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Photo by B. Elwin Sherman



# Parkinson's companion

Dartmouth-Hitchcock

A publication of the Parkinson's Information & Referral Center at Dartmouth-Hitchcock Medical Center, Lebanon, NH

FALL 2014

## Voices of Parkinson's: Steps with Sam and Cecelia

BY B. ELWIN SHERMAN

SAM AND CECILIA had been together for fifty years when I entered their lives as one of Sam's home caregivers. Sam had Parkinson's disease. So did Cecelia. Sam's was seated in his brain and body. Cecelia, as Sam's lifelong partner, had it in her heart and soul.

This is the crux of the challenge for any healthcare professional providing direct patient care in any home or clinical environment: recognizing that all our patients come to us with problems that also deeply disaffect the lives of others, and that our assessments and interventions must always include the

patient's "inner circle" of support.

In my 35 years of nursing practice, I've tried to operate from a self-imposed simple premise: meet people where they are, not where you want them to be. Easy to say, but also easy to overlook when one is so focused on fixing and healing everything (as caregivers are wont to do), even when curing has been removed from the language.

I emphasize the latter, because aside from right here, "healing" and "curing" have no business in the same sentence. I've witnessed extraordinary healing when curing has turned from elusive to

improbable to impossible. No matter the critical mass, there is always healing to be done up to the moment of a passing ... and beyond the loss, for those left behind.

To meet people where they are, we need only call up the words of Florence Nightingale: "Let whoever is in charge keep this simple question in their head: not how can I always do this right thing myself, but how can I provide for this right thing to be always done?"

With Sam and Cecelia, this presented clearly, but a clear path alone does not provide the ability needed to navigate it. As

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Sam's caregiver, my plan was to help both him and Cecelia create an environment where they could enjoy optimum quality of life, and provide times and places where they could best take what Confucius called "action steps"—measures that helped them remain true to their true characters and life together, especially when the goals changed or became unattainable due to the intractable constraints of PD.

Here, we needn't belabor the host of variables that come with Parkinson's, and how what is universal in all sufferers presents itself on so many levels. What works for one patient has little or no effect on another. Even more challenging, what works today, or even this hour to ease pain and keep one purposeful, may not work tomorrow or an hour from now.

As time passed, I watched Sam's form and function change. My interventions, often invented on the spot, had near miraculous effects in the resulting behaviors, or they had no impact at all. Frustrating for Sam and disheartening for Cecelia, as she watched her husband transform from the man she'd intimately known for half a century into a figure that she hardly recognized. Worse, and most difficult to bear ... into a man who didn't recognize her.

My job (never forgetting Ms. Nightingale) was not to do the right things, but to help create ways for

the right things to be always done.

I constantly discussed Sam's changing cognition and somatic functions with Cecelia, and we worked together to deal with what she called "little pieces of him falling away," and to find venues that Sam could effectively use in adapting to those losses, even the ones for which he was becoming increasingly unaware.

As he had more "freezing" episodes, we'd switch his walking cues from using a metronome, to following a laser pen light dot on the floor, to setting "the blue stick" down (a colored ruler that, when placed in front of him, somehow "triggered" his legs to move).

Sometimes, it was as simple as a tug on his sleeve, or a repeated verbal cue, or an awful limerick, or a suggestion of a song. Sam had sung professionally for years, and giving him the opening lyric to "As Time Goes By," could send him into a lucid and soulful rendition of it, and for reasons that only poets can explain, immediately set his feet in motion.

Using input from Cecelia on their times gone by together, I could sidetrack Sam from his difficulty finding words which he might voice as nonsensical, by showing him old photographs, taking him for rides in the country past boyhood haunts, even once visiting the cemetery where his parents were buried, prompting

him to regale me with anecdotes of them and other relatives lined up there.

Those little reorientations helped to keep Sam Sam—the Sam who knew Cecelia as his long-beloved, and who was still giving and receiving that love.

Even near the end, as Sam's tremors and halting gait increased, as his speech became softer and less intelligible, as the medications were less effective, as his windows of cognition closed, there were flashes of good humor and returns to the now.

At one late lunch, I asked Sam how he liked the pizza. He froze, holding a slice in mid-air. Several minutes passed. We sat in silence. Finally, he grinned, looked up at me and faintly said, with just a hint of his all-Sam mischievousness: "If you're waiting for me to speak, you might have a long wait."

Later, Cecelia told me: "I can see more and more that it's becoming one step up and two steps back... but we're still walking them together."

Action steps.

Healing as time goes by. ●

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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.com. Copyright 2014. All rights reserved. Used here with permission.



### A Note from the Coordinator: Diane L. Church, PhD

Dear friends,

We are delighted to welcome Dr. Mary Feldman, Movement Disorders Specialist and Co-Medical Director of the Parkinson's Center, to DHMC! Please see page 5 for more on Dr. Feldman.

I am frequently asked about the financial status of the Parkinson's Center as people recognize that we are no longer affiliated with a national organization. We continue to seek unrestricted funds from corporations to support educational events, donations from individuals and organizations to keep current operations afloat, and major gifts to fund the Center into the future. And we look forward to the day when this is no longer a hot button topic!

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# The revolutionary SlipOn Swimsuit: Help for women who enjoy aquatic exercise!



## SlipOn New Zealand Limited was born out of the incredibly caring nature of its Director and Founder Dianne Rothhammer Sheetz.

Through the years Dianne has always listened to the needs of people and tried to help where she could. One day she was waiting for a Physical Therapy teacher who had just finished an Aquatic Parkinson's class, when a husband remarked to Dianne that he had to wait 30 minutes for his wife to get out of her wet bathing suit. It dawned on Dianne that the swimsuit design of the day was a handicap for most ladies. "I always hated tugging and pulling my swimsuit on and off but had no thoughts of ladies who were not healthy, what a struggle they must have" said Dianne.

Over the next few years Dianne solicited the help of a swimsuit designer and they went to work on fine tuning Dianne's new revolutionary SlipOn swimsuit; a swimsuit that only takes minutes to slip on and a minute to slip off. It has a Utility Patent throughout the world till 2025.

Dianne went on to research how the SlipOn swimsuit could help all different types of women

from all different walks of life. She soon learnt that the SlipOn swimsuit could potentially be responsible for changing people's lives.

The importance of exercising in water was forefront in Dianne's mind and she knew the SlipOn swimsuit had to be made for all body shapes and sizes so that ALL women could get into the pool and experience the benefits that only water exercise can provide.

SlipOn swimsuits are now being worn throughout the world by ladies and young girls who are movement challenged and/or just want to look great in a stylish swimsuit.



With comfortable unmovable wide straps and high back the wearer has the option to discreetly wear a bra underneath for extra support and comfort if needed.

The flattering swimsuit is made from high quality Italian fabrics and is chlorine resistant.

The black and navy suits are made from the finest 4 way stretch Lyrca and can comfortably withstand 240 hours of use in a chlorinated pool.

The patterned floral suits are made from a Polyester and PBT blend and are 100% chlorine resistant.

All SlipOn Swimsuits come in 3 body lengths per size to ensure the best possible fit.

Sizes range from 6 to 34+. Larger sizes can be made to order on request.

The philosophy of SlipOn is one of compassion and belief that nothing should get in the way of living life to the fullest. And why not look good while doing it!

**To see more about SlipOn and their other great products please visit [sliponswimsuits.com](http://sliponswimsuits.com)**

Thanks to Suzanne B. for telling us about this helpful product; Bryan Breen, Operations, SlipOn NZ Ltd for sending a sample SlipOn Swimsuit to The Parkinson's Center; and Pauline Morris, CEO of SlipOn NZ Ltd, for permission to reprint this article, illustrations and photo.

R E S T

# New Friends, Practical Advice and Navigating the Kitchen Safely

By Gay Palazzo, with Liz Downes, OTR



## Once you are diagnosed with Parkinson's,

you find yourself out of your "comfort zone." Your relatives and friends are there for you, but you feel isolated and alone. There are, however, lots of opportunities for you to get to know a whole other set of folks – those with PD as well as those in the health care profession. Soon you realize that PD is not the only thing you have in common.

I have found the world of Parkinson's to be filled with very interesting and caring folks. There is the pleasant sales rep from Teva who I see at PD conferences, Diane Church, the Coordinator of the Parkinson's Center at Dartmouth-Hitchcock Medical Center, a nice couple from the Dominican Republic that I shared a table with at a luncheon, and a young family attending a conference so that they can find ways to help their grandfather with PD.

In addition to these great folks, I have made a new friend, Liz Downes. Liz worked for many years as a licensed Occupational Therapist and recently found out that she has PD. She is an incredibly upbeat and practical person and we decided to collaborate and share ideas that may make life easier for persons with PD as well as care partners.

We came up with several overall pieces of advice and shortened it to make the acronym REST!

## REST

- R = be realistic about what you can do,
- E = be aware of your energy level and how different activities affect you,
- S = separate out tasks, and do those activities that can be done ahead, and
- T = take a break, everyone around you will benefit if you are at your best!

Looking at our households, here are some of Liz's ideas for making your kitchen an easier place to navigate.

1. *Get rid of scatter rugs*
2. *Adapt your door handles for easy opening*
3. *Use faucets with paddle handles that are easy to turn*
4. *Use chairs that are wide, comfortable, and have arms*
5. *Do not use chairs that roll or have loose cushions*
6. *Look at your kitchen set up and place similar items together*
7. *In your refrigerator, put frequently used items in the front*
8. *Put items you use a lot at counter height*
9. *Invest in lightweight pots and pans*
10. *Avoid carrying heavy pots of hot foods or liquids*
11. *Get easy-to-hold lightweight plates and cups for everyday use*
12. *Use baskets, trays and carts - they are attractive as well as practical*
13. *Do not multi-task: Concentrate on one thing at a time*

**We invite you to share with us your own ideas and to ask questions.**

**After all, we are all friends now!**

Please email Gay (gpalazzo24@gmail.com) and Liz (goldenkayak43@comcast.net) to share your thoughts.

There are several free informative guides available to you on adapting to life with PD. For instance...



**Be Independent**  
Put out by the APDA  
(www.apdaparkinson.org)



**Coping and Caring**  
One of 10 terrific booklets produced by the NPF  
(www.parkinson.org)



**101 Hints to "Help With Ease"** for Patients with Neuromuscular Disease  
(mda.org/publications/101hints)



**Life In Balance**  
A newsletters produced by TEVA  
(www.parkinsonshealth.com)



**The Fox Focus on Parkinson's**  
(www.info@michaelfox.org)

## LESSONS FROM THE PARKINSON'S COMMUNITY:

### Fulfilling those Wedding Vows

Best wishes to Jesse Davis and Jessica Kulp, who married on June 14, 2014. Jesse is the executive director of the Parkinson's Comfort Project (PCP). In the following blog posted on the PCP website, he reflected on his upcoming wedding vows, "in sickness and in health," and on the lessons he has learned from the Parkinson's community.



## LIVING VOWS

June 12, 2014 Parkinsonscomfortquilts

As I mentioned in my last post, I am about to get married to the woman who has become the great blessing in my life. As we've prepared for our wedding, I have been reflecting on the vows we are about to make to each other and considering what it means for a lifetime.

The portion of our marriage ceremony where we are asked if we will take the other person "in sickness and in health" for as long as we shall live is perhaps most prescient to me. Why? Because I have seen this vow personified by the spouses who care for their wives and husbands with Parkinson's. I have much to learn from you.

Who but a very small few of you could have known that the person you fell in love with would develop a condition which often robs so much? How do you navigate the innumerable challenges, frustrations and maddening moments? I am convinced it is due to the depth of the relationships which have had many years to nurture and build upon the solid foundations of friendship and love with which you entered your marriages.

I see it time and time again; a nearly boundless patience, loyalty and care for your loved ones. You, the spouses of the Parkinson's community, personify the vow of taking each other "in sickness and in health." Thank you for your example, your dedication and your care of your loved ones.

Be well...Jesse

(Reprinted with permission of the author: <http://parkinsonscomfort.org/2014/06/12/living-vows/>)

## After the Wreck

by Martha Manheim

You died  
And left me out at sea  
In a life-ring, bright orange  
Against gray waters,  
Immense around me  
Empty to all horizons.  
What to do?  
I drifted, numbed by the cold,  
And drifted, could not stir,  
Could not stir.

Nevertheless, I'll swim.

Martha Manheim is a retired professor of literature. She has contributed articles to the Parkinson's Companion on the unpredictability of Parkinson's (Spring 2011), preparedness for the newly widowed caregiver (Fall 2011) and the benefit of caregiver support groups (Spring 2014). Her beloved husband Michael died of heart failure in January 2011 after living with Parkinson's for many years.



## A Warm Welcome to Dr. Mary Feldman, Movement Disorders Specialist!

We are delighted that Mary S. Feldman, DO has joined the Movement Disorders Team at Dartmouth-Hitchcock Medical Center. Dr. Feldman received her medical training in PA, completed a Movement Disorders Fellowship at Cleveland Clinic, and practiced in PA. She joined the Department of Neurology at DHMC in July 2014. In addition to seeing patients in clinic, she is Co-Medical Director of the Parkinson's Center at DHMC and Assistant Professor of Neurology, Geisel School of Medicine at Dartmouth.

**Dr. Feldman is also a classical pianist, but when not in clinic or at the piano keyboard, you will likely find her skiing, kayaking, hiking or enjoying other outdoor activities with her family. Welcome to our community, Dr. Feldman!**

*Left: Mary Feldman and family take a break from hiking in Jackson Hole, WY.*



## Wheelchair Health In Motion's 2nd Annual Summer Hike June 20, 2014

On Friday June 20, friends, members and partners of the Wheelchair Health In Motion (WHIM) program hiked the beautiful trails at Croched Mountain Rehabilitation Center in Greenfield, New Hampshire together.

Wheelchair Health In Motion (WHIM) is a peer-driven program that provides the tools for increasing quality of life and promoting wellness in individuals living with a physical disability through innovative chair exercise and peer support within their own community.

[sheinh.org/whim](http://sheinh.org/whim)

[crochedmountain.org/Programs-and-Services/Accessible-Trails/Accessible-Trails](http://crochedmountain.org/Programs-and-Services/Accessible-Trails/Accessible-Trails)

[dartmouth-hitchcock.org/documents/2013\\_fall\\_nh\\_parkinsons\\_companion.pdf](http://dartmouth-hitchcock.org/documents/2013_fall_nh_parkinsons_companion.pdf)

# ANNOUNCEMENTS & EVENTS

## THU & MON | SEP 18 - OCT 27

### Fall 2014 Parkinson's Wellness Program (Six-week program)

10 AM - 11:30 AM

DHMC, LEBANON, NH | \$149, SCHOLARSHIPS AVAILABLE ON REQUEST  
Exercise, balance, gait training, and education program led by DHMC's Rehabilitation Medicine specialists to help those with PD achieve a better quality of life.

[dartmouth-hitchcock.org/parkinsons/parkinsons\\_wellness\\_program](http://dartmouth-hitchcock.org/parkinsons/parkinsons_wellness_program)

Contact: Parkinson's Center at (603) 653-6672 or email [Diane.L.Church@hitchcock.org](mailto:Diane.L.Church@hitchcock.org)

## MON | OCT 6

### Progress for Parkinson's: An event for patients, caregivers, and the community

8:30 AM - 2:30 PM

GRAPPONE CONFERENCE CENTER, CONCORD, NH | \$20

**Topics & Speakers:**

**Parkinson's Research Update:** Understanding the landscape and key breakthroughs; Kuldip Dave, PhD, Director, Research Programs, The Michael J. Fox Foundation for Parkinson's Research

**Management of non-motor symptoms of Parkinson's disease:** Stephen Lee, MD PhD, Movement Disorders Specialist, Dartmouth-Hitchcock Medical Center; Co-Medical Director, Parkinson's Center at DHMC; Assistant Professor, Geisel School of Medicine at Dartmouth

**LSVT® LOUD & BIG: Research-based rehabilitation programs for people with PD:**

Pam Thomas, MS, CCC-SLP & David "Nick" Allard, MS, OTR/L, Rehabilitation Specialists, HealthSouth Rehabilitation Hospital, Concord, NH

Registration includes continental breakfast and plated lunch. Space is limited. Pre-registration must be received by Sep. 24 but seats may fill sooner. Registration form available by mail and at [dartmouth-hitchcock.org/parkinsons](http://dartmouth-hitchcock.org/parkinsons)

Contact: Parkinson's Center at (603) 653-6672 or email [Diane.L.Church@hitchcock.org](mailto:Diane.L.Church@hitchcock.org)

## SAT | NOV 1

### Piecing for Parkinson's: A quilting workshop by the Parkinson's Comfort Project

9 AM - 5 PM

QUAIL HOLLOW SENIOR LIVING COMMUNITY, LEBANON, NH | FREE

[parkinsonscomfort.org/piecing-for-parkinsons](http://parkinsonscomfort.org/piecing-for-parkinsons)

Contact: Parkinson's Comfort Project at (802) 299-0180 or email [ParkinsonsComfort@gmail.com](mailto:ParkinsonsComfort@gmail.com)

## SUN & MON | NOV 2 - 3

### Parkinson's Perspectives: APDA New England Regional Parkinson's Conference

HOLIDAY INN, MANSFIELD, MA | \$20 PER DAY

For more information, contact: Massachusetts APDA Center at (800) 651-8466.

### Are you interested in participating in a clinical research study?

Please contact our Clinical Research Coordinators to learn about current and future opportunities:

At DHMC, Lebanon, NH: Polly LeBlanc at [Pauline.R.LeBlanc@hitchcock.org](mailto:Pauline.R.LeBlanc@hitchcock.org) or (603) 650-4411

At Fletcher-Allen, Burlington, VT: Emily Houston (802) 656-8974

For information, please contact Diane L. Church at 603.653.6672 or send email to [Diane.L.Church@hitchcock.org](mailto:Diane.L.Church@hitchcock.org) or the contact noted for a specific announcement.

## PARKINSON'S COMPANION IS A PUBLICATION OF THE PARKINSON'S CENTER AT DHMC

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

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Mary S. Feldman, DO

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.



## *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 & Referral Center at DHMC.*

**To donate by check,**

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

PLEASE SEND TO:

Hitchcock Foundation-Parkinson's  
One Medical Center Drive  
Lebanon, NH 03756

**To donate by credit card,**

PLEASE GO TO OUR WEBPAGE:  
[patients.dartmouth-hitchcock.org/parkinsons](http://patients.dartmouth-hitchcock.org/parkinsons)  
and click on the support the Parkinson's Center link.

**For help with other types of gifts,**

PLEASE CONTACT THE DEVELOPMENT OFFICE  
at DHMC at 603.653.0759.





**Dartmouth-Hitchcock Medical Center**

One Medical Center Drive  
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**Attention: Diane L. Church**

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