After 6 years, 4 quality-of-life rules hold true

By Hal Newsom

In 2002 I wrote a book called H.O.P.E. It was developed primarily to provide encouragement to people who had recently received the shocking diagnosis of Parkinson’s disease.

Shocking to me is that the Northwest Parkinson’s Foundation has printed 10,000 copies of the book, and another 5,000 will come off the press this year. I never dreamed that this simple guide would be so popular.

I get email from people with Parkinson’s from all over the world. I even got a call from a young sailboat skipper in the South Pacific who was heading for Australia. He had read the book and wanted my assurance that the disease would progress slowly.

I couldn’t give him that blessing. I did tell him he had to find a way to exercise, even if the cabin was no more than 20 square feet.

Lots of people ask me what I would change in the book if I were to come up with a new edition. Probably very little. In the last six years my Parkinson’s has progressed. But my beliefs about how to live a full and happy life have remained the same.

Help. Optimism. Physician. Exercise. These remain the keys to a good quality life. They have become even more critical as I face a new stage of the disease.

Let me tell you what I mean. When I wrote the book, I had just finished the 200-mile bike ride from Seattle to Portland. I probably couldn’t do that today. Parkinson’s has sapped some of my energy and recovery time.

I still ride a street bike, but at 8 mph and for no more than an hour at a time. If I ride for longer, my legs cry out for me to stop. I become less stable and run the risk of weaving into the path of a car.

Before, I could gut it out. These days, extra training doesn’t seem to build extra endurance. My maximum performance level is lower than it was six years ago.

What am I doing about this decline? I’m living with it. I could quit exercising, but that would be giving in to the Parkinson’s Devil (the Satan who lures people into the Lazy Boy and causes the...
Just can’t stop: Compulsivity in Parkinson’s

By Jacob Bentley, M.A. and Jeffrey Shaw, Psy.D.

In addition to the physical and motor problems in Parkinson’s disease, some individuals also experience behavioral and psychological symptoms.

Some have difficulty controlling impulses and struggle with problematic behaviors such as excessive gambling, hypersexuality and punding.

There can also be problems associated with obsessive thoughts or compulsive behavior related to eating, shopping or Internet use.

Often the diagnosis of obsessive compulsive disorder—or OCD—applies. Obsessive thinking is characterized by interfering recurrent or persistent thoughts. These thoughts serve as a source of anxiety for people and prevent normal functioning.

Compulsive behaviors are repetitive and serve to temporarily reduce the anxiety connected to and perpetuated by obsessive thoughts.

Punding is a unique class of behaviors with obsessive-compulsive qualities. The term punding refers to repetitive, aimless actions.

Individuals prone to punding may neglect their personal hygiene, medication regimen and normal sleep patterns in favor of performing relatively unimportant tasks.

Sorting and resorting items or dismantling objects with no resolution or completion of the task at hand are examples of punding behaviors.

Others’ attempts to intervene with these behaviors may be met with opposition and irritability even though the punding individual may readily admit that the activity brings them no sense of pleasure or fulfillment.

However, those struggling with punding may not recognize the disruptive nature of the activity.

Pathological gambling is defined by an inability to abstain from gambling despite severe personal or familial loss. This loss often comes at great financial, personal and vocational expense.

The prevalence of excessive gambling among individuals with Parkinson’s is relatively low, but many people with no history of problematic gambling develop problems when taking certain Parkinson’s medications.

Enhanced sex drive may cause interpersonal tension between partners, increased use of pornography, or non-characteristic sexual behavior.

This type of compulsive behavior may be related to a lack of impulse control or an increased drive for sex, as both of these processes are related to the activity of dopamine in the brain.

A confounding factor is the often implied “don’t ask, don’t tell” policy concerning issues of sexuality. Sometimes the physician is the last to know about the problem.

Because of shame and practical considerations, partners and family members may also be blindsided by the extent of the problem.

A number of factors can contribute to the emergence of such difficulties for Parkinson’s patients. An association between dopamine-active medications, physiological brain changes and compulsive behavior has been highlighted in the existing research.

However, the development of obsessive thoughts, compulsive behaviors and reduced impulse control is likely related to the convergence of a number of factors, including the stress of coping with a chronic health issue and social isolation.

Management of impulse control and compulsivity in Parkinson’s can be assisted through several means. Many of these issues are highly personal for patients, which may keep the problem more secretive.

However, early intervention is crucial because these behaviors can have a compounding effect on individuals and families already coping with Parkinson’s.

Marital conflict, financial strain and legal troubles are potential areas of distress. Treatment for these behaviors should be tailored to fit the needs of the patient as well as the environment of the treating clinic.

Under the guidance of the neurologist, dopamine-influencing medications may need to be reviewed.

Often behavioral experts such as psychologists, psychiatrists and other mental health specialists are necessary to change patterns of behavior and rebuild damaged relationships.

Relationship counseling is often necessary to help families deal with separating the behavior from the person they love.

Hypersexuality refers to enhanced interest in sexual activity and may also be increased by medications that manipulate dopamine.

Enhanced sex drive may cause interpersonal tension between partners, increased use of pornography, or non-characteristic sexual behavior.

Coping mechanisms are necessary to help families deal with separating the behavior from the person they love.

Sometimes legal and financial experts are needed to help protect families and individuals from the actions that developed from the compulsive behaviors.

Jacob Bentley is a clinical psychology doctoral student training with neuropsychologist Jeffrey Shaw at the Booth Gardner Parkinson’s Care Center in Kirkland, W.A.
Advocates push for funding into Parkinson’s research

By Martin Hovenkotter
In early February Washingtonians joined hundreds of other advocates from across the country in Washington, D.C., where they promoted a common goal: increased federal funding for Parkinson’s research.

As Washington state coordinator for the Parkinson’s Action Network (PAN), I am pleased to follow in the footsteps of my predecessor, tireless advocate Carey Christensen. Only days after Carey passed the torch, I was off to D.C. to lead and learn.

It was a busy time for Congress, and PAN worked to be noticed in spite of primary election activities.

My main role for PAN is to help coordinate the message and advocacy that the Parkinson’s community delivers to our state’s lawmakers. We focus on issues ranging from promoting the Washington State Parkinson Disease Registry to pushing for increases in funding for Parkinson’s research.

PAN is a lobbying force for Parkinson’s organizations across the U.S., a collective voice advocating for the million-plus Parkinson’s patients and their families in this country.

Our job is to make sure every member of Congress understands the issues that affect the Parkinson’s community.

We have three opportunities to further our cause by asking our state’s U.S. senators and representatives to:

1) Sign a Parkinson’s caucus letter supporting $55 million for the Department of Defense’s Neurotoxic Exposure Treatment Research Program. This program investigates how Desert Storm troops’ symptoms, referred to as “Gulf War Syndrome,” share the same brain cell response as in Parkinson’s.

2) Support funding for the Food and Drug Administration, a critical path in Parkinson’s drug development, to help speed promising medications to the Parkinson’s community.

3) Support a $1.9 billion increase in federal appropriations for the National Institutes of Health.

Please contact me if you would like to be part of PAN’s efforts to influence lawmakers locally and nationally.

Martin Hovenkotter lives in Sammamish, WA. You can reach him at 425.301.4936 or mhoven@comcast.net. Learn more about PAN at www.parkinsonsaction.org.

Parkinson’s housing group teams up with student designers to bring plans to life

By Aly Colón
The Puget Sound PD Housing Alliance—also known as “PuSH for PD”—recently partnered with Washington State University to develop design plans for a supportive living facility geared to people with Parkinson’s.

The partnership with the Spokane-based WSU Interdisciplinary Design Institute brought together PuSH for PD representatives and design students, who worked to develop floor plans and material specifications that may eventually be used by an architectural team.

But the collaboration yielded more than just design plans, said Dick Almy, PuSH for PD vice president. It exposed design students to the needs of people with Parkinson’s disease. It strengthened the relationship between the Seattle and Spokane Parkinson’s communities.

And it created more interest among those outside the Parkinson’s arena about people with the disease and their housing needs.

“We saw people being pumped up for our program, people jazzed about what we’re doing. They got excited,” Almy said.

One of those who felt the excitement was Kathleen Warren, WSU Foundation’s director of foundation relations. Almy said she was attracted by PuSH for PD’s grassroots effort and provided guidance on whom the organization might approach for support.

PuSH for PD believes that the end product of the WSU collaboration can be leveraged as a tool for enticing prospective financial supporters. The visuals offer a concrete idea of what a facility could look like and the kind of quality it could provide.

Aly Colón lives in Seattle and has been a journalist for more than two decades, writing for newspapers, magazines and websites. Read more about PuSH for PD at its website, www.pushforpd.org.
Don’t forget there’s strength in numbers! Consider Parkinson’s educational opportunities, support groups, and events in your area as ways to build your network. Go to www.nwpf.org for a full listing.

**Well-spouse support group** | 4 to 5:30 p.m. 1st Monday | Greenwood Senior Activity Center, 525 N 85th St., Seattle, WA (206.297.0875) | Group addresses needs of the well spouse of a chronically ill partner; members care for loved ones with a variety of disabilities, including Parkinson’s. | Contact Carin Mack: 206.230.0166 or socialwkr@earthlink.net

**Parkinson’s support group** | 11:30 a.m. 3rd Friday | Tacoma Lutheran Retirement Community, 1301 N Highlands Parkway, Tacoma, WA | Contact Sharon Jung: 253.284.4488

**Meet the experts** | Noon to 2:30 p.m. April 18 | Evergreen Healthcare, Kirkland, WA | Physicians, psychologists and physical, occupational and speech therapists at the Booth Gardner Parkinson’s Care Center will discuss their team approach to treatment. | Open to patients and families; free of charge and includes boxed lunch | Call 425.299.3000

**What’s in the PD Pipeline?** | May 9 | Presented by the Parkinson’s Disease Foundation and the Parkinson Association of the Carolinas, this educational webcast will feature Dr. Katrina Gwinn of NIH/NINDS, Dr. Mark Stacy of Duke University and Dr. Clive Svendsen of the University of Wisconsin-Madison | Contact PDF: 800.457.6676, webcast@pdf.org or www.pdf.org

**Understanding restless legs syndrome** | Noon to 2:30 p.m. May 16 | Evergreen Healthcare, Kirkland, WA | Pinky Agarwal, M.D., will discuss diagnosis and treatment for restless legs syndrome. | Open to patients and families; free of charge and includes a box lunch | Call 425.299.3000

**Auction benefiting Washington Chapter American Parkinson Disease Association** | May 17 | South Lake Union Naval Reserve Center, Seattle, WA | Contact Evelyne Davis: 425.443.8269 or evedavis@gmail.com

**Introduction to yoga for Parkinson’s patients** | 1 to 2 p.m. June 20 | Evergreen Healthcare, Kirkland, WA | Hear about the benefits of yoga for Parkinson’s patients and practice basic movements and breathing in your chair | $5; registration required | Call 425.299.3000

Get moving for good health, good cause

By Dav’ne Stahley

Team Parkinson’s 2008 is gearing up and it’s time to register!

Join our dedicated team members, who support the Parkinson’s community by challenging themselves in various athletic events.

Team members take part in organized bike rides or sometimes just hop on a stationary bike for a personal challenge; they run in marathons and swim in masters programs.

Fund raising is encouraged: Most team members invite friends, family and colleagues to support their effort with donations.

Mark and Sue Petersen (pictured here) of Pendleton, OR, have been on the team since 2006. They learned about the Northwest Parkinson’s Foundation by participating in the Group Health Seattle-to-Portland Bicycle Classic.

“Mark’s brother lives with Parkinson’s,” said Sue Petersen, “and we wanted to learn more about this all-consuming disease to help him and others like him.”

As the Petersens were already regular STP riders, it wasn’t much of a stretch for them to raise money as well.

Doing so has yielded one surprise: “As we canvass our town for donor support, we’ve been touched by the number of people in our area with family or friends with Parkinson’s.”

There are many benefits to joining the team. In addition to receiving a limited-edition cycling jersey or T-shirt for raising just $150, team members have a chance to win one of a number of great prizes. And those who raise $500 or more can be reimbursed for one event entry fee (up to $85).

All this makes Team Parkinson’s a great value!

Register online at www.nwpf.org or call 877.980.7500.
Dry mouth common, manageable in Parkinson’s

By James A. DeLapp, DDS

Long before toothbrushes, dental floss and oral rinses, evolution created protective mechanisms in the mouth as defense against the bacteria that cause decay. This defense is saliva.

The simplest way to explain the role of saliva is to describe what happens when it is in short supply. A patient may complain that his mouth or throat is dry, rough, sticky or sore.

Dentists may hear complaints of “I’m hoarse—it’s so hard to talk,” or “I can’t wear my denture—my mouth is always sore,” or “My tongue is sticking to the roof of my mouth.”

Eating may be difficult and, with certain foods, impossible. With too little saliva, a patient may not be able to tell the position of food in the mouth.

Patients may complain that fillings are falling out, or that they’ve had an unusual number of new cavities.

Xerostomia (dry mouth) may result from a disease process, treatment of a disease, drug therapy side effects, or a generalized decrease in saliva associated with aging. In Parkinson’s, dry mouth is frequently the side effect of an anticholinergic medication (Cogentin, Artane, Akineton or Kemadrin).

It has been found that patients with dry mouth are not only more prone to cavities but may have tooth sensitivity. Additionally, the tissues in the mouth may become dry and painful.

Patients frequently ask what they can do to get relief. An excellent beginning point is the dentist, who has been trained to help patients deal with dry mouth and its effects on dental and oral hygiene. Following are some suggestions that you may wish to ask your dentist about:

- Relief from oral dryness and discomfort can be conservatively achieved by sipping water throughout the day, letting ice melt in your mouth, restricting your caffeine intake and humidifying your sleeping area.
- Saliva flow can be temporarily stimulated by sucking sugarless lemon drops or chewing sugarless gum. (Sorbital-based gum is a good choice.) Avoid sugared soft drinks and sweets.
- For sensitive teeth, ask your dentist about a topical fluoride gel. Your dentist or his staff can teach you oral hygiene techniques (flossing, water pick, and special brushes) most effective in removing plaque, controlling cavities and keeping gums healthy.
- There are some battery-powered and electric anti-plaque toothbrushes available (Interplak is one example) that are excellent for removing plaque and cleaning teeth.
- For the person with Parkinson’s who has difficulty with the fine hand movements required for thorough tooth brushing and flossing, these tools can be helpful.
- For dry lips, try K-Y Jelly, Surgi-Lube or hydrous lanolin (ask your pharmacist). Vaseline and petroleum-based products make your lips even dryer by pulling water out of the tissues. These should be avoided.
- Commercial mouthwashes tend to be high in alcohol and should be avoided. Alcohol and tobacco also have drying tendencies, and their use is discouraged.

These are just a few suggestions to help deal with dry mouth. Discuss these suggestions with your dentist, who can help you implement a program to maintain a healthy smile.

Note: Many people with Parkinson’s complain of an excess of saliva (causing drooling) and believe that Parkinson’s actually causes more saliva to be produced. There is not actually an excess of saliva in Parkinson’s. The cause is a reduction of the times per minute that the person swallows. In Parkinson’s, the involuntary act of swallowing is slowed as well as the number of swallows per minute, allowing more saliva to accumulate.

This article is reprinted with the author’s permission, James DeLapp practices dentistry at the Cottonwood Dental Group in Highlands Ranch, CO.
I think of my body as being like a car. If a car runs out of gas, it won’t move. If I don’t supply a pill that activates dopamine, then my body runs out of gas.

When I wrote H.O.P.E., I was taking what I might call a modest amount of medication. It consisted of taking my medication three times a day. In 2008 I am up to taking my medication three times a day and no excitement in your life. The thought is that if you close out activities without replacing them with others, you may wind up with 24 hours a day and no excitement in your life. The added medication is necessary and seems to work for me. Otherwise, my “off periods” would be more intense and frequent. I would spend more time bent over like a man carrying a load of bricks and shuffling like someone with chewing gum stuck to his shoes.

I’ve read about some drugs becoming ineffective if used long-term and in large quantities. But I don’t worry about that. I’d rather be functioning well at the moment than sitting in a “wear-off” funk day after day.

Fortunately, my body responds well to medication even though I never took any pills of any kind before this Parkinson’s thing.

My doctor and I work as a team. I feed her the changes that are occurring. She listens well and seems to always recommend the dose that does the trick. Together, we are constantly monitoring the dosage.

If you don’t have a good talking relationship with your doctor, I strongly urge you to get a second opinion.

The mistake all of us can make is to compare our progression and symptoms to another person with Parkinson’s. The disease does not have a universal pattern.

I am 78 years old and was diagnosed 13 years ago. At support groups I hear people ask if the medication that Joe is on will work for Martha. I see others figure if he’s had it for three years longer, then they’ll be like him in three years.

That’s not how it works. I make this preface before I go into what’s going right for me at this time.

I’m still as active as I was six years ago. I drive my wife’s new Prius (even at night). I go to Husky football games (climbing to the upper deck). I usually walk two or three miles a day (a little slower than before).

I go to evening activities (“Jersey Boys” was terrific). I like to go out to eat (Chinese food is my favorite). I like to travel (Peggy and I go to Maui twice a year). I enjoy company in our home (I make a popular Manhattan that seems to attract people).

I still attend meetings (the Northwest Parkinson’s Foundation board is a great group). I read a lot, do crossword puzzles, compose by the hour on the word processor (though Peggy thinks my poems are corny).

These activities are possible because I am religious about taking my medication precisely on time.

I have seen far too many Parkinson’s people in trouble because they don’t take the timing of their medications seriously.

I think of my body as being like a car. Most cars run on gasoline. My body runs on dopamine. If a car runs out of gas, it won’t move. If I don’t supply a pill that activates dopamine, then my body runs out of gas.

When I do forget to fill the dopamine tank, the results are mind-boggling. I sputter to a stop. But if I can maintain a steady supply of dopamine in my body, then I can operate on all eight cylinders.

By the way, I have another book title in my mind. It’s Living with Parkinson’s When You’re 100 Years Old. But it’s on the back burner and will have to wait a bit for publication.

Hal Newsom and his wife Peggy live in Seattle, W.A. Newsom is author of H.O.P.E.: Four Keys to a Better Quality of Life for Parkinson’s People as well as a booklet for caregivers. Both are available from the Northwest Parkinson’s Foundation.
**Tribute Gifts**

Gifts to the Northwest Parkinson’s Foundation support educational programs including our website, email updates, caregiver booklet, newsletter, patient education programs, and conference. Donations also fuel outreach and advocacy efforts on behalf of patients and families.

We are privileged so many in the Northwest Parkinson’s Foundation family support our mission by giving generously throughout the year in honor or memory of special friends and loved ones.

Thank you, all, for your support.

Listed here are tribute gifts made between January 1 and February 24, 2008.

**Honor**

Carey Christensen
Mr. and Mrs. David M. Lorente

The Hon. Daniel J. Evans
Elk Highlands

Roger Evans
Elk Highlands

Hal Newsom
Mr. Al Johnson
Mr. David W. McIntire

Larry Riegert
Ms. Alice A. Litton

Marcie Sewell
Mr. and Mrs. Sam Sewell

Michael Shanahan
Patrick Shanahan

David Shannon
Mr. and Mrs. William L. Shannon

Tina Torrance
Bill and Margo Bell

Fred Van Leperen
Mrs. Jill E. Borden

Jeanette Williams
Ms. Robin Clark

Josephine Forner
Ms. Rosella Zuber Roff

John Hall
Ms. Betty N. Langhauser
Mr. and Mrs. Robert Saunders

Norman Hovet
Ms. Rita M. Basile

Bob Hulbert
Mr. Mac B. Madenwald

Wayne Hunter
Mrs. June Hunter

David Israel
Mr. and Mrs. Michael M. Israel

Gary Johnson
Ms. Louise E. Klood
Mr. and Mrs. Russell A. Nogg
Bob and Dav’ne Stanley

Dave Johnson
Ms. Sarah Anne Johnson

Gerard Kroese
Ms. Kathryn DeCaprio

Richard Larsen
Ms. Eleanore I. Bauman

Allen E. Linn
Mr. and Mrs. LeRoy W. Christenson
Mr. and Mrs. Donald Larsen
Mr. and Mrs. I. L. Pedersen
Mr. Samuel J. Smith
Mr. and Mrs. Peter F. Flones

Clair Mackie
Mr. and Mrs. Arnie Venditto

Melvin Conrad Monsen
Ms. Suzanne Simchuk

Richard Clinton Names
Mr. and Mrs. Aaron A. Goodwin
Mr. Sidney W. Names
Mr. and Mrs. John P. Ostlund
Mr. and Mrs. Wayne Thronson
Mr. and Mrs. Roger L. Boyd

Arthur Roy Parr
Abby, Heather, Sally and Archie Gardner
Mr. and Mrs. Richard R. Rodman

Rosalie Powell
Mr. and Mrs. Ralph Chapman
Ms. Geraldine Johns
Mr. and Mrs. Thomas W. Kiehl
Mr. and Mrs. Leon L. Smith
Capt. and Mrs. Robert W. Witter (USCG Ret.)
Mrs. Barbara Maddux

Ivan Shilling
Ms. Eunice Allan
Mr. and Mrs. Richard McCutchan
Mr. and Mrs. Myron C. Sjoblom
Ms. Rae A. Verhey

Fred Van Lepere
Mrs. Jill E. Borden

Supporter motivated by chance to learn

When Breanne Fortun’s grandmother was diagnosed with Parkinson’s in 2004, Fortun knew right away she wanted to learn more about the disease.

“Educating myself about Parkinson’s meant I would have more information about the disease and how to help (my grandmother),” said Fortun, who lives in Seattle, WA. “I was really glad to find the Northwest Parkinson’s Foundation right here in my area.”

Fortun makes a charitable donation each month using automatic payroll deductions through her employer, Microsoft. She said giving by payroll deduction is a convenient way to make a difference.

Fortun said she gives because she wants to positively impact her grandmother’s life as well as support her mother, who is closely involved in her grandmother’s care.

“Keeping informed about Parkinson’s disease is important to me,” she said. “And while I don’t directly care for my grandmother, I can help by learning all I can about Parkinson’s.”
Board and Staff

The Northwest Parkinson’s Foundation is a cofounder and partner of the Booth Gardner Parkinson’s Care Center (13030 121st Way NE, Kirkland, WA 98034). This comprehensive care facility is home to physicians, neuropsychologists, physical and occupational therapists, and speech pathologists, all specialists in working with Parkinson’s patients. To make an appointment, call 425.899.3123.

Bill Bell
William Benfield, PharmD
Gov. Booth Gardner
Monique L. Giroux, M.D.
Karen A. Hadley
Richard Hadley
Craig Howard
Lyman Hull
Bill Johanson
David Likosky, M.D.
Hal Newsom
Matt Ramerman
Paula Rose
Robert E. Story
Priscilla Tanase
Directors Emeritus
Gov. Daniel J. Evans
Nancy Evans
Arthur Harrigan Jr.

Service makes car donation easy

Avoid the hassle of car lots, expensive ads and price haggling and get a charitable gift tax deduction instead!

Through our vehicle donation program, you can donate your car, truck, van, SUV, RV, motorcycle or boat to the Northwest Parkinson’s Foundation through the Northwest Charity Donation Service, which sells vehicles and sends us the proceeds.

Most vehicles are accepted, although some restrictions apply. Northwest Charity Donation Service will determine if your vehicle qualifies.

Making a charitable contribution through our vehicle donation program is an easy way to help us fulfill our mission to improve quality of life in the Parkinson’s community.

Ready to help? Call Northwest Charity Donation Service at 800.961.6119 or visit www.nwcds.com and say that you want the proceeds from your vehicle sale to go to the Northwest Parkinson’s Foundation.

Northwest Charity Donation Service will determine the market value of your car, pick it up free of charge, complete all title transfers, and provide you with a tax receipt.