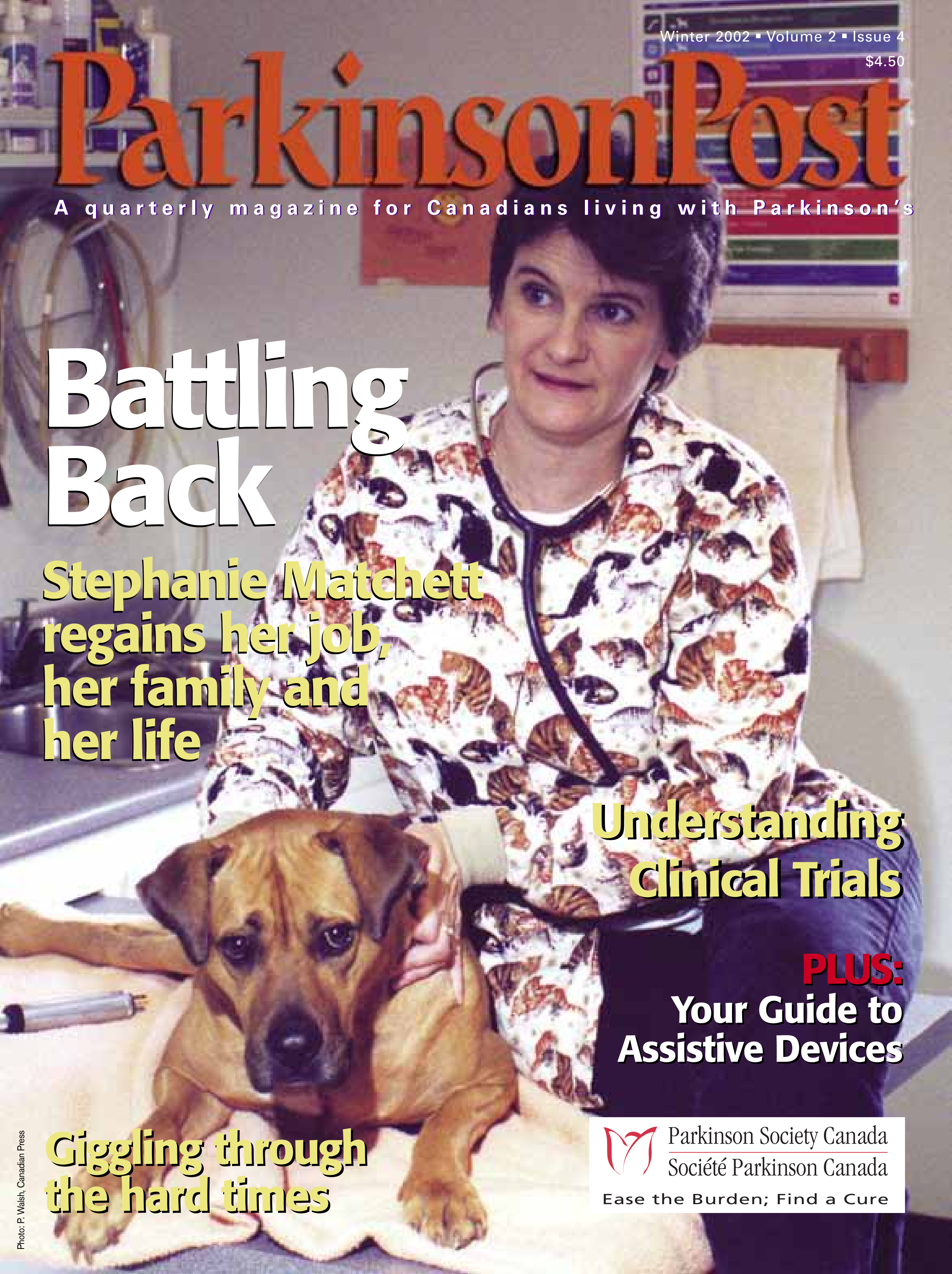

Winter 2002 ▪ Volume 2 ▪ Issue 4
$4.50

ParkinsonPost

A quarterly magazine for Canadians living with Parkinson's

Battling Back

Stephanie Matchett regains her job, her family and her life

Understanding Clinical Trials

PLUS: Your Guide to Assistive Devices

Giggling through the hard times

Parkinson Society Canada
Société Parkinson Canada
Ease the Burden; Find a Cure

Photo: P. Walsh, Canadian Press

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Pharmaceutical Group

Letter from Parkinson Society Canada

Inspiration abounds

On a crisp Sunday morning this past September, my family and I crossed the finish line of the 11th Annual SuperWalk for Parkinson's. As we did, we knew we were far from finished: at this point, our journey has no end.

I became involved with Parkinson Society Canada three years ago, just a year after my father died of complications related to an aggressive Parkinsonian syndrome called Multiple System Atrophy. Even in failing health, my father's resolve never waned – he was committed to supporting SuperWalk and raising funds to fuel the search for a cure for Parkinson's. After his death, it was important to me to keep his campaign alive and so I joined the Board of PSC and became National Chair of SuperWalk.

SuperWalk has blossomed over the past three years. A committed group of staff and volunteers from across the country has taken this walk and developed it into a truly national event – the single most important fundraising event for PSC and our premier opportunity to raise awareness both within our community and beyond. Over the past two years, we have doubled our revenues and increased our total number of walks from 38 to 65. This year, our first national team challenge garnered 147 teams nationwide and accounted for approximately 10% of our total revenue.

The inspirational stories from this year's event abound. One brand new walk in Saskatchewan, organized by a woman whose husband has Parkinson's, raised over $50,000 with 300 walkers. In Truro, Nova Scotia, a sister stepped up to the plate on behalf of her brother and organized this year's walk, more than doubling last year's total to $1,800. In Medicine Hat, a young onset Parkinsonian raised more than last year's total – all by himself. On Gabriola Island in BC, one man, severely affected by Parkinson's, summoned the courage to walk the three kilometre course while family and friends cheered him on.

These stories are just the tip of the iceberg. They are the stories that remind us every day why it is so important to raise money to fight this disease and to help those afflicted by it. Fundraising is not easy. In fact, I, like many others, find it difficult to ask for money. But, when I hear stories like these and meet people who fight physical and emotional battles each and every day, I know that I have to do my part to help write the end to this story. I invite you to join me.

Best wishes for a happy and healthy new year.

Margot Greenberg
National Chair, SuperWalk
National Board Member, PSC
Toronto, Ontario

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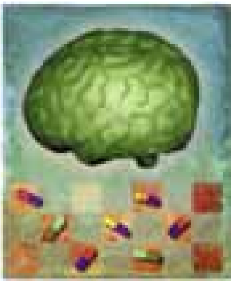

COLUMNS

ParkinsonPost
A quarterly magazine for Canadians living with Parkinson's

Parkinson Post Vol. 2, Issue 4, Winter 2002

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Our mission

Parkinson Society Canada/ Société Parkinson Canada is the national voice of Canadians living with Parkinson's. Our purpose is to ease the burden and find a cure through research, education, advocacy and support services.

Parkinson Society Canada
Société Parkinson Canada

National Office and Regional Partners

For information, programs and services in your area, or to make a donation, contact the following offices:

PSC National Office
4211 Yonge Street, Suite 316
Toronto, ON M2P 2A9
Ph: (416) 227-9700
Toll Free: (800) 565-3000
Fax: (416) 227-9600
www.parkinson.ca

Parkinson Society British Columbia
890 West Pender Street, Suite 600
Vancouver, BC V6C 1J9
Ph: (604) 662-3240
Toll Free (BC only): (800) 668-3330
Fax: (604) 687-1327
www.parkinsonbc.ca

- SuperWalk held in 10 communities. Total raised: $116,000.
- Co-sponsored a scientific symposium in partnership with the Brain Research Centre at UBC.
- Held first Facilitator Conference in October. Thirty-five of our 41 facilitators attended.
- The first Newly Diagnosed Patient Conference was held October 26, 2002. Speakers included Dr. Jon Stoessl, Susan Calne, RN; and several others. *A Newly Diagnosed* video was launched at this event.

Victoria Epilepsy and Parkinson's Centre Society
813 Darwin Avenue
Victoria, BC V8X 2X7
Ph: (250) 475-6677
Fax: (250) 475-6619
www.vepc.bc.ca

- First annual SuperWalk was a great success with 275 participants and a revenue of $22,000.
- September and October daytime meetings held on “Constipation and other GI Problems” by a clinical resource nurse and on “Medical Management of PD” by a geriatric physician.
- September meeting held on “Complementary Medicine and PD” with presentations by a massage therapist, acupuncturist, chiropractor and others.
- Short-term group for early stage PD to be facilitated by Maureen Matthew, Parkinson Program Coordinator in October/November.
- Currently 50 registrants in our four weekly PD exercise classes conducted by kinesiologists.

The Parkinson's Society of Alberta
Edmonton General, Room 3Y18
11111 Jasper Avenue
Edmonton, AB T5K 0L4
Ph: (780) 482-8993
Toll Free: (888) 873-9801
Fax: (780) 482-8969

- SuperWalk/Run for Parkinson's highlights: First walk in Grande Prairie raised almost $10,000; the Edmonton walk doubled the number of participants, raising $70,000 which resulted in a 100% increase of SuperWalk revenues from 2001!
- The six-week “Education in Action: Speech, Swallowing and Communication” program in conjunction with the University of Alberta was offered this fall.

The Parkinson's Society of Southern Alberta
480D 36th Avenue SE
Calgary, AB T2G 1W4
Ph: (403) 243-9901
Toll Free (Alberta):
(800) 561-1911
Fax: (403) 243-8283
E-mail: pssa@canuck.com
www.parkinsons-society.org

- Four successful SuperWalks: Calgary, Red Deer, Medicine Hat and Lethbridge all surpassed last year's total.
- Set up a new Young Onset Support Group in Red Deer.
- National Parkinson's Convention held in Calgary November 1–3.

Saskatchewan Parkinson's Disease Foundation
Box 102, 103 Hospital Drive
Saskatoon, SK S7N 0W8
Ph: (306) 966-8160
Fax: (306) 966-8030

- First SuperWalk a huge success. National Honorary Chair Vicki Gabereau of CTV; Roger Ali, Director of Development, Parkinson Society Canada; and Dr. Ali Rajput, Parkinson disease specialist and researcher, Saskatoon Honorary Chair all attended. Raised about $53,000.
- Parkinson Awareness Week held with Dr. Doug Hobson, Director of the Movement Disorder Clinic, Winnipeg, speaking in Regina and Saskatoon.
- Sold tulip bulbs across the province.

Parkinson Society Manitoba
825 Sherbrook Street, Suite 204
Winnipeg, MB R3A 1M5
Ph: (204) 786-2637
Fax: (204) 786-0860
Toll-Free: (866) 999-5558

- A new Executive Director, Mark Brown, has been hired.
- SuperWalk was a success, raising over $36,000.
- New part-time social worker is proving to be a popular and helpful service.
- Two hundred and eighty Manitoba healthcare professionals attended a two-day educational conference in October.

Continued on page 6

Parkinson Society Canada
Société Parkinson Canada

PSC Ontario Division

4211 Yonge Street, Suite 316
Toronto, ON M2P 2A9
Ph: (416) 227-9700
Toll Free National: (800) 565-3000
Fax: (416) 227-9600

- Working with people with PSP to better coordinate support service delivery and referrals.
- Support Services Committee planning to improve access to Parkinson's information.
- Held stakeholder consultation meetings to plan enhanced service delivery.
- Held successful Sharwood Golf Tournament.

PSC Central & Northern Ontario Region

4211 Yonge Street, Suite 316
Toronto, ON M2P 2A9
Ph: (416) 227-9700
Toll Free National: (800) 565-3000
Fax: (416) 227-9600

- Seventeen SuperWalks held.
- Planned and organized three conferences in Sault Ste. Marie, Barrie and Kingston.
- Sold 60,000 fresh-cut tulips in Toronto with plans to expand campaign to new sites in 2003.
- Developed new support group in Halton Hills-Georgetown and launched new activities with Taoist Tai Chi Society.
- Hosted in-service training sessions in long term care facilities.

PSC Southwestern Ontario Region

4500 Blakie Road, Unit #117
London, ON N6L 1G5
Ph: (519) 652-9437
Toll Free Ontario: (888) 851-7376
Fax: (519) 652-9267
www3.sympatico.ca/pf.swo

- Raised over $170,000 at six regional SuperWalks.
- Monthly Friday Social Support Group in London increasing in popularity – combines an outing for people with Parkinson's and caregivers with the educational Parkinson Corner.
- Mall displays highlight Christmas card and boutique items for sale in time for Christmas.
- Increase in requests for group presentations and training in private clubs, groups, healthcare facilities and retirement residences.

Parkinson Society Ottawa

1053 Carling Avenue
Ottawa, ON K1Y 4E9
Ph: (613) 722-9238
Fax: (613) 722-3241
www.parkinsons.ca

- Added on-site speech therapy program to accommodate high needs people with Parkinson's, who need more than the once a month program offered in the hospital setting.
- Dr. Jean Saint-Cyr spoke to members on "Wired for Life: Advances in Deep Brain Stimulation."
- Very successful SuperWalk 2002 with 30% more walkers raising over 50% more money.
- A new Director of Client Services, Maria DaSilva, was hired to expand services such as support groups, exercise programs and resource materials to people with Parkinson's outside of Ottawa's central core.

Parkinson Society Québec

1253 McGill College, Suite 402
Montreal, QC H3B 2Y5
Ph: (514) 861-4422
Toll Free: (800) 720-1307
National francophone line
Fax: (514) 861-4510
www.infoparkinson.org

- Raised $32,000 (net) at an annual corporate golf tournament, presided by Jacques M. Saint-Denis of Celmed BioSciences.
- Invested our surplus of over $60,000 in PSC's research program.
- Six regions organized SuperWalks and raised a total of $95,000 in the province.
- The regions started selling fruitcakes and will continue to do so until the end of December.

PSC Maritime Region

5475 Spring Garden Road, Suite 407
Cornwallis Building
Halifax, NS B3J 3T2
Ph: (902) 422-3656
Toll Free (NS, NB & PEI):
(800) 663-2468
Fax: (902) 422-3797

- The Maritime Region met its goal of $60,000 for SuperWalk 2002 as a result of the incredible efforts of our region's many volunteers.
- A Maritime Parkinson resource book, a helpful tool for sourcing important information, will be launched at the Moncton Forum.
- Debbie Buott is our new Maritime Region's Coordinator of Fund Development.
- Volunteers sold over 55,000 tulip bulbs during this year's campaign exceeding last year's total by 16,000.
- The Third Annual Golfing for Parkinson's was a great success. Plans are underway for next year.

Parkinson Society Newfoundland and Labrador

31 Peet Street, Suite 219
St. John's, NL A1B 3W8
Ph: (709) 754-4428
Toll Free (NFLD/Labrador):
(800) 567-7020
Fax: (709) 754-5868

- Two successful SuperWalks: St. John's raised a record $10,045; Grand Falls raised a record $3,700.
- Sold 20,000 tulip bulbs!
- Parkinson's Awareness/Education Team blitzed the Island in October and held well attended information sessions.
- National Executive Director Mary Jardine visited in November and attended Monte Carlo Night activities where Parkinson Society is one of the recipients of proceeds.
- Porridge for Parkinson's event scheduled for February 2003.

Parkinson Society Canada
Société Parkinson Canada

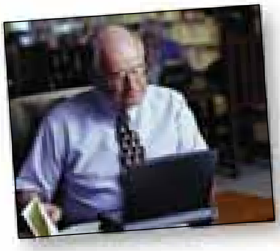
The Advocate

Issues of interest to people with Parkinson's

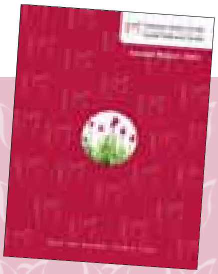
Health care report card released

The Senate Standing Committee on Social Affairs, Science and Technology has released its final report on Canada's healthcare system. The advisory can be accessed through the Parliamentary website: www.parl.gc.ca. Follow the link for *Committee Business*, then under the Senate listing select *Committee List*, then select *Social Affairs, Science and Technology*, and finally *News Room*.

Keep abreast of disability tax credit changes



If you are interested in The Disability Tax Credit and some of the recent proposed government changes, visit the website of the Sub-Committee on the Status of Persons with Disabilities at www.parl.gc.ca/disability. PSC continues to work with other organizations to support the implementation of the Committee's original recommendations in *"Getting it Right for Canadians: The Disability Tax Credit."*



PSC *Annual Report 2002* now available

Call 1-800-565-3000 to request a copy or view it on-line at www.parkinson.ca

PSC lends voice to new neurological group

Parkinson Society Canada has recently joined a newly formed Canadian Brain and Nerve Health Coalition, which functions under the umbrella of the Canadian Congress of Neurological Sciences. Its efforts will improve the quality of life of Canadians with brain, spinal cord or nerve disorders and injuries, and help develop the delivery of cost-effective medicines, treatments and health services to patients and caregivers.

Surf, shop, support

If you are planning to do some shopping on-line, consider visiting www.cangive.ca. When consumers visit this shopping portal website they can make purchases from vendors such as Indigo, Eddie Bauer, Canadian Tire, Expedia.com and many others and direct a percentage of the sales to a selected charity, including PSC.

Ease the Burden; Find a Cure

Health Tips

Keep fit to stay mobile

Evidence continues to grow that physical exercise is a key element of slowing or preventing physical disability. A recent study in the *New England Journal of Medicine* found that strength and balance exercises do help older adults stay mobile. Yale University researchers found that frail elderly people, 75 years or older, who were following a physical therapy exercise program reduced disability by 45% after seven months. The exercise program consisted of daily balancing exercises lasting 10 to 15 minutes each, and muscle strength training with elastic resistance bands three days a week.

These results continue to support the importance of exercise for people with Parkinson's. ✪

Bowel management information available

A Parkinson's-specific bowel management program, prepared by Dr. Shalin Letwin and Susan Calne at the Pacific Parkinson's Research Centre at UBC is now available from PSC national office. Please call Jill Pritchard at 1-800-565-3000, ext. 245 to request a copy. ✪

Parkinson's information on-line

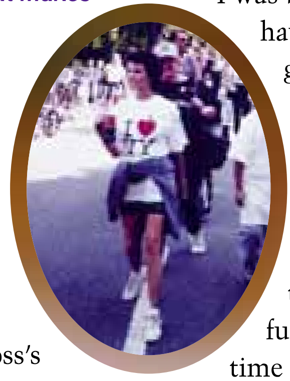
Are you aware of the Parkinson Information Exchange Network (PIENO), an international Internet discussion group? It was founded by Barbara Patterson of Hamilton, Ontario in 1993 as a Parkinson's support group on the Internet. Visit www.parkinsons-information-exchange-network-online.com. ✪

Battling back:

Stephanie Matchett regains her job, her family and her life

By Ian Corks

Stephanie Matchett plans to work as a veterinarian for another two or three years before retiring, in her mid-40s, to spend more time with her young son Frederick. This will mark the second time Stephanie will be leaving work. But this time it will be her choice. And, according to Stephanie, that makes a world of difference.



It was the symptoms of Parkinson's disease that forced Stephanie to quit her job in a New Brunswick veterinary clinic the first time around. "It wasn't my boss's decision," she emphasizes. "It was totally mine. People would look at me strangely in the office. I couldn't do surgery. In fact, I couldn't do the job properly at all."

The fact that Stephanie is again practising her profession and is in a position to decide when and how long she will work is remarkable. It is also the result of a long journey that has carried her through despair and anger, threatened her family life, and seen her work to overcome many people's negative attitudes about her condition – including her own.

Stephanie Matchett was in her first year of veterinarian college in Prince Edward Island when she was diagnosed with early onset Parkinson's. She was 29. "At the time, I knew nothing about Parkinson's and I had no idea of what lay ahead," she recalls. "If I had, and being the person I was back then, I may never have tried to pursue the goals I did."

For the first several years, Stephanie's life went forward relatively smoothly. She graduated in 1994 and started practising veterinary medicine full time. She also found time to start a family, having a son (Frederick) in 1992 with her partner, Fred. The symptoms of Parkinson's were mild and when they did occur, were restricted to one side. Annoying as they were, they did not stop Stephanie from pursuing her life goals.

Spiraling symptoms

Then things began to change. Her symptoms – tremors, fatigue, and loss of concentration – became progressively worse and she developed dyskinesias as a drug treatment side effect. Before long the tremors and dyskinesia began to affect both sides. People would stare at her on the street, and she could hear them talking about her. She found herself having panic attacks. Work was no longer an option. Stephanie had gone from someone who could confidently wield a scalpel during complex surgery to someone who could barely hold a knife and fork. So, she made the agonizing decision to quit her job and set out to face the realities of her 'new' life.

"I basically did nothing," Stephanie remembers. "Except walk." She walked long and often, through the streets of her hometown of Mayfield, New Brunswick. "It was my way of keeping going," she explains. "I put on my headset, turned on the music and headed out the door. I'd go at any time, even in the middle of a social event. If I found myself getting flustered, I'd just start walking."

Stephanie would travel for miles, and on more than one occasion she 'out-distanced' herself. "Sometimes I'd walk while my medications were working, and then the effects would wear off," she states. "Then I'd find myself in the middle of nowhere, often unable to move. Fred would get a phone call and have to drive out to pick me up. Needless to say the police soon got to know me."

Walking really got Stephanie going – both literally and figuratively. It became more than therapy.

Stephanie is now back at work, examining 'patients' and even performing surgery again.

Spending more time with her son Frederick (above) is one of Stephanie's joys.

In many ways, it became an obsession. Her passion led to Stephanie's decision to take part in the Parkinson Unity Walk. This may not seem remarkable in itself, as many people with Parkinson's participate. The catch was that this particular event was in New York City and Stephanie intended to walk the hundreds of miles from New Brunswick to get there.

"The idea, the planning and the actual walking gave me a real purpose," Stephanie notes. "There were a few people who were going with me and we were going to raise awareness about Parkinson's on the way."

Then Stephanie got sick and ended up in hospital a few weeks before the event. By the time she was released, everyone had dropped out. Stephanie was disappointed – and hurt. But, with typical New Brunswick stubbornness she decided to go anyway.

She more than proved herself, walking (as much as possible) from the border town of St. Stephen, New Brunswick to New York City. "Some people thought I was drunk or called me weird, others treated me wonderfully, or better yet, treated me as if there was nothing wrong," she recalls. "It wasn't easy. But I feel if I changed even one person's mind about Parkinson's, it was worthwhile."

Hitting bottom

The walk, however, took its toll. By the end of the journey, Stephanie was physically and emotionally drained. She took a hard look at herself and didn't like what she saw. Walking had been a double-edged sword for Stephanie. On one hand, it kept her motivated and she reaped the physical benefits of the exercise. On the other hand, it kept her from facing the person she had become.

> *"I had really hit bottom. I was so miserable."*

Stephanie looks back at those days ruefully. "I was angry all the time," she confesses. "I'd be up very briefly, and then sink into depression. It was almost as if I was manic-depressive. I was very tough on my friends. I thought they were dumping me. And all the time, I was the one being unfair. They were scared of me and didn't know how to react, so they stayed away."

"Heck, I wouldn't have wanted to be with me back then if I had a choice," she laughs.

The worst, however, was the effect her emotional condition was having on her family. Things got so bad that Stephanie eventually moved out of the family home. "We were separated for a few months," she explains. "I couldn't help care for Frederick or Fred and that was so frustrating. I couldn't do anything. And they couldn't do anything for me. Not because they didn't try, but because I wouldn't let them. I pushed them, and everyone else, away. I guess I had really hit bottom. I was so miserable."

A light in the darkness

It was during this dark time that Stephanie started to think seriously about undergoing deep brain stimulation (DBS) – a treatment for Parkinson's that she had been thinking about on and off since 1998.

With the desperate need to turn her life around, she made a decision that would change her life.

"I had the operation in Toronto in early 2001," Stephanie relates. "My sisters were with me. Fred and Frederick stayed home in New Brunswick. Frederick was only eight and I didn't want him to worry. Anyway, there wasn't anything they could do."

Stephanie spent her 40th birthday in hospital waiting for the operation. "In fact, I remember I was more concerned about turning 40 than I was about the surgery," she chuckles.

The six-hour operation, involving deep brain stimulation on both sides of Stephanie's brain, was conducted by Dr. Andres Lozano and his team at the Toronto Western Hospital in February 2001. To everyone's relief the surgery was a success – to the point that Stephanie recalls one of the nurses later calling her a 'poster child for DBS'.

For Stephanie, the happiness was at first tempered by the long recovery period, complicated by an infection that left her hospitalized in Toronto and subsequently Saint John, where she was sent to be closer to home. In all, Stephanie spent eight weeks in hospital on IV therapy.

"It was a depressing time," notes Stephanie. "I knew I was better, but things were moving so slowly and I thought I'd never get out of hospital."

Another unexpected complication Stephanie faced was, ironically, walking. She had walked so much under the influence of her symptoms that she had developed her own strange and unnatural gait. Now, with the symptoms in check, she had to, as she puts it, "re-learn how to walk."

Then the clouds began to clear. The infection cleared and Stephanie was sent home. Her symptoms under control and boasting a new attitude, Stephanie re-entered her world. "My whole mind set had changed," she remembers. "I could not believe how negative I had been before, or how tough I had been on everyone."

She started to regain her life – starting with her family. "Now things are better than ever," she smiles. "I'm happy to be with them. My son has a mother again. He loves to play ball with me, or just to be able to talk to me, without me being angry all the time."

Back in the clinic

And, remarkably, Stephanie is working again. She puts in about 10 hours a week at the Mayfield Vet Clinic. She does in-clinic consultations, handles a bit of on-call emergency work and is even doing surgery again.

It may be a far cry from the 40 to 60 hours a week she worked before, but that's just fine with her. While obviously enjoying the opportunity to be working again, she admits that it is no longer her first priority. "More than anything else, I want to spend time with my family," Stephanie admits, noting that she and Frederick have just started taking piano lessons together.

She has plans for similar activities that will let her participate fully in her son's growing up – something she feels she missed out on during the rough times before the surgery.

Stephanie Matchett knows that she will hang up her scalpel again, sooner rather than later. But the thought no longer bothers her. "I will likely stop working in a little while," she smiles. "And when I do,

Share your story!

Parkinson Post would love to hear how you or someone you know has adjusted to coping with Parkinson's. If you know of an inspiring story our readers would enjoy please contact:

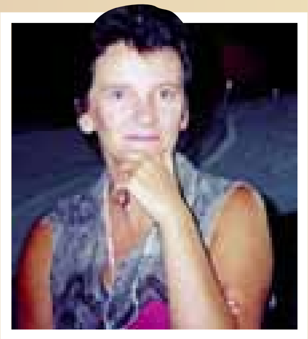
The Editor, *Parkinson Post*,
4211 Yonge St., Ste. 316,
Toronto, ON M2P 2A9.
Telephone: (800) 565-3000
E-mail: editor@parkinson.ca

Lessons learned along the way: Stephanie's advice to people with Parkinson's

"My Parkinson's has been a journey that has taught me many things about people and myself. As I've walked, I've learned a lot about what it means to be handicapped. I've learned that some people can treat you badly. They'll talk about you. They'll think you are drunk. Some may even laugh at you or call you 'weird'. In most cases, it is ignorance or even fear. Some people don't know how to react when they see something that doesn't fit in. The best way to face that is through education.

I've also learned a lesson about dealing with those people, and I've learned it the hard way. It is easy to let them get to you. It is easy to become paranoid. You start to worry about these people, even though they are in the vast minority. You begin to waste your energy and your life worrying about what people might say or do. Then you can start to question everyone. You can become defensive and suspicious. You can end up pushing away the ones you care for and other people who don't deserve it.

My advice to anyone in a similar position is to not let yourself become imprisoned – either by others or by you.



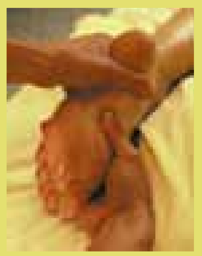
Five months after surgery.

I know too many people who sit in their living room all day staring at the world outside. Never be afraid to do things because of what other people may think. Never be afraid to go out and do whatever you are capable of, even if it means you have to do it your own special way. Sure I may have walked funny. But I walked, and I wouldn't have made it through the tough times without that."

Ask the Experts

Q ***Why is it important for me, as a person with Parkinson's, to take care of my feet and what are some ways I can do that?***

A Make sure that you wear the proper shoes. As you get older, your feet get longer and wider. Shoes should be fitted properly. If there are abnormalities in your feet such as bunions, calluses, corns, etc., seek professional advice from a podiatrist. A postural assessment should be performed to collect clinical evidence of walking/gait abnormality.



- If you have developed sweaty feet since being diagnosed, it is probably drug-induced. Sweat is good, but only if in normal quantities. Excess sweat can put you at risk for developing smelly feet and fungal infections.
- If you think you have a fungal infection, consult a podiatrist. Fungus grows in moist, dark, warm places so the foot is the ideal breeding ground. If you have fungus, sometimes you get itchiness between your toes and on your skin. The skin can be macerated-looking, reddened and patchy. Always change your socks daily. Cotton breathes better, so moisture is wicked away from the foot and eliminates damp feet. Use anti-fungal creams and sprays.

  Keep shoes out of closets and dark places. Place them in an airy environment. Fungus does not like sunlight, so even placing shoes outside in good weather is great.
- Sometimes, due to drug-induced reactions, the skin takes a real beating and you can suffer from oily, scaly skin or dry skin so you should use a good moisturizer.
- If you have no tremors in your hands and your eyesight is not impaired, you can usually take care of your feet as you did prior to the disease. If you do have tremors or reduced vision, you can do severe damage – sometimes the consequences are far worse, such as open wounds which will predispose you to infection.
- If possible, treat yourself to a pedicure, even occasionally. Your feet are key to your overall health – treat them well!
- Consider seeing a podiatrist – the only true specialist of lower limbs.

Dr. Pamela Hopper
Podiatrist
Feet Come First Inc.
Calgary, Alberta

Q ***I sometimes shake so much that it is very difficult for me to eat without spilling food all over the place. This makes eating out uncomfortable and embarrassing. Any tips to help me enjoy holiday meals?***

A To be 'fully operational' during the holidays, make sure you continue to take your medication as prescribed – do not skip doses and do not skip meals either. If, however, your meals or sleeping pattern vary over the holidays, ask your pharmacist, doctor or nurse to help you plan around them. Depending on your medication, you could delay or anticipate a dose to be more mobile at the time of a special meal.

- Choose foods that are easy to eat: most menus have food that can be eaten with your fingers.

- Bring your own special utensils with you: cutlery, glasses or cups with large handles, 'antiskid' mat to place beneath your plate, etc.
- Avoid difficult to grasp foods such as slippery noodles, hard to 'spear' small peas. Use a spoon rather than a fork if it helps.
- Ask that your soups be served in a cup rather than in a bowl. Request a straw or bring one along if you find it helpful for drinking liquids.
- Ask for help. Friends and family members will be happy to help you cut your food, butter your bread, etc., enabling you to then eat on your own.
- Eat sitting in a high backed chair.
- Drink alcohol in moderation and, if necessary, use a thickener as you would in other beverages.
- Concentrate on one thing at a time, and do not talk while eating – it can greatly increase the risk of choking.
- If people stare or make fun, let them, nothing should stand in the way of enjoying yourself. It's the holidays for everyone, you most of all.

Martine Gaudreault, dt p(RD)
Chief Clinical Dietitian
Institut universitaire de gériatrie de Montréal
Montréal, Québec

Research Report

A look at current Parkinson's research arou

Gene transfer therapy approved for human trials

A gene transfer technique that has shown promising results in animal studies has been approved for testing in a small number of Parkinson's patients.

The technique involves injecting genes that produce a vital neurochemical into the brain. The neurochemical, called GABA, works in the subthalmic nucleus to inhibit or calm the motor movements of the body. Studies have shown that individuals with Parkinson's have very little GABA. This deficiency is believed to be linked to symptoms such as tremor and freezing.

The U.S. Food and Drug Administration (FDA) approved the trial on 12 Parkinson's patients by Dr. Matthew During of the University of Auckland, and Dr. Michael Kaplitt of New York's Cornell University. The trial will involve patients who have exhausted all the standard methods of treatment without significant improvement.

Reference: *Science*

PSC now accepting nominations for the Donald Calne Lectureship

This lectureship was established in 2002 to honour Dr. Donald Calne for his outstanding service to the Parkinson's community as Professor of Neuroscience, University of British Columbia, and past chair and long time member of the PSC Scientific Advisory Board.

A distinguished neuroscientist of international reputation, whose work is primarily in the area of Parkinson's disease, will be awarded the Lectureship each year. The recipient will deliver a "state of the illness" lecture on Parkinson's disease to the Parkinson community at the PSC Annual General Meeting, held each year in November. The first Lectureship will be awarded in early 2003, and the lecture given in November 2003.

Eligibility, nomination and selection criteria are now available at www.parkinson.ca or by contacting Lysa Toye, Grants Administrator, at 1-800-565-3000 or 416-227-9700, ext. 249.

Deadline for nominations is February 3, 2003.

Alzheimer's and Parkinson's share genetic link

A gene variant already known to increase the risk of Alzheimer's disease and heart disease, appears to increase the risk of Parkinson's, according to new research.

A research team at Duke University found that people who had a variation of the apolipoprotein E gene APOE4 were more susceptible to developing Parkinson's, and to getting the disease at an earlier age than those with other APOE variations. The Duke study compared 1,000 individuals with Parkinson's to the same number of siblings without the disease and is the largest study of its kind to date.

Previous studies have linked the presence of APOE4 with an increased risk of Alzheimer's. The variant has also been recently linked to heart disease.

According to Dr. Jeffery Vance, co-director of the Center for Human Genetics at Duke, "We now have evidence that there are several genes that control the onset and risk of Parkinson's and Alzheimer's." He notes that the increasing evidence of similarity between the two diseases will help researchers to determine the causes and, eventually, to help prevent them.

Reference: Reuters Health

Common and rare Parkinson's share genetic pathway

A common pathway has been found for the most common type of Parkinson's disease and a rare hereditary form of the condition.

Experiments conducted on mice at New York's Columbia University were designed to determine whether a specific alpha-synuclein pathway may play a role in both common (or sporadic) and hereditary Parkinson's. Environmental factors are suspected in the development of sporadic Parkinson's, while genes are implicated in the hereditary form.

Normal mice and mice without alpha-synuclein were exposed to MPTP, a toxin that triggers Parkinson's-like symptoms. While the normal mice developed neurological symptoms, the mice lacking alpha-synuclein showed a definite resistance to MPTP.

"It appears that genetic and environmental factors converge on the alpha-synuclein pathways," notes lead researcher Dr. William Dauer. "If we can learn something about the familial form, for which we can manipulate the gene, it might provide us with insight into the more common form."

Reference: *Proceedings of the National Academy of Science*

nd the world

DBS may aggravate pre-existing behavioural disorders

Deep brain stimulation (DBS) may not be an appropriate treatment for individuals who have pre-existing personality disorders, such as behavioural problems, addictive behaviour or depressive episodes.

These are the findings of a study by a French research team. The team at Hôpital de la Salpetrière in Paris studied 24 Parkinson's patients undergoing bilateral DBS surgery, including a retrospective assessment of previous behavioural disorders.

In general, the surgery improved motor disability and reduced levodopa usage. However, of the 12 patients who reported depressive episodes in the past, five experienced at least one episode following surgery; in two out of the four patients who had a history of agoraphobia (fear of open spaces or public places), the symptoms worsened; and all of the 17 patients who reported prior anxiety, experienced episodes of anxiety afterwards.

The researchers noted that while psychiatric disorders are often considered a contraindication for DBS surgery, this option is sometimes selected because the severity of the Parkinson's symptoms and levodopa related complications exceed the psychiatric disorders in severity.

The authors concluded that, "Patients should undergo a careful psychological and psychiatric interview before surgery to evaluate the existence of prior personality disorders, addictive behaviour or depressive episodes."

Reference: *Journal of Neurology, Neurosurgery and Psychiatry*

Focus on…

Dr. Lara Fallon
Parkinson Society Canada
Post Doctoral Fellow

Dr. Lara Fallon has an unusual distinction. After working at the Harvard Medical School with researchers studying two of the three genes identified as playing a role in Parkinson's disease, the native of Boston now has an opportunity to study the third gene, *parkin*.

Her research into the *parkin* gene is being conducted at the Montreal Neurological Institute as part of a two-year Post Doctoral Fellowship funded by Parkinson Society Canada.

"It's very exciting," Dr. Fallon states. "As recently as five years ago, we hadn't identified any of the genes associated with Parkinson's. Now we have something solid to look at…targets to investigate. It brings us so much closer to finding an answer."

The *parkin* gene, which Dr. Fallon is studying as part of a team under the direction of neurologist Dr. Edward Fon, is believed to be associated with hereditary Parkinson's. Mutations in the *parkin* gene cause a form of the disease called Autosomal Recessive-Juvenile Parkinsonism, which generally affects people under the age of 45. Studies indicate that 25% of people with early onset Parkinson's (under 30 years of age) may have an abnormal *parkin* gene.

The Montreal Neurological Institute project is looking at basic cell biology to determine why and how the parkin protein malfunctions.

"This will give us an idea of what types of systems are affected by the loss of function of the parkin protein, along with some indication of how neural degeneration starts," Dr. Fallon explains. "This possibly could help us to develop ways to recognize the problems earlier or develop screening methods. It is a tremendous opportunity to learn more about Parkinson's."

Coenzyme Q_{10} may slow disability

The administration of coenzyme Q_{10}, a naturopathic substance, may slow the development of functional decline in individuals with early stage Parkinson's disease, according to a U.S. study supported by the National Institutes of Health.

The study tracked the development of disability and functional decline in 80 patients diagnosed with early stage Parkinson's who were not yet receiving levodopa therapy. Participants received either coenzyme Q_{10} or placebo during the course of the study. Participants were followed for 16 weeks or until they needed levodopa.

The researchers noted that less disability developed in the 60 individuals receiving coenzyme Q_{10} compared to the 20 receiving placebo, and the benefit was greatest in the 20 subjects receiving the highest dosage. The results of this small study are inconclusive. More studies are needed to assess the benefit of coenzyme Q_{10} as a treatment for Parkinson's disease.

EDITOR'S NOTE Please remember that clinical studies, research findings and other information featured in *Research Report* are often of a preliminary or investigative nature. Results may not be applicable to all cases and actual treatments resulting from findings can take time to be developed. The information contained here is for interest only, and should not be construed as advice or recommendations.

Making life easier: Assistive devices can help

By Ian Corks

Dealing with Parkinson's is not easy. As the disease progresses, you and your family will have to deal with a number of challenges. Among these is a potential decline in your mobility and independence. You may find yourself unable to get around as easily – and as safely – as you once did. You may also have difficulty with some specific everyday tasks that used to be a snap. You may find that you need help in one way or another.

Using ADLs is not an admission of weakness.

Assistive devices can provide that help. These often simple tools are referred to by a number of different names, including adaptive living aids and aids for daily living, or ADLs for short. If used wisely, they can make a tremendous difference and help you maximize your mobility, safety and independence.

Designed to help

The first thing to realize about these assistive devices is that they are designed to help. They are not an admission of weakness, or age, or anything else. They are simply there to make your life easier. Unfortunately, some people find that message hard to accept.

"People who have a disease like Parkinson's, might not initially be receptive to using an assistive device because they perceive it to mean that the condition is progressing, and that in itself is threatening," notes Sylviane Andrews, an occupational therapist (OT) at Out Patient Rehab, Healthcare Corporation of St. John's, Newfoundland.

Laila Karmali, an OT with Community Therapists in Vancouver, agrees. "One of the hardest things about this kind of disease is the realization that you have to have help doing basic things," she states. "It's hard to give up your independence, especially when your mind is totally functioning. But if your muscles aren't responding to the instructions, there is nothing you can do."

Laila and Sylviane, like many other OTs, frequently encounter reluctance on the part of people with Parkinson's to accept assistive devices. However, their professional experience has told them that with education and by pointing out the benefits, people invariably come around – and rarely look back.

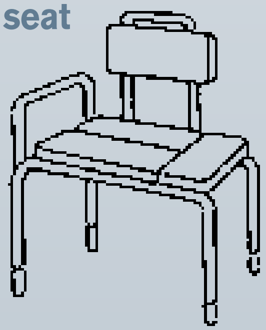
Talking to a professional – such as an occupational therapist, your doctor, or a qualified retailer of assistive devices – can help put you at ease and take away the stigma.

"If someone is reluctant to try a device, such as a bathtub grab bar, it is our job to educate them," notes Sylviane. "That education includes not only what is available, how it can help and where to get it, but also the risks and consequences of not using it."

Martha McCall, Senior OT at Toronto's Baycrest Centre,

10 functional products to improve your

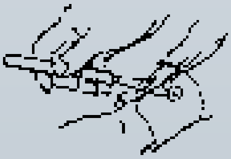
Bath seat



A padded seat used to simplify entry/exit and prevent slipping in the shower or tub.

Button/zipper pulls

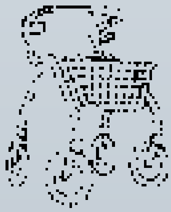
These special devices have hooks for zippers or buttons and can help in dressing.



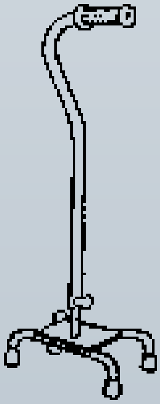
Velcro closures

Available in a variety of styles, these can make fastening clothes much easier.

Walkers and canes



They can provide added support, increasing confidence and mobility.



maximize your independence

emphasizes that collaborating with an OT prior to purchasing an assistive device is critical. "It's important to identify solutions together which take into account individual coping styles. Not every device is effective for everyone."

However, she adds that once the right devices are chosen, "they are extremely effective in easing the challenges of daily living and making activities safer and more comfortable."

Even a small device can make a big difference.

What's out there

The number and variety of gadgets and devices available that can make life easier and safer for people with Parkinson's is impressive.

Exactly what will help whom is dependent on a number of factors, including age, level of function, living environment and other variables. Even habits and leisure activities can play a role. For example, someone who likes to cook will have different needs than a person who doesn't; while a gardener might benefit from some specialized aids, like a gardening stool.

Even a small device can make a big difference to some people. For example, Baycrest Centre OT assistant Tracey Morrow relates the case of a gentleman with Parkinson's who was too embarrassed to go to restaurants (one of his favourite activities) or eat in public because of his mild tremors. Peas and other small items would fly off his spoon. Then he bought a set of specially weighted cutlery – including a fork, knife and spoon. He could control these utensils and his problem was solved. Taking the set with him, he was able to enjoy eating out again.

While available items number in the hundreds, below is a look at 10 of the most popular and useful devices that can improve your independence, function and safety.

Where can I find assistive devices?

Just about anywhere! Assistive devices for improving everyday life are easily found in local general and specialty stores.

For example, your **neighbourhood pharmacy** may have a good selection. Qualified pharmacy staff are happy to provide information on their available products.

Specialty home health care stores are your best bet, especially for devices such as walkers, bath seats and grab bars. Check under stores that sell *Medical supplies* or *Wheelchairs* in your local Yellow Pages.

Most stores are staffed by trained specialists who will ensure you get the right device with the right 'fit'. (For example, a cane needs to be of proper weight, length and handle style.)

These stores may also allow you to borrow or rent a device to find out whether it serves your needs. This is particularly helpful if you're unsure of which device to purchase, like whether to buy a wheelchair or a walker.

Hardware stores offer many "universal design" kitchen utensils, as well as other items for home use, such as wheeled garbage bins that are more easily moved or intercom systems that allow you to communicate with someone at your door.

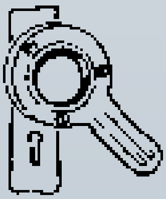
Don't forget your **family physician**! They're an excellent source of information and can even help you identify the best device to use for your particular situation.

Finally, ask **family and friends** where they got their useful gadget that you feel could improve your daily life.

Sources: Health Canada, Veterans Affairs Canada

independence

Door knob extenders

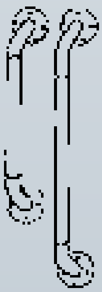


These fit over most door handles, allowing the user to easily grip and operate the handle.

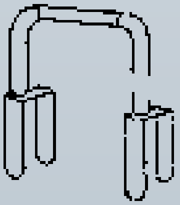
Foam grippers

These are simple foam or rubber grips that fit over handles of utensils, tools, or even pens and pencils, thus increasing gripability.

Grab bars



Properly installed, these sturdy bars help to prevent falls in the bathroom, bedroom, or just about anywhere in the home. (Remember – towel racks should not be used as grab bars.)



Push-up bars

These unique devices – essentially a portable seat with handles – make it easier to get up and sit down.

Pill splitter

An easy way to divide pills into 1/2 or 1/4 doses as required. (Remember that controlled release tablets should only be split on a doctor's order.)

Swivel cushions

Foam cushions on a turntable make it easier to enter and exit vehicles.

Giggling through the hard times: Lightening the load of Parkinson's

By Sandra Lammers, Mission, BC

I remember the first time I allowed myself to laugh at Parkinson's disease.

It was several Christmases ago. I was looking through the job section in the newspaper. "Hey," I said to my husband Mark, "Here's something. The Salvation Army is looking for bell ringers for their Christmas Campaign."

There was no answer. "I could skip my meds for one dose," I replied. "Then all I have to do is stand there and the rest will happen naturally."

Mark didn't laugh. I did, though. That's when it occurred to me. I had almost forgotten about laughter.

From that moment on, laughter would become part of my 'coping' strategy – a way to deal with having a progressive disease that made its first appearance when I was just 30 years old. I had two young children, a growing career with my own preschool, and so much living to do yet! I didn't have time for this 'interruption' in my life.

The interruption came like a turtle slowly making headway in a race against the clock. Every time I adjusted to a change, that turtle would inch forward.

I felt like little bits of my life were being stolen. First some of my hobbies, then my career. What would the thief take next?

My family and I have since found many ways of thwarting that thief. Humour, I've found, is the most freeing of these. It is easier for my kids to deal with my condition when they laugh about it. When one of them gets a sliver in their finger, for instance, I approach them with a needle in my unsteady hand. "Here, let me take it out!" I'll joke.

Above: The Lammers family (left to right) Jesse, Sandra, Mark and Aaron have found an ally in humour.

Right: Sandra with her mom, grandma and nine-month-old Aaron. It was around this time that her symptoms started.

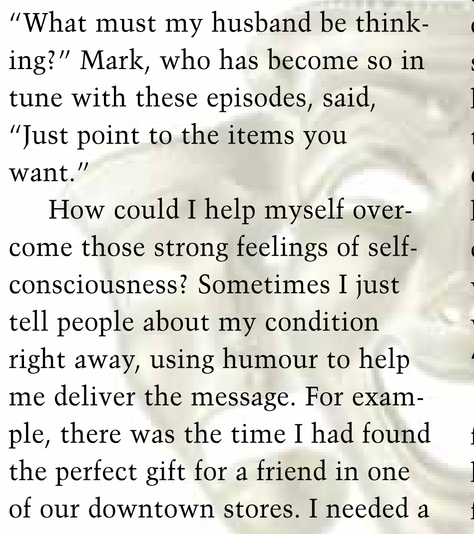
Finally catching on

I have learned that my friends love a good laugh as well – especially since they have caught on that I don't mind. "I'm holding up the wall with Sandra," someone will jest, or "Let's get Sandra to toss that salad." I also get accused of cheating in Yahtzee because I shake the dice so easily.

My husband found it hard to understand at first. Laughing at my condition didn't come easily to him. I knew he had caught on, though, when someone asked him, "Does Sandra shake in her sleep?" and he quipped back, "No, but her right leg packs a pretty good kick!"

I realize that some people might not understand this light-hearted approach to Parkinson's. And, to be honest, there are times when I can't even muster a smile, yet alone a giggle. I'm becoming famous for saying. "If the shower walls could talk you'd be in for a shock!" That shower – my private sanctuary – has been witness to plenty of tears, anger and even some self-pity. But humour is precious. It's just that, in re-discovering laughter, I've unlocked a part of me that I can share with others. Humour has the ability to put me, and those around me, at ease.

Dancing to my own music



One of the hardest things to overcome has been the self-consciousness I feel in public places when I have difficulties with balance or my foot trails behind me. There was one day, in particular, when my dyskinesia was very noticeable. Mark and I were in a local produce store. "What must people be thinking?" I thought to myself. "What must my husband be thinking?" Mark, who has become so in tune with these episodes, said, "Just point to the items you want."

How could I help myself overcome those strong feelings of self-consciousness? Sometimes I just tell people about my condition right away, using humour to help me deliver the message. For example, there was the time I had found the perfect gift for a friend in one of our downtown stores. I needed a box so I stopped a passing clerk. She smiled. "It's hard to keep the toe from tapping to the music, isn't it?" she asked, referring to the holiday music playing throughout the store and my shaking. I laughed and said, "Actually I have Parkinson's; I dance even when I don't want to!" Humour helped to lighten what could have been an awkward moment for me.

I think I'll keep them

So what about the days that are not so easy? I finally was brave enough to ask my family one evening during dinner, "Do I embarrass you guys some times?" My nine-year-old looked at me as if I had just sprouted horns. "No way; never!" he stated. There was no hesitation there. My husband took my hand. "I could care less what people think!" he said, looking me straight in the eye. My oldest son, not one of many words, was nodding his head the whole time. I think my boys are 'keepers', don't you?

Learning – together with my family – how to giggle through the hard times has been a wonderful gift from God.

The journey ahead is not going to be easy, but I'm going to keep putting that old thief in a headlock with my sense of humour. As long as I continue to hear him squealing "O.K. I give!" I know I'm going to be all right.

Sandra's strategies…

Seven tips for exiting a crowded room

1 Hope that everyone leaves before you do.

2 Tell everyone that dessert is in the other room and, while everyone is distracted, make an ambling get-away.

3 Pretend to fall asleep in the chair or couch.

4 Wait until the next dose of meds kicks in.

5 Really fall asleep on the chair or couch.

6 Hide behind your spouse.

7 Hold your head high and gracefully, or at least with dignity, walk out. You have nothing to hide except your pride.

Do you have a story to tell? *Parkinson Post* welcomes your submissions about what it is like to live with Parkinson's. Please e-mail your 1000–1100 word story to editor@parkinson.ca. Don't forget to include your phone number!

WEBSITE HIGHLIGHTS

Visit Us Online: www.parkinson.ca

We are always adding new content to our site. Check out the following sections:

- We've updated the information about Parkinson's disease. **(see Parkinson's Disease/Newly Diagnosed)**
- Parkinson Society Canada's *Annual Report 2002* is now available in English and French. **(see The Society/Annual Report)**
- New detailed information is available about The Parkinson Legacy, a new program to make planned giving easy and understandable. **(see Donating/Planned Giving/Parkinson Legacy)**
- If you are interested in learning more about upcoming clinical trials, see the new links we've added to several informative websites. **(see Parkinson's Disease/Links and scroll down to Clinical Trials)**
- A Parkinson's-specific bowel management program, created by experts at the Pacific Parkinson's Research Centre at UBC, is now available online in English and French. **(see Parkinson's Disease/Brochures)**

Send your comments and suggestions for our website to general.info@parkinson.ca

Should you participate in clinical trials?

Knowing the facts can help you make an informed choice

By Jan Duff and Lisa Johnston

One of the most important battlefields in the fight against Parkinson's disease is in the laboratory, where new treatments and medications are researched and developed. When a new treatment shows particular promise, however, it must move out of the laboratory and into the clinic. In other words, it needs to be tested on actual patients. That's where clinical trials come in.

While the types and design of clinical trials vary greatly, they all have one thing in common – the need for people who are willing to try new medication. Due to the nature of Parkinson's disease and the inherent difficulties in developing a perfect treatment, people with this condition are often approached to participate in clinical trials.

Why are clinical trials important?

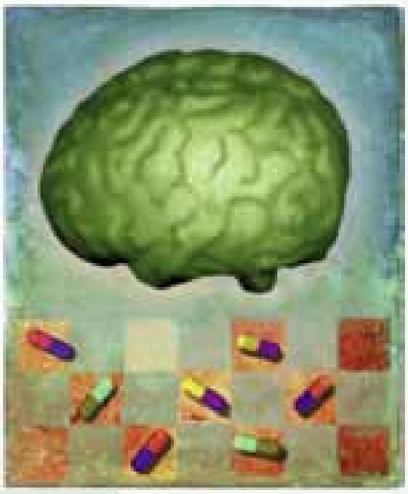
All of today's treatments for Parkinson's (levodopa, dopamine agonists or surgery) are based on the results of past clinical studies. Clinical trials do not always lead to new treatments, but they often answer important questions and help move research forward.

How do clinical trials work?

Clinical trials are carefully controlled scientific research studies designed to evaluate the safety and efficacy of new treatments. Before any new Parkinson's (or other) treatment can be made widely available, it must be proven safe and effective in clinical studies. This process involves steps or phases.

The first step, Pre-Clinical Research, looks at a compound or procedure, testing it in the lab setting. This involves *in vitro* studies (on human cells in test tubes) and *toxicology* studies (on laboratory animals). One of the primary purposes is to test its safety. Only once safety has been established – a process that can take as many as five years or even longer – can testing on humans begin.

If pre-clinical studies show that a drug appears to be safe and useful in animals, the developer (usually a pharmaceutical company) must apply to the Therapeutic Products Program (TPP) of the Health Protection Branch (HPB) of Health Canada, or the Food and Drug Administration (FDA) in the U.S., for permission to test the drug in humans. Clinical trials can start only after TPP or FDA has given approval.



Clinical trials actually involve four distinct phases:

Phase I trials usually involve a small number of healthy volunteers, though they may include people with the condition that the medication is intended to treat. In this phase, investigators are trying to find the best way to give the study treatment and to determine the safest dose.

Phase II trials examine how well the appropriate treatment works in a small group of patients, over a longer period of time.

Phase III trials further test how safe and effective the drug is, often comparing it to a standard treatment. In this step, hundreds or thousands of patients participate.

Phase IV trials, or post-marketing studies, are conducted after the treatment has been approved and is available for prescription use.

Phase IV studies typically involve large numbers of patients and look at possible new uses of the treatment.

Want to know more? See this article on-line for a list of 'Questions to ask your doctor' and key websites to visit. Visit **www.parkinson.ca**, select *Parkinson Post*, and see the 'Should you Participate in Clinical Trials?' article.

At each phase of a clinical trial, the drug is reassessed and approved by the Bureau of Human Prescription Drugs before it can go on to the next stage of testing.

Who conducts clinical trials?

Study participants can include the principal investigator (a doctor with a special interest in the specialty area and experience supervising studies), the coordinator (a nurse, with similar expertise), the sponsor (usually a pharmaceutical or biotech company that developed the new drug, a hospital or university), the Ethics Review Board, research groups, clinical research organizations, monitors, auditors and most importantly, study subjects.

How safe are these trials?

The safety and well-being of study participants must always come first. The TPP in Canada and FDA in the U.S. have strict guidelines and safeguards to protect participants in clinical trials.

All federally regulated clinical trials must be approved and monitored by an independent committee of doctors, scientists, advocates and others to ensure that the rights of study participants are protected. These committees are called *Institutional Review Boards* (IRBs) or *Ethics Review Boards* (ERBs).

The IRB/ERB reviews submissions from the investigators that detail all aspects of a proposed clinical trial. If they are satisfied, they will give permission to conduct the study. This permission is reviewed whenever there are changes to the original study plan, and once per year.

An independent group of experts, called the *Data and Safety Monitoring Committee*, carefully watches over each clinical trial. These experts look for evidence of benefit or harm to the study participants during a clinical trial. A study can be stopped at any time to ensure the safety of participants.

Why should you take part in a clinical trial?

There may be benefits for you directly. You will have access to the latest therapies, which have the potential to improve your condition. You may wish to participate for humanitarian reasons – to help people with Parkinson's and to contribute to medical science.

What are the potential risks and benefits?

Potential benefits include:

- Health care provided by a leading neurologist in the area of Parkinson's treatment and research.
- Access to new treatments/drugs before they are generally available.
- Frequent and close monitoring of your health.
- Being among the first to benefit if the investigational compound proves effective.
- A chance to make a valuable contribution to Parkinson's research.

Potential risks include:

- New drugs and treatments may have risks or side effects thus far unknown to doctors.
- New drugs or treatments may be ineffective, or less effective than current treatments.
- Even beneficial treatments may not be effective for your situation.

In the end, the decision comes down to whether possible benefits outweigh possible risks. And in the end, only you can decide.

What is informed consent?

Informed consent is an essential part of the process of taking part in a clinical trial. This process includes a review of why the study is being done, what will be done during the trial and for how long, what are the risks and benefits of participating and other treatments that are available to you. This is important information to review with family, friends and others such as your family doctor before you decide to participate in any clinical trial.

DON'T MISS AN ISSUE!

Coming in the Spring 2003 issue of *Parkinson Post*

Read about two award-winning individuals and their compassionate efforts to provide information and improve services to people with Parkinson's in their communities. Judy Hazlett of Ontario and Gina Rohs of Alberta were recently awarded the *Mimi Feutl Award for Patient Services* – find out why.

Senator John Nichol of BC recently received the first *David Simmonds Parkinson's Leadership Award*. His remarkable achievements have led to significant improvements for Canadians living with Parkinson's. We'll tell you his story.

Having a Power of Attorney for Personal Care (also known as a Health Care Directive) or for Property is a legal way to give someone else the authority to manage your affairs if you are incapacitated. We'll cover what you need to know and highlight how regulations vary from province to province.

Muhammad Ali came to Canada in October to raise awareness of Parkinson's. Learn about the impact of his visit and hear first-hand how it affected various Canadians who met or saw him.

Parkinson Society Canada
Société Parkinson Canada

Saskatoon

Dr. Ali Rajput, Saskatoon Honorary Chair; Vicki Gabereau, National Honorary Chair; and Wayne Kartusch, President, Saskatchewan Junior Hockey League, Regina; at the Saskatoon SuperWalk.

Rise and shine! This enthusiastic family was one of the first on the scene in Saskatoon.

Victoria

Victoria participants walk along the historic Galloping Goose Trail.

SuperWalk fo raises over

During the month of September, 65 communities across Canada participated in SuperWalk for Parkinson's 2002 raising over 1.2 million dollars – a new record and a 28% increase over last year. In fact, the money raised during SuperWalk 2002 is almost twice as much as was raised during SuperWalk for Parkinson's 2000, only two years ago!

With nine new walks this year, SuperWalk 2002 has been a great success due to the involvement of many committed individuals across Canada, the excitement of new participants who joined us this year and those who responded to our national team challenge. Parkinson Society Canada gratefully acknowledges the support of our Honorary Chair Vicki Gabereau, and our many sponsors: National Bank of Canada, CTV, GlaxoSmithKline, The Running Room, Eldertreks, Air Canada, Draxis, Hayhoe Mills,

Gabriola Island

This is a new walk that had 100 walkers attend. Twenty-one of them were from the McCarthy family (picture) – includes parents, sons, daughter, daughters-in-law and eight grandchildren. Twenty-nine friends of the McCarthy family also attended the walk.

Toronto

Mark Watson, Regional Manager South Central Ontario Region, National Bank, presents a cheque for $50,000 to Margot Greenberg, National Chair of SuperWalk.

St. John's

Tom Goodyear, Arch and Alice Lake join the 400 walkers in St. John's who together raised over $10,000.

The SuperWalk begins at the Montreal Botanical Gardens, with 650 walkers participating.

Participants from the corporate team Ruby Stein Wagner, which raised $9,140 and came in second in the national Team Challenge. Left to right: Jeff Orloff, David Orloff, Jonathan Reisler and Stephen Reisler.

r Parkinson's $1,200,000!

Bristol-Myers Squibb, Allison Canada and Rio Can.

The draw for our National Grand Prizes took place this November. The winners of the Costa Rica Rainforest Adventure, courtesy of Eldertreks, are Annalee and Doug Bartlett from Fredericton, NB; the winner of two Air Canada tickets is Stephanie McKay from Toronto and the winner of the Famous Players Big Card is Ernie Fuchs from Saskatoon. The Daniels Family from Edmonton was also declared the National Team Challenge winner with a team total of $10,628!

Get involved in SuperWalk 2003! Planning in your area has already started so get involved as an organizer, volunteer, walker or team member. Visit **www.superwalk.com** and plan now to participate in September 2003.

Cutting the ribbon at the first-ever Markham SuperWalk. Over $23,000 was raised by 130 walkers.

Reach for the sky! Walkers from Sarnia-Lambton stretch in preparation for their walk at Sarnia Bay Marina.

Meet the Cronkwright Crusaders: one of the new family fun teams in Southwestern Ontario at the London SuperWalk in Springbank Park.

SuperWalk for Parkinson's

A year in the life of *Parkinson Post*

By Suzanne Tobin, Editor

DECEMBER 2001

After months of work, the first issue of the new *Parkinson Post* rolls off the press. The marketing campaign begins: 25,000 complimentary copies are sent to people across Canada. Our regional partners begin to promote the magazine through their events, support groups and newsletters. Copies are also sent to all the movement disorder clinics.

JANUARY 2002

Subscriptions arrive almost immediately by mail and phone! We work madly to complete a database to store all subscription information and to pull the content together for the Spring 2002 issue. We also load subscription information and sample articles onto our website **www.parkinson.ca**.

FEBRUARY 2002

Our subscription database is coming together. We send a follow-up mailing to all the people who received a complimentary issue – subscriptions really begin to pour in, sometimes 100 per day!

MARCH 2002

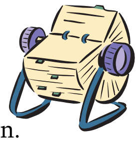
Our Spring issue starts to ship to subscribers. We are still getting so many new subscribers that we do a second mailing rather than make people wait for the Summer issue to begin their subscription.

APRIL 2002

We send sample copies to select general practitioners across Canada. The Summer 2002 issue is in progress and we are already planning the Fall issue. I review the budget and realize we need to sell more subscriptions to break even.

MAY 2002

Finally, the James Parkinson tulips that I planted last fall in my garden are coming up. I take pictures in case we need them to illustrate a story. We build a small mailing list of media contacts and send them the *Parkinson Post* so they will be informed and, we hope, cover Parkinson's more often.

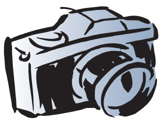


JUNE 2002

The Summer issue arrives! 'First Person' stories are coming in more often. I find reading these stories so motivating – they are a powerful reminder of why we need a national magazine for Canadians living with Parkinson's.

JULY 2002

I attend the photo shoot for our Fall cover story and am inspired by how the three Valeriati-Breda sisters and their families share in their mother's care. After the shoot, I stay for cake and coffee on a sunny summer evening, chatting with a remarkable family.



AUGUST 2002

How can we contact our one-year subscribers to encourage them to renew? We decide to run simple renewal letters in-house and mail them out from our office.

SEPTEMBER 2002

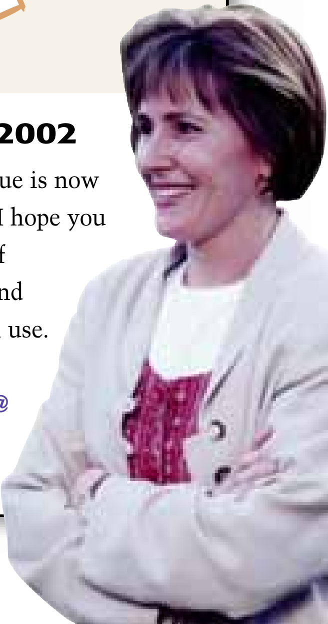
We send magazines to SuperWalks across the country to help drive subscriptions. I go to SuperWalk in Toronto with my family and am amazed again by how welcoming the Parkinson community is to newcomers. I come home full of ideas.

OCTOBER 2002

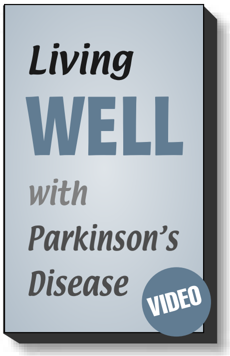
We have created a promotional piece for the *Parkinson Post* and insert it in receipts sent to PSC donors. We mail the renewal letters out to our one-year subscribers and the response is immediate. Within weeks, over 50% of the subscribers have renewed and many are now opting for a three-year subscription!

NOVEMBER 2002

The Winter 2002 issue is now being produced and I hope you will agree it is full of compelling stories and information you can use. I welcome your comments at **editor@parkinson.ca**. Here's to another year!



Resources



Living Well with Parkinson's Disease

Parkinson Society British Columbia

Reviewed by Kathryn Webber

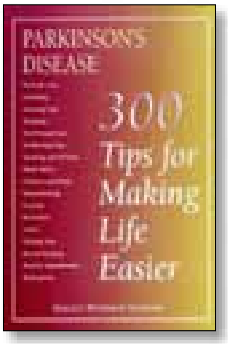
This informative video offers newly diagnosed Parkinson's patients and their caregivers valuable information for adjusting to life with the disease.

People with Parkinson's and their families share personal experiences, offer suggestions on coping with the initial diagnosis and advice on how to include family in managing the disease.

Interwoven with these touching, personal accounts are interviews with specialists in nutrition, neurology, physiotherapy, nursing and speech language pathology.

Although the video is geared towards the newly diagnosed patient, it may interest anyone with Parkinson's disease.

Video is available for $10 (includes shipping within Canada). To order, call Parkinson Society Canada at 1-800-565-3000, ext 245.



Parkinson's Disease: 300 Tips for Making Life Easier

Shelley Peterman Schwartz

Reviewed by Shirin Hirji

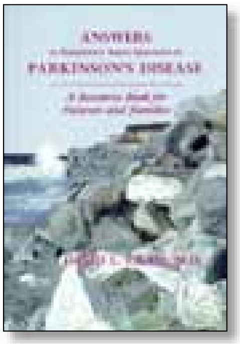
The book is based on interviewing over 100 people with Parkinson's, caregivers and health professionals. It includes simple time and energy saving tips and excellent ideas for caregivers too.

It covers basic concepts such as how to stay positive, reduce stress and keep your sense of humour. Tips I liked were "Give yourself permission to say *no* without feeling guilty" and "Eliminate people and activities that drain your energy."

The book also provides advice on making your home accessible, empowering yourself, handling medical issues and getting out and about.

The book covers almost all the stages of PD, and is full of websites (although most are U.S.).

Available at select Canadian bookstores or by calling 1-800-532-8663. $18.95 U.S. plus shipping.



Answers to Frequently Asked Questions in Parkinson's Disease

David L. Cram, M.D.

Reviewed by Marg Turner

This second book by Dr. Cram, a retired M.D. diagnosed with Parkinson's in 1989, is even more enlightening than his earlier book: *Understanding Parkinson's Disease: A Self-Help Guide.*

Dr. Cram's positive attitude is evident as he addresses, in easy-to-understand terminology, common questions and concerns from persons with Parkinson's disease.

A definite must-read not only on frequently raised questions, but also on many of the less-commonly discussed issues (i.e., heredity factors, hospital advocacy, drug interactions, vision problems).

I especially liked his recommendations for leading a fulfilling life after diagnosis.

To order from Acorn Publishing, for $19.95 U.S. plus shipping, call 1-877-700-2219.

Falls Prevention Information Kit

Health Canada

Health Canada and Veterans Affairs Canada have collaborated on the important *Falls Prevention Information Kit.*

This educational package includes "You can prevent falls," a series of eight fact sheets containing tips, facts and advice. A CD with reference documents plus other important information round out this educational kit.

Prevention is stressed throughout: from exercise to home safety and more, readers receive practical information which they can implement right away.

Free English and French copies can be ordered by calling Health Canada at (613) 952-7606 or by visiting www.hc-sc.gc.ca/seniors-aines

Please remember that while Parkinson Society Canada provides information about the availability of new resources in this section, this does not necessarily imply recommendation or endorsement of the contents.