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## From mother to daughter, lessons shared

BY MARY JACOBSON

My mother, Carol Butterworth Jacobson, was an outgoing personality with a sunny disposition. A Seattle native, she was a happy full-time mother during her younger years. She was active in her community, always busy volunteering for children's and health causes. And she was social, enjoying games of tennis and bridge with her many friends.

At 49 she became a full-time caregiver to her husband, my father, Bill. His health changed suddenly and drastically when, at 51, he was felled by a stroke. For the next 15 years, until he succumbed to a lung carcinoma, my mother set a standard for loving, in-home care that became my guidepost when she was diagnosed with Parkinson's disease in 2004.

Mom was 79 at the time of her diagnosis, and she often expressed gratitude for the many years of good health she'd had until then.

Yet her vulnerabilities were apparent and her need for a caregiver clear. I didn't hesitate to leave a job in Idaho and return to Seattle to take care of her.



Courtesy photo

The author with her mother, Carol Butterworth Jacobson, on Mother's Day in 2007.

I didn't know much about Parkinson's when my mother was diagnosed, but in the poignant five years until her death in 2009 I learned a lot about the disease.

I was a strong, capable force during the years I managed her care, but I was worried when I rather suddenly began exhibiting tremors shortly after she died. And I was stunned when, 10 months after her death, I was diagnosed with Parkinson's disease myself.

Since then I have become committed to doing what I can to promote awareness of the disease. I often daydream of being around for the cure... of miraculously losing my uncomfortable rigidity and right-hand tremor.

My mother's experience inspired me to write a short story of her life. The title of the book, *One in a Million*, is a reference to the estimated million people in the

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Our mission is to establish an **optimal quality of life** for the Northwest Parkinson's community through **awareness, education, advocacy and care.**

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## Care out there for caregivers

DID YOU KNOW THAT 2011 is the Year of the Caregiver? The U.S. Administration on Aging is sponsoring this yearlong celebration to commemorate the 10<sup>th</sup> anniversary of the National Family Caregiver Support Program and to spotlight the role of family caregivers.

Family caregivers are the bedrock of America's long-term care system and come from all walks of life. Every day they assist relatives and loved ones with tasks ranging from simple support like helping with household chores to complex care such as bathing, dressing and moving around the home. Others provide lifesaving measures such as administering medications and monitoring their side-effects.

Family caregivers can be devoted partners or spouses, children or other relatives, as well as nurses, home-health aides, paralegals and financial advisors for their loved ones.

National research has shown that caregivers are everywhere and their numbers are growing. For example, 66 percent of older people with chronic disabilities are cared for by a family member, and 65 million people provide care for a chronically ill, disabled or aged family member or friend each year.

Although most caregivers view their work as rewarding, many experience significant stress and negative health impacts. To help alleviate the toll of caregiving, family caregivers need supports and services that safeguard their health and emotional well-being while relieving some of the financial burdens that often accompany caregiving duties.

Just as the challenges of living with Parkinson's change over time, so do your

experiences and needs as a caregiver. A flood of emotions and frustrations can overwhelm the caregiver from the time of diagnosis to many years into the disease. It is normal to feel like you are alone, losing your identity, losing a relationship to caregiving, and taking less time for yourself and your own needs.

As a result of years of planning, infrastructure development, and program design and implementation, each state's Area Agency on Aging (AAA)/Senior Information and Assistance offers a comprehensive array of programs and support to family caregivers.

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### **Family caregivers are the bedrock of America's long-term care system. They come from all walks of life.**

AAA offices are a tremendous resource and one of the best places to start for any adult over 60 who needs or wants support or services. Your local AAA staff are expert in the services available where you live.

AAA staff can help assess the current situation and plan for what is needed. They are also a valuable resource for family or friends who are providing care to an aging adult and need information, support or respite services.

The Family Caregiver Support Program is a service available to unpaid caregivers of adults needing care.

There are local Family Caregiver Support Program or Senior Information and Assistance offices throughout the region staffed with caring and knowledgeable people who can help you to:

- ◆ find local resources and services;
- ◆ find support groups and counseling;
- ◆ connect to training on specific caregiving topics;
- ◆ get respite care when you need a break; and
- ◆ talk through specific issues you are having and offer caregiving suggestions.

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# What to do if you're new to Parkinson's

BY SIERRA FARRIS, PA-C

FOR MORE THAN A DECADE I have worked as a physician assistant providing care to people with Parkinson's. I have learned that there is much more to genuinely caring for and treating a person with a chronic condition than one can learn in school.

The most significant visit with a patient is the appointment during which the diagnosis is given. On hearing a Parkinson's diagnosis, many people immediately feel their life is shattered, that the bottom has just fallen out.



Sierra Farris, PA-C

In the time following diagnosis, common reactions include anxiety, depression, stress, grief and sadness.

To address some of these feelings, one of your first moves after diagnosis should be to ask your doctor to recommend a "newly diagnosed" appointment or class. These appointments offer you the first exposure to helpful insights and information for coping with the disease.

When I meet with newly diagnosed patients I provide a multitude of facts about Parkinson's, but I recognize that the patient's and family's ability to absorb the information all at once might be limited. I let them guide the appointment in the direction that best meets their needs.

Some have a long list of questions, while others simply want to know what to expect from Parkinson's and what the latest treatment can do for them. Sometimes we discuss science and other times we just talk about the changes and symptoms that led to the diagnosis.

Following are some of the more common questions that come up in these appointments. Use this list and add your own questions for review with your doctor.

- ◆ How fast will the Parkinson's progress?
- ◆ When and why do I need to start medication?
- ◆ Is Parkinson's genetic?
- ◆ Should I tell my employer I have Parkinson's?
- ◆ What kind of exercise should I be doing?
- ◆ Should I take certain vitamins or supplements?

One thing that clearly stands out at every "newly diagnosed" appointment is a patient's feeling of losing control.

Patients and families express this in different ways, but loss of control is generally experienced as fear about the unknown impact of the disease on their future.

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BY COLLEEN CROWLEY, J.D., CFRE



MORE THAN A MILLION people in the United States are thought to have Parkinson's disease. In the Northwest region of Washington, Alaska, Idaho, Montana and Oregon, some 70,000 people are living with Parkinson's—at least 30,000 of those here in

Washington. And hundreds of thousands of family members, friends and health professionals provide daily care to people with Parkinson's.

Big numbers like those can seem overwhelming and difficult to relate to. But we know that behind each figure is an individual person—someone's father, mother, brother, uncle, friend, neighbor or colleague—with a story to tell.

Here at the Northwest Parkinson's Foundation we try to highlight as many of the stories as possible. We know that those who read this newsletter may find a little bit of themselves in each story. We hope you are inspired and encouraged by the strength and determination of others facing the disease, who are finding new ways to cope.

We strive to increase awareness and provide information and education to as many people in the Northwest as possible. We are increasing our efforts to reach out to support groups; local, regional and state government agencies that provide resources to seniors; and the medical community that cares for people with Parkinson's.

We believe our greatest outreach is through each of you reading this *Parkinson's Post*. We ask you to spread the word about the Northwest Parkinson's Foundation and our resources. And we invite you to stay on top of the latest by regularly visiting our website at [nwpf.org](http://nwpf.org).

*Thank you for inspiring us with your stories!*

## SAVE THE DATE...

...FOR AN EVENING IN SODO!

**WHAT?** Every year we set aside one night to celebrate the Northwest Parkinson's community and to raise funds for the programs and services that make such a difference. This year's celebration—An Evening in SoDo—promises to be more special than ever. We'll showcase Mark Morris' Dance for Parkinson's program, presented by Spectrum Dance and with a special performance by the Spectrum Dance Academy. **WHEN?** Wednesday, September 28.

**WHERE?** SoDo Park in Seattle's South of Downtown district.

**MORE?** Contact Joseph DiChiaro (206.748.9481 or [joseph@nwpf.org](mailto:joseph@nwpf.org)).

### AROUND THE REGION



INFORMATION WON'T CURE PARKINSON'S, but it's the first step to understanding the challenges and discovering the possibilities of living well. Here are a few upcoming opportunities

around the Northwest. Find further details on our Events page at [nwpf.org](http://nwpf.org) or by calling 877.980.7500.

#### In Washington

◆ Motivation: Overcoming Obstacles for Change, and Take Back Your Energy. August 17, 11:30 a.m. to 2 p.m. Lynnwood Convention Center, Lynnwood. Lunch provided. No cost. To register call 877.980.7500.

◆ Telehealth presentations. July 11 (Sleep and Fatigue) and August 8 (Bone Health), 2 to 3:30 p.m. Visit [nwpf.org](http://nwpf.org) for a location near you.

◆ Team Parkinson's rides in the Group Health Seattle-to-Portland Bicycle Classic. July 9 and 10.

◆ Motivation: Overcoming Obstacles for Change, and Take Back Your Energy. September 12, 2 to 3:30 p.m. Kent Senior Center, Kent. No cost. To register call 877.980.7500.

◆ 6<sup>th</sup> Annual HOPE Conference on Parkinson's. October 29. Hilton Seattle Airport and Conference Center. Details to come.

#### In Alaska

◆ Prescription for Brain Health with Parkinson's. September 22, 2:30 to 4 p.m. Providence Alaska Medical Center, Anchorage. To register call 877.980.7500.

◆ Nurse and Physician Assistant Workshop and Dinner. September 22, 6 to 9:30 p.m. Crow's Nest Restaurant, Anchorage. No cost. Reservations required. To register call 877.980.7500 or email [alecha@nwpf.org](mailto:alecha@nwpf.org).

◆ Telehealth presentations. July 11 (Sleep and Fatigue) and August 8 (Bone Health), 1 to 2:30 p.m. Providence Hospital, Anchorage.

#### In Montana

◆ Telehealth presentations. July 11 (Sleep and Fatigue) and August 8 (Bone Health), 3 to 4:30 p.m. Deaconess Billings Clinic, Billings; and Community Mental Health Center, Miles City.

#### In Idaho

◆ Telehealth presentations. July 11 (Sleep and Fatigue) and August 8 (Bone Health), 2 to 3:30 p.m. Locations include Grangeville, Coeur d'Alene and Sandpoint. For details, visit [nwfp.org/careandsupport](http://nwfp.org/careandsupport).

#### In Oregon

◆ Parkinson's summer hikes in Portland. July 12 is a 3-miler and August 3 is a 5-miler. Registration required at [pro.eventbrite.com](http://pro.eventbrite.com).

# On the Parkinson's road, discovering the self

BY TERRY SHAPIRO

In June 2008 I sought medical attention for the chronic fatigue and depression I was feeling after a series of losses—my job of 18 years, a close friend, my loyal cat and my apartment. On September 17 that year, a neurologist told me I have Parkinson's disease.

That was the day I started a journey that is likely to take the rest of my life to complete.

There's always the optimistic hope that a cure will be found. But realistically, I will be fighting this thing for years to come. So dealing with the emotional side of having Parkinson's is something I need to face.

I've learned a lot about the condition and its various treatments, but some of the most important discoveries I have made are not about Parkinson's itself. They're about me.

◆ *My attitude is important.* One of the factors that will influence my experience of Parkinson's is my own mindset. For sure, I have to face up to the effects of Parkinson's. But dealing with the issues effectively will be the key to maintaining the positive attitude that is so important.

◆ *Parkinson's is not my life.* I have Parkinson's but I am working hard so it will not be the one focus of my life. I plan to carry on doing things I enjoy. And although they may be affected by my condition, I am working on a balance. For as long as I am able, I will not let Parkinson's be the dominating thing in my life, as it was when I first diagnosed.

◆ *I am in this for the long haul.* At first I was in denial, then I was hungry for information. But I found that I soon suffered from information overload, so now I pace myself a little better when it comes to learning about Parkinson's.

◆ *Part of my role is to help others come to terms with my Parkinson's.* Telling family and friends that I have Parkinson's has been the most difficult thing of all. I was emotional and nervous at first, and I knew the news would be a shock to them. I find that most people know little about Parkinson's. I tell them it's what Michael J. Fox and Mohammad Ali have. Some verbalize genuine concern and support; others just don't know what to say. After my immediate family knew, it became easier for me to tell others. But sometimes I'm the one comforting those I tell, rather than vice versa.

◆ *Some people never ask how I am.* Some take the trouble to inquire, but I get the feeling few want the true answer. Perhaps they'd struggle with what to say if I told them I'm

having problems, so they avoid the subject.

◆ *I need no longer worry about work.* In April 2008 I was let go from my job of 18 years in one telephone conversation from the owner of the company. After being praised for years as a top sales producer, I was kicked to the curb in one unexpected conversation because my employer feared keeping me on board would cause her to lose business. It was upsetting that she did not stand by me. This was a wake-up call for me. I went into a depression immediately and started to seek medical help, which led me down the road to Parkinson's.

◆ *My pride can get in the way.* There is help available but, having been a single working woman for all of my career, I have always been proud of my self-sufficiency. Family and friends encourage me to ask for help with some of the things I used to do that are now difficult. For now I'll try to manage, but I know for certain there will be a time I will need help with daily living activities.

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## Some of the most important discoveries I've made are not about Parkinson's itself. They're about me.

◆ *Will receiving help knock my confidence?* When the time comes that I need help, will it make me feel less able? Will it affect my confidence? Will this change my attitude from someone who strives to achieve to someone who doesn't push herself at all? I am wrestling with these thoughts.

◆ *The one upside to having Parkinson's?* For me it is that I have met and made friends with a group of people I'd never have met otherwise. They have helped me see the way forward. I hope I have helped them a little as well. It's a blitz mentality, I suppose—comrades in adversity. It makes the whole experience somewhat bearable to see others who are more seriously affected than me, continuing to live their lives and not feel sorry for themselves, but to fight their illness with dignity and inner strength.

◆ *I know I am not alone.* There are doctors, nurses, therapists, researchers, support groups, fund raisers, friends and family members all out here to help. And there are other people just like me who are facing the challenge of Parkinson's because the lottery that selected me also came up with their number. Somehow I think that if we all put our heads together we can make the journey we face easier to cope with—and we might have some fun along the way.

*Terry Shapiro lives in Southern California, is a public relations consultant and works to raise awareness and support for people with Parkinson's disease.*



## TRIBUTE GIFTS

**GIFTS TO THE NORTHWEST**  
Parkinson's Foundation support our educational publications and self-care tools, including this newsletter, weekly email news updates, a content-rich website, patient-education programs and our annual HOPE Conference on Parkinson's.

In addition to sustaining existing programs, your donations support our efforts to develop and implement innovative new programs that respond to the changing needs of the Parkinson's community.

We are privileged that so many in the Northwest Parkinson's Foundation family support our mission by giving generously throughout the year. In each issue we list tribute contributions made in honor or memory of loved ones touched by Parkinson's.

Those wishing to establish a permanent memorial may create a family fund with a minimum donation of \$2,500, either from a single gift or many. New family fund donors are listed below. To learn more, contact Joseph DiChiaro at 1.877.980.7500 or [joseph@nwpf.org](mailto:joseph@nwpf.org).

Listed here are tribute gifts received between **April 14** and **June 9, 2011**.

*Please notify us of any errors in spelling or attribution.*

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# Assistance is just three numbers away

BY RUTH EGGER, M.S.

Did you know each state has a 2-1-1 phone line? But what is it for?

The 2-1-1 Community Information Line provides expert information and referral assistance to people seeking help with community resources.

Information and referral specialists help connect people with services that are most appropriate to their needs. Staff members are trained in the art of assessment and problem-solving.

The 2-1-1 Community Information Line can provide information on these topics and more:

- ◆ Paying your rent and utilities
  - ◆ Feeding your family
  - ◆ Caring for a disabled loved one
  - ◆ Finding in-home care services
  - ◆ Getting home-repair assistance
  - ◆ Finding shelter for the night
  - ◆ Enrolling in a computer class
  - ◆ Obtaining family planning and health services
  - ◆ Seeing a low-cost mental health or chemical-dependency counselor
  - ◆ Acquiring legal and civil rights assistance
- In addition, the 2-1-1 Community Information Line offers specialized information and assistance to people with disabilities and caregivers of adults 18 years and older with an illness or disability.

This website [crisisclinic.org](http://crisisclinic.org) has



Courtesy graphic

special information on locating disability and caregiver resources.

Just call 2-1-1 and you will be connected to the agency in your county.

If there is no 2-1-1 line in your county, call your local United Way office for assistance.

*Ruth Egger is social services manager with the Northwest Parkinson's Foundation.*

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#### **MILLION** | CONTINUED FROM PAGE 1

United States who have Parkinson's.

The kindness and support of the Northwest Parkinson's Foundation last year (a special thank you to Bill Bell, its cofounder) helped me accept my diagnosis.

Now I want to do what I can to help support the Northwest Parkinson's Foundation in its mission, and I hope my book will do that.

*One in a Million is a print-on-demand, self-published book available through bookstores until the end of the year. The author, who lives on Vashon Island, WA, is pledging 50 percent of the proceeds of sales to the Northwest Parkinson's Foundation.*

#### **CAREGIVING** | CONTINUED FROM PAGE 2

Generally, these services are free or low-cost. Eligibility requirements may apply and availability varies by community. Check out [www.eldercare.gov/Eldercare.NET/Public/Index.aspx](http://www.eldercare.gov/Eldercare.NET/Public/Index.aspx). Or look here for your state office:

◆ **Washington:**

[www.aasa.dshs.wa.gov](http://www.aasa.dshs.wa.gov)

◆ **Oregon:** [www.oregon.gov/DHS/spwpc/caregiving/home.shtml](http://www.oregon.gov/DHS/spwpc/caregiving/home.shtml)

◆ **Montana:** [www.dphhs.mt.gov/sltc/services/aging/ADRC/IndexADRC.shtml](http://www.dphhs.mt.gov/sltc/services/aging/ADRC/IndexADRC.shtml)

◆ **Idaho:** <http://idahoaging.com/AreaAgencyonAging/tabid/127/Default.aspx>

◆ **Alaska:** <http://hss.state.ak.us/dsds/grantservices/adrc.htm>

*This article was excerpted from [celebratingfamilycaregivers.org](http://celebratingfamilycaregivers.org).*

#### **NEW TO PD** | CONTINUED FROM PAGE 3

This is why it is so important for newly diagnosed patients to understand there are coping techniques available to them that can significantly impact their power to reclaim and keep control.

I have listened to hundreds of patients and families over the years, and there is one thing I am certain of. For most, maintaining control so that the disease doesn't take over is crucial to living a happy life with Parkinson's.

Seeking guidance and support through a "newly diagnosed" appointment is one way to put yourself in the driver's seat.

*Sierra Farris is a board-certified physician assistant specializing in Parkinson's disease. She thanks and acknowledges her teacher and mentor, Dr. Monique Giroux, from whom she has learned much regarding the care and treatment of people with Parkinson's.*