great role models, I am confident that I will not be upset with what I get. ●

Learning some new tricks: Lee Silverman Voice Therapy

BY LEE NEMLICH

Immediately upon meeting me,

Dr. Stephen Lee, my neurologist at Dartmouth-Hitchcock Medical Center, recommended that I take the Lee Silverman Voice Therapy (LSVT) LOUD® course designed specifically for Parkinson's patients. I hadn't realized that my voice, which has always been soft, had weakened to the degree that it had. Dr. Lee first ordered tests to establish the health of my vocal cords and throat and to assess my swallowing ability. There was no physical obstruction; PD was simply changing my voice.

Because the program involves 16 visits with a speech-language pathologist over four weeks, I signed up at the Rutland Regional Medical Center in Vermont, which is near to my home. My therapist, Kelly Parker, is certified in LSVT LOUD® and is the manager of the Rutland Hospital Speech Therapy Department.

I worked intensively with Kelly, one on one, for one full hour each session. The first lesson was especially important for me because Kelly was able to make me realize where I truly was with regard to loudness and decibel level. I had a major misconception of my speaking voice. In order to be heard by my friends in a crowded situation, I had to shout at them. And because I don't like shouting at people, I held back from speaking altogether. But by recording my voice and playing it back, Kelly proved to me very quickly that my perceived shouting was barely audible compared to another person's normal speaking voice. Now that the psychological obstacle was identified, I was ready to proceed to the physical aspect of the program.

Kelly made me feel confident that with serious hard work I would greatly improve and strengthen my voice. The two of us, as a team, went to work.

The sessions consisted of various exercises...holding one high note as long and as loud as I could, while being timed and measured in decibels, doing the same while going up and down the scale...and also engaging in conversation, reading aloud, and reciting "Ten Commonly-Used Phrases/Sentences" that I would speak at home, for example: "What's for dinner?", "Do you have your hearing aids in?" You get the picture. Reciting loudly these ten sentences, three times each session, over and over again, had the Pavlovian effect of conditioning me to speak louder. It worked! You CAN teach an old dog new tricks!

I had great trepidation entering this program, but it all disappeared half way through the first session. Kelly pushed, pulled, explained, whipped and cajoled me into giving maximum EFFORT. Hard to believe, but Kelly made all this strenuous work fun. To keep what I gained, I do two sessions (15 to 20 minutes) daily. I know Kelly will call to check on me periodically. Thank you, Kelly. ●

For more information on the LSVT LOUD® and BIG® programs, see www.lsvtglobal.com



Improve Your Balance and Avoid Needless Falls

Some remedies require common sense; others require classes in balance and tai chi.

BY SALLY WENDKOS OLDS • ADAPTED FROM A RECENT ARTICLE THAT APPEARED IN NYCITYWOMAN.COM

IN MY CIRCLE OF FRIENDS, practically everyone—including me—has fallen recently.

One friend hit the floor when the chair she was standing on to reach a high cabinet tipped over. One tripped over a small rug in her apartment. One tumbled downstairs when, wearing her progressive lenses, she could not see the bottom of the staircase. I ended up spread-eagled on a sidewalk when, looking up at the theater marquee, I caught my toe in a

crack in the cement. The ways we fall are varied and the ways to prevent falls are also varied. As we get older our vision changes and our muscles become weaker; these may cause changes in our balance, our bones and our ability to judge distances. "Reaching your sixties should be a wake-up call," says Celeste Carlucci, a former dancer and the founder of the fall prevention and strengthening program FallStop...Move Strong™ at

Jewish Community Center in Manhattan.

Fortunately, we can do a lot to prevent mishaps. Some of these remedies only require common sense, but improving our balance and way of moving sometimes requires physical therapy or classes in balance or tai chi. The stronger our muscles become and the more our sense of balance improves, the more adept we will become at catching ourselves if we trip or if someone bumps into us.

Listed below is a compendium of recommendations from several experts.

PAY ATTENTION TO YOUR BODY:

If you sometimes feel dizzy or unsteady, have your doctor analyze your medications (including over-the-counter) to see whether these are causing a problem, either singly or in combination. Visit your eye or ear doctor to make sure your glasses are appropriate and you don't have an ear infection.

WEAR SHOES THAT GIVE GOOD SUPPORT:

Never walk in stocking feet. Wear shoes or slippers with a back AND rubber soles to give your feet structure and prevent slipping.

STRATEGIZE YOUR MOVES:

- Since most falls happen when we shift our weight and lose our balance, focus on keeping your body weight over your feet, especially when changing direction.
- To pick up an item from the floor, bend your front leg, keep your rear leg about a foot behind the other, and bend down. To reach something on a high shelf, take the same stance: one foot forward, one back.
- When walking down steps, if you're feeling off balance, place your feet sideways and hold the railing.
- When you wake up in the morning, or after sitting for a long time, organize your body and, as Celeste says, "pump the gas" for a couple of minutes before getting up by alternately flexing and pointing your feet.



WALKING OUTSIDE:

- Consider every walk a mindful meditation, so you're constantly thinking, "Where are my feet?" "Where is my body?" "What is the road surface like?" Focus on every step.
- Walk heel-toe. Make good contact with the ground by hitting it first with your heel, then your toe, with your legs a little bit apart so you're not shuffling.
- Use your whole leg and body to develop a good stride, but don't make your steps so large that you lose your balance keeping up with them.
- Practice using your STOP muscles: lunge forward, then pull your body back to catch yourself. Make this a habit so that if you trip, you can pull yourself back.
- Swing your arms when you walk. This can be a challenge, but it's important to keep your body loose and have an easy gait.

CREATE A SAFE ENVIRONMENT AT HOME:

- Check your home for safety issues.
- Keep a lamp by your bed and a flashlight handy, at home and when traveling, so you never have to walk in the dark.
- Rearrange your home so items are within reach. Avoid climbing to reach high places.
- Always keep your cell phone or life alert system with you so if you do fall you can summon help.
- Keep your floors free of clutter.

VISIT A PHYSICAL THERAPIST AND ENROLL IN CLASSES TO IMPROVE YOUR BALANCE AND STRENGTH:

As one FallStop...Move Strong™ participant says, "My whole body is stronger and more flexible now. We all trip, but now I can right myself if I start to trip and I don't fall down."

Adapted from article by Sally Wendkos Olds, sallywendkosolds.com. ©2015. All rights reserved. Used with permission. Celeste Carlucci trains exercise specialists to run FallStop...MoveStrong™ classes. For more information or to order DVDs, see <http://fallstop.net>.

Shake, Rattle and Sit BY B. ELWIN SHERMAN

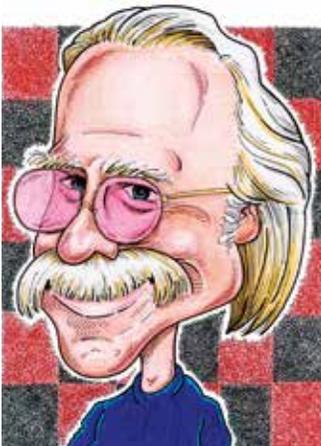
AS A PRACTICING NURSE who has combined 35 years of bedside care with writing humor, I must hold with the French philosopher Voltaire, who wrote that “the art of medicine consists in amusing the patient while nature cures the disease.”

My research on the history of Parkinson's disease supported this, after I perused articles published in such late 19th century newspapers as the Sedalia Weekly Bazoo and The Kansas Agitator. They detailed what was called the “Vibratory Principle”

used in treating PD, known then as “the trembling palsy.”

It also affirmed Shakespeare's “What's past is prologue” when I compared the old reportage with what is now its modern application equivalent of WBV (Whole Body Vibration) training. Today, WBV is an exercise regimen using a vibrating platform, and the jury is still out on whether or not its benefits outweigh conventional exercises used in standard rehabilitation programs for people with Parkinson's disease.

For now, I'll have to leave century-plus old testimonials for Dr. Williams' Pink Pills for Pale People, Dr. Scott's electropathic corset and Dr. Vigouroux's “enormous tuning fork” for another time, but let's end at the beginning, with Professor Charcot's vibrating arm chair:



Senior Wire News Service
Syndicated Humor
Columnist B. Elwin
Sherman writes from
Bethlehem, NH. He is
an author, humorist and
long-time eldercare and
hospice nurse. His latest
book is “Walk Tall and
Carry a Big Watering
Can,” from Plaidswede
Publishing. You may
contact him via his
website at Witbones.
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TREMBLING PALSY (Parkinson's disease) is characterized by an incessant trembling of the hands, a stooping attitude and an odd gait that makes it seem as if the invalid is going to precipitate himself headforemost. It is a painful nervous disorder that deprives the unfortunate who is afflicted with it of rest and sleep.

Some invalids who are troubled with this infirmity derived decided relief from long rides on a railroad or in a carriage. The more the vibrations caused in the compartments by the train running at full speed, and the more the carriage was jolted over an uneven pavement, the more the relief experienced. At the end of a day's journey they felt better and experienced an inexpressible comfort. One of them conceived the idea of having himself wheeled about for hours in one of those heavy carts used for carrying paving stones.

Contrary to the experience of all travelers, those afflicted with trembling palsy felt fresher and more active on alighting from the cars. The longer the trip lasted, and the worse the line, the more durable was their improvement. This was the starting point for a most curious therapeutical application designed by a Professor Charcot of Paris. It is an oscillating chair in which those afflicted with the terrible disease are rocked and racked in a most alarming manner.

“Vibratory Therapeutics”—Scientific American Volume LXVII Number 17 (October 1892).
The Chemist And Druggist—VolXLII, No. 1 (January 7, 1893).



As it was impossible to think of having the invalids carried by rail from Dunkirk to Marseilles, or of making them pass their days in omnibuses, Mr. Charcot had his vibrating arm chair constructed for patient use:

“A to and fro motion is given by means of an electrical windlass. These motions produce a series of very strong trepidations. There could be nothing more insupportable for a well person than such shocks, which demolish you, put you out of order, shake up your intestines, and after a half minute's experience you would ask for mercy. The invalid, on the contrary, lolls in the chair as you would do on a soft sofa. The more he is shaken the better he feels. After a sitting of a quarter of an hour, he is another man. His limbs are relaxed, the fatigue has disappeared and the following night his sleep is perfect.”

Parkinson's clinical research studies at DHMC

Contact: Polly LeBlanc
at 603.650.4411 or email
Pauline.R.LeBlanc@hitchcock.org

Treatment of gait disturbance in Parkinson's disease with visual adaptation

The investigators hope to discover new insights into the treatment of gait problems in people with PD. The study requires two visits to DHMC 14 days apart and two weeks of twice-daily visual adaptation exercises (5 minutes per session) at home. Clinic visits include a neurological exam plus assessments of posture, gait and activities of daily living. Additional follow up is obtained through questionnaires by mail at one week, one month and three months post treatment. Participation lasts for about 100 days.

STEADY-PD III (Safety, Tolerability and Efficacy Assessment of Isradipine for PD -Phase III)

STEADY-PD III is a multi-center, randomized, double-blind, placebo-controlled study of isradipine in people with early Parkinson's disease. The study will see whether isradipine is able to slow progression of disability in PD. Isradipine is a medication that is approved by the Food and Drug Administration (FDA) for the treatment of high blood pressure, but not for the treatment of PD.

This study is recruiting participants with early stage PD who do not require dopaminergic medication (eg, carbidopa-levodopa). The use of amantadine and/or anticholinergics (eg, trihexyphenidyl) may be allowed.

Participants will be randomly assigned to take isradipine or placebo twice daily. Participation lasts for 36 months and requires 12 visits to DHMC (after the Screening Visit) and four follow-up phone calls.

ANNOUNCEMENTS & EVENTS

FRI | APR 24 | 9:30-11:30 AM

Parkinson's Disease Question & Answer

DHMC AUDITORIUM B,C & D, LEBANON, NH | FREE

With David J. Coffey, MD; Mary S. Feldman, DO; Stephen L. Lee, MD, PhD; and Diane L. Sherman, PhD. Registration is necessary as space is limited.

Contact: Aging Resource Center at 604.653.3460 or email AgingCenter@hitchcock.org

MON & THU | MAY 4 – JUNE 15 | 10-11:30 AM

(SKIPPING MEMORIAL DAY, MONDAY MAY 25)

Spring 2015 Parkinson's Wellness Program (Six-week program)

DHMC, LEBANON, NH | \$149

Exercise, balance, gait training, and education program led by Rehabilitation Medicine specialists at DHMC to help those with PD achieve a better quality of life.

www.d-h.org/parkinsons/parkinsons_wellness_program.html

Contact: Parkinson's Center at 603.653.6672 or email Diane.L.Sherman@hitchcock.org

SAT | MAY 16 | 9:30 AM-NOON

Learning about Essential Tremor

GRAPPONE CONFERENCE CENTER, CONCORD, NH | FREE

Speakers include Stephen L. Lee, MD, PhD and David W. Roberts, MD

Registration is necessary as space is limited.

Contact: International Essential Tremor Foundation (IETF) at 888.387.3667 or www.essentialtremor.org/seminars

SAT | JUNE 27 | 8:30 AM-2:30 PM

Personalizing Parkinsons: An Event for Patients, Caregivers and the Community

DHMC, AUDITORIUM ABCD, LEBANON, NH | \$15

Topics: PD, Exercise Research & YOU; Legal Issues and Your PD; Personalizing Comfort Quilts

Speakers include Dr. Mary S. Feldman, DO; Timothy Caldwell, Attorney (NH/VT)

Registration includes continental breakfast and box lunch. Space is limited.

Pre-registration must be received by June 17 but seats may fill sooner.

Registration form available by mail and at www.d-h.org/parkinsons

Contact: Parkinson's Center at 603.653.6672 or email Diane.L.Sherman@hitchcock.org

SAVE THE DATE! WED | SEP 9 | 8:30 AM-2:30 PM

Parkinson's Educational Event for Patients, Caregivers and the Community

ATTITASH GRAND SUMMIT HOTEL & CONFERENCE CENTER, BARTLETT, NH | \$20

Topics: To be announced; registration form available by August 2015

Speakers include James T. Boyd, MD; Parminder K. Padgett, PT, DPT, NCS

Contact: Parkinson's Center at 603.653.6672 or email Diane.L.Sherman@hitchcock.org

We are grateful to all who have made donations in honor and in memory of their beloved family and friends and in support of the Parkinson's Information and Referral Center at Dartmouth-Hitchcock.

TO DONATE BY CHECK,
PLEASE MAKE CHECK PAYABLE TO:
"Hitchcock Foundation," noting
"Parkinson's" in the memo line.

PLEASE SEND TO:
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Lebanon, NH 03756

TO DONATE BY CREDIT CARD,
PLEASE GO TO OUR WEBPAGE:
www.d-h.org/parkinsons
and click on the "support the Parkinson's
Center link" in blue.

FOR HELP WITH OTHER TYPES OF GIFTS,
PLEASE CONTACT THE DEVELOPMENT OFFICE
at DHMC at 603.653.0759

PARKINSON'S COMPANION IS A PUBLICATION OF THE PARKINSON'S CENTER AT DARTMOUTH-HITCHCOCK

The Parkinson's Center at Dartmouth-Hitchcock is an information and referral center supporting the needs of the Parkinson's community.

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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.



Dartmouth-Hitchcock Medical Center

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Attention: Diane L. Sherman

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