Fall/Winter 2007 • Volume 7 • Issue 3
$5.75

ParkinsonPost

A magazine for Canadians living with Parkinson's

Partners in Parkinson's:
Caregivers share their personal stories

PLUS
SuperWalk raises $2 million for research

The caregiving journey:
Sharing the Parkinson's path

Support across the regions:
Where to turn for help

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

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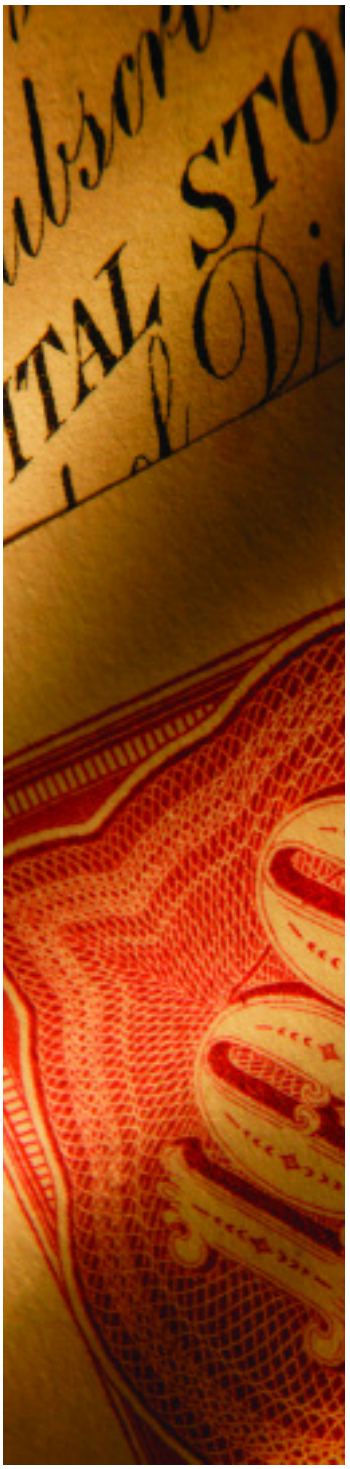

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For more information contact:
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Parkinson Society Canada
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ON OUR COVER:
Pam Barry (left) is a great source of support to her partner, Beth Holloway (right). Read more about Pam, Beth and other caregiving partnerships on page 11.

Welcome to our family

This issue of *Parkinson Post* is dedicated to the topics of care and support and is directed to the many caregivers who help people with Parkinson's.

Support comes in many forms from many health care professionals, but no one knows more about what it means to provide care and support than the families of people living with Parkinson's. It is our families who are there for us from diagnosis to late stage Parkinson's. It is family members who offer understanding and a sympathetic ear, drive us to appointments and provide encouragement. And it is our families who provide more involved caregiving when we need it.

The strength and support of a family is critical. Together, a family, large or small, can meet a challenge that might defeat an individual.

Parkinson Society Canada (PSC) has been providing support for over 40 years through support groups, funding research, education and advocacy. Recognizing that we are stronger when we work together and understanding that there are many different kinds of support, I want to welcome your family to our family. Together, family members can have a greater impact helping people with Parkinson's now and in the future.

For this reason, we at PSC are pleased to introduce *The Family Fund*, which has been developed to offer yet another kind of support. Its purpose is to allow individuals like you to combine your giving as a family, enabling you to collectively make a generous donation that perhaps you individually could not make.

As a contributing family, you will be part of a bigger family where, as we all know, the sum is greater than the parts. Together, family members can contribute to leading edge research that will enable us to get closer to the cause, to find new treatments and ultimately, to find the cure.

Our Family Fund goal is $3 million. It will enable individuals to join together to make a significant contribution as a family. And it will help us increase the money committed to research.

Being part of a family of someone with Parkinson's has its challenges, but it also has so many rewards. We want to welcome you to the PSC family; you can count on us for the support you need.

To learn more about joining our Family Fund, please contact Jim Allen at 1-800-565-3000 ext. 3385 or jim.allen@parkinson.ca.

Joyce Gordon,
President and CEO,
Parkinson Society Canada

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ParkinsonPost
A magazine for Canadians living with Parkinson's

Parkinson Post Vol. 7, Issue 3, Fall/Winter 2007

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Publisher:
BCS Communications Ltd.

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Parkinson Post (ISSN #1489-1964) is the official publication of Parkinson Society Canada and is published three times a year by BCS Communications Ltd., 255 Duncan Mill Road, Suite 803, Toronto, ON M3B 3H9. Tel: (416) 421-7944 Fax: (416) 421-8418.

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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.parkinson.bc.ca

- Two new support groups (New Diagnosis Group and West End Group) have been added in Vancouver.
- In collaboration with the Physiotherapy Association BC, a Parkinson's physio and exercise referral list has been developed.
- The PSBC conference "Parkinson's: The Journey," held on October 26, had 200 delegates in attendance.
- Ms. Rasheda Ali will be the guest of honour/speaker at the Third Annual "An Affair to Remember" fundraising gala on Thursday, April 3, 2008.

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

- The stress management program has expanded and will now include professionally facilitated goal-setting and action-planning.
- Newly designed educational meetings have been moved offsite to a seniors' wellness centre.
- We are conducting an outreach phone link with 100 isolated clients and their caregivers. Common interventions include helping to clarify issues needing physician follow up, making referrals to community health services and offering counselling support.

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
www.parkinsonalberta.ca

- PSA's Gunnar Henriksson took part in the 2007 Alberta Provincial Powerlifting Championships and won the Masters II (50-59 years) 275 lbs class.
- Lorraine Mills, RSW, has joined PSA's staff as Client Services and Education Manager.
- The 12th Annual SuperWalk for Parkinson's, held in Edmonton, raised $90,000.
- Brad Mates/E-Drive Charity Concert was held in September for the Emerson Drive Scholarship Fund in conjunction with GPRC.
- Brad Mates/E-Drive Celebrity Golf Tournament was held in September at the Spruce Meadows Golf Club in Grande Prairie with proceeds going to PSA.
- The First Annual Gordon and Diane Buchanan Gala for Parkinson's was held in conjunction with PSA on September 13 at the Union Bank Inn in Edmonton.
- Dr. Wayne Martin, MD, FRCPC, Director Movement Disorder Clinic, presented "Recent Advances in Management of Parkinson's Disease," at the Edmonton General Auditorium.

The Parkinson's Society of Southern Alberta
102-5636 Burbank Crescent SE
Calgary, AB T2H 1Z6
Ph: (403) 243-9901
Toll Free (Alberta): (800) 561-1911
Fax: (403) 243-8283
www.parkinsons-society.org

- PSSA welcomes new CEO, John Petryshyn.
- In July, the annual PSSA golf tournament raised over $37,000.
- In September, PSSA welcomed physical therapist Neera Garga to its team.
- The Lethbridge, Medicine Hat, Red Deer, Cochrane/Airdrie and Calgary SuperWalks raised approximately $145,000.
- Aarti Shankaranarayananhe has been named the recipient of PSSA's annual Dr. Frank Ramsay Graduate Award in Neuroscience.
- PSSA has been chosen as one of the beneficiaries of the 2008 Vehicles and Violins fundraising gala by the Calgary Motor Dealer's Association.

Saskatchewan Parkinson's Disease Foundation
103 Hospital Drive, Box 102
Saskatoon, SK S7N 0W8
Ph: (306) 966-1348
Fax: (306) 966-8030
E-mail: spdf@sasktel.net

Parkinson Society Manitoba
171 Donald Street, Suite 302
Winnipeg, MB R3C 1M4
Ph: (204) 786-2637
Toll-Free: (866) 999-5558
Fax: (204) 786-2327

- The Regional Advocacy Committee has initiated a process to define specific regional needs for people living with Parkinson's. The Committee has started to develop the blueprint for a provincial strategy on Parkinson's research and service delivery.
- The ninth annual Golf Classic raised over $69,000 with a full field of 144 golfers and 35 sponsors, led by Gold Sponsor Lawton Partners Financial Planning Services.

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Parkinson Society Canada
Société Parkinson Canada

- SuperWalk for Parkinson's was held in Brandon, Gimli, Morden, and Winnipeg. All events had excellent attendance and were organized by volunteer committees.

PSC Central and Northern Ontario Region

4211 Yonge Street, Suite 321
Toronto, ON M2P 2A9
Ph: (416) 227-1200
Toll Free National: (800) 565-3000
Fax: (416) 227-1520

- SuperWalk for Parkinson's was a great success in 19 communities across the region.
- CNOR has been divided into five districts. District meetings are now being held regularly throughout the region.
- The Toronto chapter hosted its 2007 conference, "Living Really Well with Parkinson's." The conference provided a unique, non-medical approach to living with Parkinson's.
- Voice for Hope, a choir for People with Parkinson's, has been piloted in Toronto.
- Great gifts are available for sale, including Tulip Cards ($12.00 for a pack of 12) and Love/Hope/Tulip Candle sets ($15). Contact the regional office for more details.

PSC Southwestern Ontario

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

- The Ontario Trillium Foundation has granted Southwestern Ontario Region $210,000 for Community Development Programs in Waterloo Regional Municipality; Essex, Lambton and Kent Counties; and, Grey, Bruce, Huron and Perth Counties. A Community Development Coordinator will be hired in each of the three communities.
- SWO has increased its capacity to educate health care professionals who work with people with advanced Parkinson's through the Parkinson education program "PEP for Community Caregivers." Fifty presentations were booked between May 2, 2007, and December 4, 2007, by nine community health care professionals. The second Train-the-Trainer series was held in September.

Parkinson Society Ottawa

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

- One hundred golfers raised money to support people living with Parkinson's at the Sixth Annual Dr. J. David Grimes Memorial Golf Tournament on June 20 at the Meadows Golf and Country Club.
- A joint open house was held by The Taoist Tai Chi Society and Parkinson Society Ottawa at Carleton Place on August 25 to promote the benefits of Tai Chi for people living with Parkinson's.
- Five-hundred-and-fifty walkers participated in the SuperWalk for Parkinson's, setting a new record for funds raised ($93,000) and number of SuperStar walkers (22).
- PSO volunteers raised funds and awareness in eight community malls across Eastern Ontario by selling tulip bulbs as part of the national Hope in Bloom campaign.

Parkinson Society Quebec

550 Sherbrooke Street West
Office 1470, Tower West
Montreal, QC H3A 1B9
Ph: (514) 861-4422
Toll Free: (800) 720-1307
National francophone line
Fax: (514) 861-4510
www.parkinsonquebec.ca

Parkinson Society Maritime Region

5991 Spring Garden Road, Suite 830
Halifax, NS B3H 1Y6
Ph: (902) 422-3656
Toll Free (NS, NB & PEI):
(800) 663-2468
Fax: (902) 422-3797
www.parkinsonmaritimes.ca

- Vogue Optical's SuperWalk for Parkinson's raised a record $170,000, a 42% increase over 2006.
- The Region's Fall Conference, "Fighting Back," was held from October 19 and 20 in Halifax with keynote speaker Dr. David Heydrick, creator of The Parkinson Pyramid.
- Online chat groups for young onset and general Parkinson's have been launched on the region's website.
- "POP for Parkinson's," an evening of '80s music, was held in Halifax and featured six bands including Juno nominees In Flight Safety. Charlottetown sponsored "The Brown Jug Derby Raffle" in which participants could win a trip for two to the Derby in Ohio. The Society was the beneficiary of proceeds from the "RCMP Musical Ride" in Fredericton, sponsored by the Y's Men.
- 2008 is PSMR's 25th anniversary.

Parkinson Society Newfoundland and Labrador

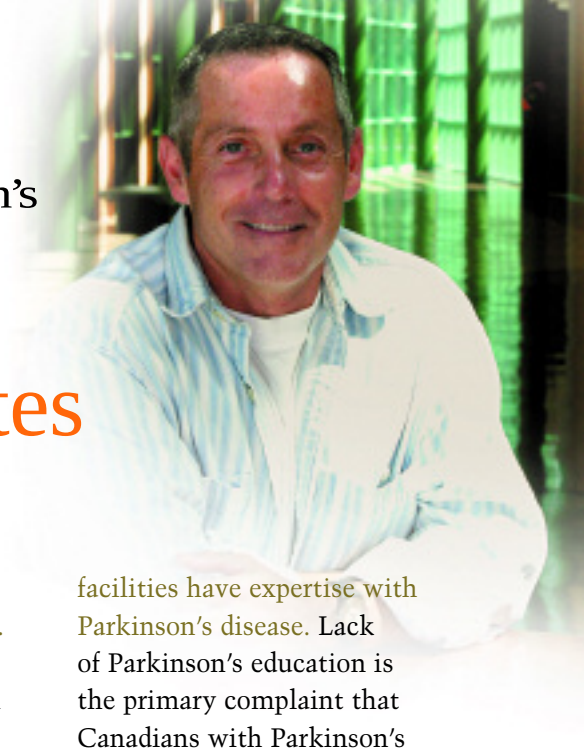
The Viking Building
136 Crosbie Road, Suite 305
St. John's, NL A1B 3K3
Ph: (709) 754-4428
Toll Free (NL): (800) 567-7020
Fax: (709) 754-5868

- Dr. John Stoessl visited the region and lectured at the Health Sciences Centre in St. John's. The conference was webcast across the Province.
- PSNL held six SuperWalks reaching its fundraising goals and garnering excellent media coverage.
- The region sold 23,000 tulip bulbs in September.
- PharmaChoice golf tournament for Parkinson's was a great success.
- Lana Roestenberg has been hired as the new Fund Development/ Office Coordinator.

Parkinson Society Canada
Société Parkinson Canada

Issues of interest to people with Parkinson's

Taking action:
Care partners as advocates



By Yvon Trepanier, Chair, National Advocacy Committee

Parkinson's is a family disease, one that takes a team of involved and supportive loved ones to help an individual with Parkinson's thrive. In most cases, however, the bulk of responsibility lies with one main care partner: a spouse, a child or a friend. For this individual, life is changed forever when their loved one is diagnosed with Parkinson's and they must take on many new roles. Theirs is a demanding job involving compromise, encouragement and strength. Their focus is on providing emotional and physical support to their loved one, advocating on their behalf, and learning all that they can about Parkinson's disease.

Lessons learned

Over and over, care partners report similar experiences about the challenges they face. Because of the progressive nature of Parkinson's, a care partner is challenged to know what degree of support their loved one needs at any given time. It is important that a person with Parkinson's be able to speak for themselves and to manage their own life for as long as possible; however, the care partner is a key member of the team. The relationship is sometimes described as one that begins as "care partner" and evolves into "caregiver."

Here are a few practical steps for care partners to follow:

1. Be an active member of the team. Attend medical appointments, and be involved in every decision about your loved one's care. Research shows that people with actively involved care partners tend to do better.
2. Ask questions until you understand the answer. Parkinson's is a complex, neurodegenerative disorder and, as such, there is a lot to understand. Don't hesitate to ask questions until you feel comfortable that both you and your loved one understand the answer fully. This includes information about medications (what it's for, side effects, when to take, things to avoid, etc.).
3. Keep your loved one honest. People tend to leave out important pieces of information when speaking with their doctor or therapist either due to embarrassment or because they simply think it doesn't matter. Care partners must encourage their loved ones to tell their doctor everything, including symptoms, changes in behaviour, other medications or supplements, etc.
4. Speak up for your loved one. Sometimes people with Parkinson's simply cannot communicate for themselves, so care partners must speak up for them.
5. Know what hospitals and/or care facilities have expertise with Parkinson's disease. Lack of Parkinson's education is the primary complaint that Canadians with Parkinson's and their care partners have about health care professionals coast-to-coast. If you have the opportunity, choose a facility that understands how to best care for someone with Parkinson's disease.
6. Get to know the nurses. Whether in hospital, a care facility or a movement disorder clinic, get to know the nurses that will be caring for your loved one. If necessary, explain the importance of administering medications on-time and act as a Parkinson's resource for them. Your efforts will not only benefit your loved one but also every other person with Parkinson's that the nurse will care for in the future.
7. Take the opportunity to educate. Whether in a hospital, walking down the street or sitting in a restaurant, chances are that some aspect of Parkinson's will draw the attention of others to your loved one. Make the most of the situation by explaining what is happening and letting others know how they can help.
8. Become an expert about supports and services. Find out what

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Lorraine Dumoulin and John Lacoste share the care for their father, Lucien.

The caregiving journey:
Sharing the Parkinson's path

As anyone who has experienced Parkinson's first hand will tell you, it is an incredible journey. For those who choose a positive approach, it can be an enriching and rewarding gift. It does have ups and downs as well as plenty of frustrations along the way. It is a journey without a map. However, it can also be a journey of understanding and many firsts. It can be a time of great bonding and a time when relationships are enriched with the realization of just how truly blessed one is with a truly supportive spouse, family and friends.

Mary Baker, former President of the European Parkinson's Disease Association, noted that Parkinson's disease (PD) is very much like a journey, not only for the person with the condition but also for the caregiver. Just as the person with PD will travel through multiple stages of the disease, those who care for them will follow their own Parkinson's path, taking them through a variety of roles, each with its own challenges.

An unknown voyage

"The image of the journey is, I think, very appropriate," says Lucie Lachance, a Clinical Nurse Specialist in Movement Disorders at the McGill University Health Centre. "We might know when and where the PD experience starts for us, but we don't know the route we will have to take and who our travelling companions will be as the disease progresses."

"Some people are natural nurturers. Some come to the role of caregiver with years of experience. Others who are new to the role may find themselves entering a strange new world for which they have had no preparation," explains Sandie Jones, Client Services and Education Coordinator, Parkinson Society Canada (PSC) Central and Northern Ontario Region. Often, the need to step in sneaks up on people and they go from care partner to caregiver with no warning.

Caregivers have often said "One day my relative with Parkinson's was managing fairly well, and the next day I suddenly needed to intervene." It is very important throughout the journey for families to keep an open mind and be willing to creatively decide how best to meet the needs of the individual with Parkinson's as well as the needs of the care partner/caregiver as PD progresses.

A relief and a shock

A diagnosis of PD can be a relief after months and sometimes years of knowing something is not right but not knowing specifically what. "When I finally had a diagnosis I was relieved. At least now I know what we were dealing with," say many people with Parkinson's. "It can be both a relief and a huge shock," adds Jones.

Because of the nature of PD, each person's experience is different. Understanding PD and all that may be involved is important, especially in the beginning. For the caregiver, coming to grips with the reality of the diagnosis means anticipating the changes and health concerns to come. The concept of caregiving may still seem distant.

"Many family members simply don't like the term 'caregiver'," notes Jones. "They feel it implies hands-on, non-personal care, like a health professional. 'Care partner' is a better, more accessible term, especially at these early stages." Jones believes that the best thing to do in the beginning is to gather information and find out about the condition. Care partner Don Turner agrees, "One of the first things we did when Marg was diagnosed was to head to the Parkinson Society Canada office to get information. It was the best thing we

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Living with Parkinson's disease

Every Parkinson's experience is unique. The symptoms and progression will vary from person to person. Living with Parkinson's requires an individualized approach which includes all aspects of your life (a holistic approach).

It is important for caregivers to actively participate in managing the disease. Members of your care team might include some or all of the following:

Neurologist—Ideally a specialist in movement disorders who might make or confirm the diagnosis, decide on treatment, adjust medication.

Family doctor—Ideally someone who is knowledgeable about Parkinson's, may be able to diagnose PD, initiate treatment, and provide ongoing care, including annual physical exams.

Parkinson's nurse specialist—Many movement disorder specialists have a nurse who specializes in Parkinson's. The nurse can provide information on how to manage your condition.

Psychiatrist/psychologist—An expert in mental and emotional health issues such as depression or cognitive abilities.

Physiotherapist—Makes assessments of mobility, balance and posture; offers techniques on how to move safely; recommends sports or exercise programs.

Occupational therapist—Makes assessments of living and working environments to ensure safety; suggests equipment or devices that can maintain independence.

Speech-language pathologist—Helps improve voice projection or swallowing difficulties.

Dietician—Advises on how to plan a healthy diet and maintain ideal weight; helps with dietary issues caused by medications.

Social worker—Advises on financial and family concerns; helps to access resources and services in your community.

Other professionals—Pharmacists can provide information on medication, drug reimbursements plans; a urologist can help with urinary problems or sexual functioning for men; a geriatrician can answer questions related to aging.

The healing power of humour

While dealing with Parkinson's is no laughing matter, many with PD say that humour is an essential element in navigating it. Taking a lighthearted approach can help. As Judy Hazlett says, "You will live in a much more intimate way than you ever imagined. Humour is a way of getting through it."

ever did. More information about the disease better enabled us to cope. It makes life much easier for both of you to get through."

"Call it the honeymoon. When she told me she had Parkinson's, I didn't know much about it other than it wasn't fatal. I had a little learning to do," says Al McKenzie, husband and care partner of Lynda.

A link to support

The prospect of being the sole support for someone with PD can be daunting. Caregiving is not everyone's forté, and it can be totally overwhelming. If so, PSC regional offices can help in finding the right kind of help. Over 235 support groups and chapters across the country provide help and an opportunity to share experiences.

Over time, the role of caregiver/care partner evolves into more decision-making and planning. "It's a new lifestyle," says Bruce Rathbone. "When we are going to events, we have to make sure everything with my wife, Pamela, is working well so we are not late."

And every day is different, according to John Martin whose wife, Mary, has good days and bad. "It's situational and depends on the medication on any given day. Some days they [people with Parkinson's] need a lot of help. Some days they need a lot of distance and privacy. On the days they need help, you have to anticipate it and watch for a chance to help, then take advantage of it."

Over time, the need for care increases, sometimes gradually and sometimes quickly. The task can seem immense. That's the time to seek help. It's also a good idea to spend some time researching what community services and other resources may be available. Your regional PSC office can help. (See pages 5 and 6 for a list.)

"The care providers who embark on the journey of Parkinson's caregiving should know that they don't need to travel alone," says Lachance. She explains that the caregiving can and should be shared by others—from friends and family to the health care team. Whether it involves keeping a cautious eye on the time to ensure pills are taken at regular intervals, or taking more initiative in decision-making and planning in many areas (including finance and legal issues), the caregiver's role can become all consuming.

A need for self-care

According to a Statistics Canada survey, the most severe adverse effect from providing care cited by caregivers is deterioration in their own health.

The caregiver can end up ignoring other family members—a spouse perhaps—when looking after a parent or, in the case of young onset Parkinson's, a son or daughter. There is a risk that the role of caregiver will take over one's identity. Caregivers need to ensure they make time for their own interests and pursuits, as caregiving is only one role of many. Finding alternatives to being the primary caregiver is important. Respite care may be an option.

Looking after one's self as well as the person with Parkinson's requires a concerted effort. "You need to remember to take care of yourself if you are effectively going to take care of somebody else," says Lachance. "Otherwise, everyone will suffer."

Eating well, staying active, and getting enough rest are important strategies for ensuring that caregivers retain their own health. Holistic therapies and exercise such as yoga and Tai Chi are often helpful. (See "Finding time for yourself" on page 14.)

Coping with Parkinson's can be as challenging for the caregiver as it is for the person with Parkinson's, according to Roger Buxton, husband and care partner of Judy Hazlett for 30 years. "You both have to cope to the best of your ability," he says. "It's a joint effort."

However, as Jones points out, not everyone is cut out for caregiving. "Some people are natural nurturers and move into the role quite comfortably," she explains. "For others, it's simply not who or what they are. If you are one of these people, you have to realize that it's OK. You just do the best you can under the circumstances. Trying to be someone you are not is just going to cause stress—for everyone."

If you are going to travel the caregiving journey, educating yourself and having the right attitude will make things easier.

Life with Parkinson's:
Care partners share their stories

By Ian Corks

Pam's story

Listen with your heart

Pam Barry became involved with Beth Holloway about seven years ago. Beth was in her 40s then, and as Pam relates, "was well into her Parkinson's disease." In fact, Beth had been diagnosed with young onset Parkinson's disease at the age of 33 and showed her first symptoms in her late 20s.

"Beth was reluctant to enter a relationship at first," Pam recalls. "She warned me about Parkinson's and what might lie ahead. So you can say I went in with my eyes open. But the bottom line is that I was interested in the person, not the disease."

Photo: Andrew Edwards

The first thing Pam did was read up on the disease so she could try to understand what Beth might be going through. There was no master care plan developed. "Nothing was written in stone," says Pam. "We didn't sit down and come up with a grand strategy; we just decided to keep doing what we do, and make adjustments when we had to."

For the first few years, Beth experienced little change, and life carried on fairly normally.

The two stayed active, going camping each year, playing golf and bowling.

Photo: Andrew Edwards

Pam Barry (left) and Beth Holloway enjoy playing guitar together.

The last two years have seen a few changes in Beth, but nothing to really slow them down. "Beth can still do most of the things she used to, so we are lucky," Pam says. "Of course, she has her off days—but then again, so do I."

How does Pam handle those days, and the other challenges of care partnering? Basically, with a bit of common sense and what she calls "listening with your heart."

"You have to maintain your own identity and independence," she advises. "So many people get so lost in their relationships—caregiving and otherwise—that they don't know who they are any more. Sure, we do a lot of things together, but we also do a lot of things separately. I have my own interests, and you should always try to find time to sit back and relax, alone or together.

"And never be pushy," Pam adds. "If one day your partner is ready to do anything, but the next day they are having trouble, you need to back off. Try to hear what's behind the words. And if they don't want to talk, or want to be alone, give them that space."

The final piece of advice Pam offers is a simple one. "Never lose your sense of humour," she says. "We always try to find something funny in everything."

John's story

Let others help

Since his father, Lucien, was diagnosed with Parkinson's 10 years ago, John Lacoste has seen the disease "slowly eat away at him."

"In the last four years, this once-strong man has gone from 5' 10" and 220 pounds to 5' 3" and 136 pounds," John notes. "It's not been easy for any of us. Perhaps the hardest part for me is trying

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Photo: Mike Heffernan

John Lacoste cares for his father, Lucien.

to always put on a happy face—to keep a positive demeanour—even though it's really getting to you."

John shares the caregiving responsibilities with his mother Therese and sister Lorraine, although his mother isn't able to do as much any more. "When Dad and Mom are both in the best of health they can just about look after each other, but when there is even the slightest complication—like a simple cold—things are 30 times worse," he relates.

So John, who lives 25 minutes away, finds himself there three or four days a week and Lorraine, who is still working, helps out on weekends and nights. "As a caregiver you gradually take on more responsibilities, and it can be frustrating," he comments.

Like most people, John has his own personal issues to deal with, in addition to looking after his dad. As such, he feels that he needs to find balance in his life, and take time for himself. "Even though at 55 I'm pretty young to do so, I joined a senior citizens' group, and have become involved in cooking and other things," John says. "It gives me an outlet and keeps my mind busy, for a little while."

John offers some advice for Parkinson's caregivers. "Caregivers sometimes put their all into looking after the person, and they don't think anyone else can help. But you have to let people help. Health professionals, community workers and support groups can all make a difference. If help is offered, take it."

He cautions against keeping the disease a secret. "People with Parkinson's often try to hide what they are going through," John explains. "Don't be afraid to acknowledge it. Talk to friends or family members."

Alan's story

Trust in your friends

By the time you read this story, Judith Richards will have undergone deep brain stimulation (DBS) surgery. "It's been three years since we made the decision, so we've been waiting a long time," says her husband Alan. "In truth, it was mainly Judith's decision. She is an independent thinker, so when she makes up her mind, I go along with it."

For the Richards, DBS surgery was the logical choice, given the progression of Judith's condition. "Judith was diagnosed in 1991 and at first we were fortunate," he explains. "But in the last two or three years, it has progressed. Every once in a while we discover something else that doesn't quite work the same any more."

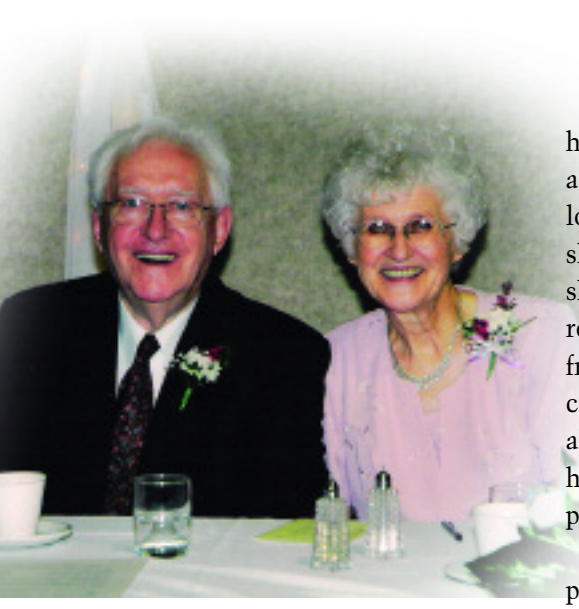
Alan has continued to care for Judith over the years, facing some of his own challenges along the way. "For one thing, I miss a lot of sleep," he says. "But the thing that bothered me most was not being able to devote time to my personal hobby: geneology."

Losing that outlet put a strain on Alan's emotional health, so he adapted. "You learn how to cope," he notes. "I manage to keep up with my hobby via the Internet, and by having friends help out with the research. I've also learned to take pleasure in things Judith enjoys, like shopping trips."

The local Parkinson's support group has also proved invaluable. "Now our personal best friends are members of that group," Alan notes. "We've formed a little social clique, going to meals or the theatre together. You know they understand what you are going through, so you are at ease with them."

Like many others, Alan and Judith also rely on their sense of humour to help cope. "We enjoy watching the Comedy Network in the evenings—at least until it gets too raunchy," he laughs.

Alan Richards supports his wife, Judith, in every way he can.



Frank and Mary Funk find that their faith has been a source of support over the years.

Mary's story

Stay physically and emotionally healthy

Diagnosed in 1995, Frank Funk has coped reasonably well with his Parkinson's. "In fact, because of the clinical trials Frank has been involved in at the Royal University Hospital in Saskatoon, his condition is, in some way, actually better than when he first was diagnosed," notes Mary. "Although, of course, we notice some deterioration."

Her husband was a missionary, and the couple's faith has been a source of strength over the years. Mary admits that there have been and continue to be challenges along the way. These include taking over the day-to-day responsibilities that Frank used to handle and admitting that he has changed in so many ways.

"It's hard," Mary says. "I still find it difficult to accept that I now do the caregiving when he used to be the 'caregiver,' so to speak, before Parkinson's."

Despite her love, faith and commitment, Mary acknowledges caregiving is challenging, and that as a caregiver, she needs to keep herself emotionally and physically healthy. "Take time for you," she advises others. "Rest when your loved one rests—if you can. Go shopping, even if only window shopping. Read, if you find that relaxing. Go out with personal friends at a time when it is most convenient to leave the person alone, or have someone stay with him or her. Take advantage of support groups to share your concerns.

"Take good care of yourself physically: walk, swim or join an exercise group, if possible," she adds. "You want to be in good shape to provide the care your loved one needs. And always keep looking up!"

Carmel's story

Make decisions together

In 2003, Carmel Boosamra made the decision that she could no longer provide her husband, Frank, with the level of care that he needed. Frank had been diagnosed with Parkinson's in 1992, a situation further complicated by his diabetes and heart disease.

Over the years, Carmel had done all that she could. Frank's PD continued to progress, to the point he was experiencing hallucinations. "I used to tell friends that I had no idea what to expect every time I opened the door," she recalls.

Eventually, Carmel arranged for daily help from the local community care agency.

"This worked for two years," she says. "Then I realized that he couldn't be home alone any more. He was falling and it wasn't safe for him.

"Once I admitted to myself that I couldn't carry on, it was clear to me," Carmel continues. "Luckily, Frank was realistic and we had talked about the possibility of long-term care years earlier when he was diagnosed. But that didn't make it any easier when I had to tell him I couldn't look after him any more."

When Frank had been in hospital in 1998, the couple had discussed and agreed on giving Carmel power of attorney. This decision made things a lot easier when the time came for long-term care. "Don't look at it like closing a door," Carmel adds. "It's not. You can still be involved, and you can still provide the care you want to.

"Many people avoid the issue of power of attorney," she notes. "They think the person is giving up all decision making. But that's not necessarily true. You can still discuss things, and the person can give verbal permission if they are able. You can still make joint decisions."

"I'm not so angry or stressed anymore... our time together is quality time."

Carmel Boosamra

Carmel admits that the decision was very difficult and "took a lot of fortitude." However, she also admits that things are better for her, Frank and their marriage. "I'm not so angry or stressed anymore," she says. "Our time together is quality time."

Finding time for yourself

Caregiving can be a demanding job that involves compromise, encouragement and strength. As a caregiver, you play many roles. You may be providing assistance by preparing meals, driving to appointments and helping with personal care activities. You might also be sharing information about Parkinson's and working with a health care team; and you are also providing emotional support to your partner. You will be experiencing a variety of emotions and reactions, including frustration, guilt and fatigue.

Every caregiver needs "time out" on a regular basis. The first step to finding time for yourself is to recognize your own limitations. Parkinson's is progressive, so it may be increasingly difficult to provide care all on your own. Start by identifying your supports: friends, neighbours, family; community resources: home care, day programs, housekeeping services; and so on.

Start with friends and family. Can a friend visit for an hour to play a game of cards with your spouse while you go out on your own? Can a neighbour take your spouse shopping so that you can have some time to yourself in your own home? Can one of your children take your spouse to their place for the weekend? Make a list of tasks that others can do. People want to help, but often they don't know how. Let them know specifically how they can help and include them in your plans.

Identify community resources that may be helpful. Consider a day program: your family member with Parkinson's could attend a social day program one or two days a week. For a longer break, you can arrange for temporary, short-term stay in a long-term care facility for your family member. This would give you an extended period of respite.

For more ideas on how to take a break from care, contact your regional Parkinson Society office. For a list of regional offices, see pages 5 and 6.

With thanks to the Parkinson Paper, *Parkinson Society Ottawa.*

10 tips for caregivers

Find out more at www.parkinson.ca

1. Be positive! Advice from those who have been there is not to focus on "Why me?" or "Why us?" but rather on "Let's deal with it."
2. Accept change. Accepting and adapting one's life is important.
3. Do the things you've always said you wanted to do. Whether it's hiking, mountain biking, or seeing the world, now is the time to do it.
4. Take time for yourself. See friends and continue those activities you most enjoy.
5. Encourage the person with Parkinson's to maintain his or her independence. Know when *not* to help.
6. Allow extra time when planning an outing. It will reduce stress for everyone.
7. Live each day. Everyone's experience with Parkinson's is different.
8. Address financial and legal issues early.
9. Accompany the person with Parkinson's to appointments (medical, physiotherapy, etc.), and ensure all of their questions are answered.
10. Learn all you can about Parkinson's. Visit our web site or contact your regional Parkinson Society. A list is included on pages 5 and 6.

Home alone

In order for caregivers to take a break, they may need to leave the person with Parkinson's home alone. To ensure a safe environment while maintaining the person's autonomy, here are some questions to consider:

- Can he prepare and eat a meal without your assistance?
- Does she experience choking when eating?
- Is it easy for him to use the bathroom without your help, or does he require aid every time?
- Is she routinely experiencing falls? Does your home have many hazards for falls?
- Does he routinely experience emergencies, which might jeopardize his safety? Does he suffer from orthostatic hypotension, epilepsy or shortness of breath that may need monitoring all the time?
- Can she remember to take medications as directed and on time?
- Does he appear anxious or worried at the first sign of you leaving?
- Does her behaviour and temperament change between the time you leave and the time you return?
- Is he able to call 9-1-1 or neighbours if an emergency occurs?
- In case of emergency, is she able to leave and seek shelter outside?
- Is he aware of smoke alarms, which may trigger danger, or is he likely to overlook all such noises?
- Does she suffer from Alzheimer's disease or dementia? If so, is she likely to leave on her own and not return safely?
- Can he distinguish friends and family from strangers if someone wants to come in?

Your answers to these questions will help you decide whether to leave your loved one home alone. You may need to find help through a family member or home care worker who can fill in while you are out.

Adapted from PSSA's Newsworthy Notes, *issue no. 166, January 2006.*

Support across the regions

By Gina Collymore

For people with Parkinson's, the term "support" covers a multitude of factors, from providing care and ensuring a safe environment to overcoming financial burdens. Knowing what to do, how to best be supportive and where to go for help are really important.

Parkinson Society Canada (PSC) and its regional partners are dedicated to providing support for people living with Parkinson's that goes beyond advice and tips. Over 235 support groups have emerged throughout Canada to deal with topics such as coping with being newly diagnosed to conserving your energy to avoid burnout.

Help from others

Generally, people attend support groups to obtain information, to learn from others about coping with a chronic illness, to interact with people who are living with Parkinson's, and to know they are not alone. The more popular support groups for people with PD include the young onset support group and the advanced PD groups.

Parkinson Society British Columbia (PSBC) offers basic support that includes being available to meet with people with Parkinson's and care partners in person, over the phone or by e-mail.

"We offer an information and referral service, professional counselling, information packages, and conferences, and provide leadership to 44 self-help support groups throughout BC, some of which are caregiver specific. Along with providing information, we know that sometimes a listening ear is most helpful, and so we fund a toll-free number where people can find that listening ear without worrying about the cost," says Carmen Dyck, Director of Support Services, PSBC.

The Victoria Epilepsy and Parkinson's Centre also incorporates similar programs designated for the caregiver, including non-traditional programs and workshops to offer caregivers respite and support.

"We offer regular support groups for people with Parkinson's, but we also facilitate programs strictly for the caregivers—like the stress management program, transportation coordination to provide the caregiver respite, and even a program that links our support group members with a massage college at a specially reduced rate," says Maureen Matthew, Victoria's Parkinson Program Coordinator.

People with Parkinson's who can't attend support groups in person can turn to the Maritimes on-line chat room for help.

Tools for change

Else Manz is a facilitator with the Saskatchewan Parkinson Disease Foundation and a person living with Parkinson's. "The goal behind the regional support groups is not only to cope with change but to give people the tools to adjust to change. Due to the progressive nature of PD, support groups offer guidance on the different stages of the disease, how to manage your life and how to make changes to your routine to accommodate those changes," says Manz.

Support for the person with Parkinson's is important, but equally important is the caregiver, who, alongside the person with Parkinson's, must adjust his or her life to accommodate the other. Gisele Marcoux, the Coordinator of Direct Services for Parkinson's Society of Southern Alberta, offers support groups to caregivers for all stages of PD. They meet separately from people with Parkinson's, and the meetings are facilitated by professionals. "Our support groups follow the journey from diagnosis to long-term care, to ease them through the changes that are inevitable," says Marcoux.

Groups on the rise

With the number of people diagnosed with PD increasing as the population ages, different types of support groups have emerged to address this change and more are being organized to represent the needs and concerns of the caregiver. In the past five years, the number of support groups across Canada has grown by 15 per cent. There are online support rooms (web-based), groups for care partners, couples support groups, social and exercise groups, and deep brain stimulation support groups.

In Newfoundland, Patricia Morrissey, Executive Director of Parkinson Society Newfoundland and Labrador, has coordinated annual events throughout the region to educate and support people with Parkinson's and caregivers. Annually, at alternating sites, she organizes the Parkinson Community Education Program, offering seminars and groups on various concerns.

"We address caregivers at this conference because their position is so important to people with Parkinson's. A separate meeting takes place with only caregivers where they have the opportunity to voice their concerns without worry. Some may see it as venting, but it is the caregiver's chance to get off their chest concerns that they cannot share with their partner," says Morrissey.

Online support

In the Maritimes, Denise Hubley coordinates all support groups and services for people with Parkinson's and their caregivers. They not only offer the traditional support groups but also facilitate a chat room for people who want to remain anonymous or who may be reluctant to attend a support group.

"Our online chat room is designed for people who are scared to tell their family or friends they have the disease. They might be intimidated by telling all to a group of strangers. At the same time, they still want their questions answered. The popularity of the chat room is overwhelming. It attracts people from all over the world and is available to anyone who registers," says Hubley.

Because the nature of PD is different in everyone and care must adapt at the same pace, support groups can help.

Topics covered in the chat room include "When should I tell my family and friends?", "When should I retire?", and "Now that I'm not working, what's next?"

Topics covered can be equally important to the caregiver as to the person with Parkinson's. A diagnosis of Parkinson's is an adjustment for everyone. Consequently, the chat room accommodates caregiver questions and concerns pertaining to such things as dealing with someone's desire for secrecy, safeguarding their anonymity, and managing the financial burden when someone must leave the workforce unexpectedly.

Care that adapts

The role of the caregiver develops and changes sometimes as quickly as the disease progresses. Because the nature of PD is different in everyone and care must adapt at the same pace, support groups can help. To find one in your community, contact your regional Parkinson Society office. (See list on pages 5 and 6.)

End-of-life and Parkinson's

Parkinson Society Canada and its regional education and support services team is developing a resource for end-of-life care for Parkinson's. We need your feedback to identify the issues faced by care partners and family members. For more information, e-mail general.info@parkinson.ca.

Parkinson's SuperWalk raises record $2 million for research

With the help of some amazing heroes, SuperWalk for Parkinson's has raised a record $2 million. SuperWalk is Parkinson Society Canada's (PSC) largest annual fundraiser and was held in more than 80 communities across Canada in September.

"With an ever increasing number of communities participating across Canada, we are confident that SuperWalk will continue to break records so we can support people living with Parkinson's and find a cure some day," says Joyce Gordon, President and CEO of PSC.

Enthusiastic walkers

A record 12,000 walkers turned out at walk sites across Canada to raise funds and awareness for a disease that affects more than 100,000 Canadians. Many communities, including Vancouver and the Maritimes, set new all-time records.

The Vancouver walk raised $190,000—over $45,000 more than last year. "This year's walk was our best ever. We worked very hard to achieve our goal, and we surpassed it by more than we could have expected," says Parkinson Society British Columbia's Executive Director Diane Robinson.

Dedicated volunteers

The Maritimes set a new record by bringing in $170,000, almost triple what was raised just three years ago. "There are many reasons why we continue to break records here in the Maritimes, but the most significant is the dedication of our volunteers," states Parkinson Society Maritimes Region Executive Director, Paul McNair.

Parkinson's is a progressive neurological disease. When cells in the brain that normally produce a chemical called "dopamine" die, symptoms of Parkinson's appear. The most common symptoms are tremor (shaking), slowness in movements, muscle stiffness, and problems with balance. Other symptoms that may also occur for some people include fatigue, difficulties with speech and writing, sleep disorders, depression and cognitive changes.

A significant event

For over 40 years, PSC has been the national voice of people living with Parkinson's disease. PSC has over 235 chapters and support groups. PSC's mission is to fund research, support services, advocacy and education. SuperWalk continues to be the organization's most significant fundraising event. For more information, visit www.parkinson.ca or call 1-800-565-3000.

One red wagon and one goal

When his grandfather was first diagnosed with Parkinson's disease, six-year-old Ryan Kay was aware of the challenges that his grandfather faced. Ryan was motivated to help in any way he could, so he made it a priority to participate in SuperWalk for Parkinson's. In 2006, Ryan held a garage sale, selling his toys and baked goods to raise money. With the help of family he raised $1,500, making him a SuperStar Walker and earning him a coveted "blue hat."

Ryan Kay's little red wagon is loaded to the max as he turns bottles into cash for Parkinson's disease.

Wanting to do better

His family was so proud of him, because he raised that money in an unselfish manner, but Ryan was not satisfied. He wanted to do better. Ryan's fundraising goal for 2007 was $2,500 and the SuperStarWalker Supreme "red hat" that came with it. Ryan thought long and hard how to reach his goal, and a family friend suggested raising money by collecting wine and beer bottles.

Overwhelming response

Ryan went to every house on his street and put a note in their mail boxes asking them to donate their bottles. The response was overwhelming! Every Monday, Ryan, his three-year-old brother and his mother would go out with his wagon to collect the beer bottles from people's door steps. Once the collection was complete, he would sort the bottles, take them to the beer store and receive cash for his efforts.

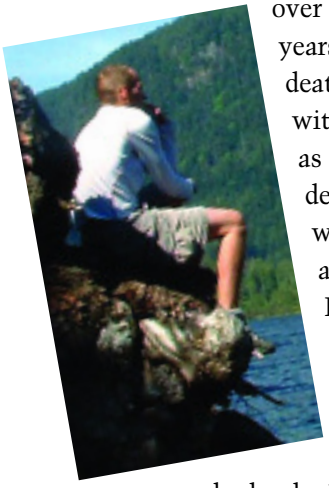
After a summer of hard work and determination, the new first grader raised $2,720, earning him both the coveted red hat and the respect of his grandfather.

A hero and an inspiration

By Graham Pipher

For most people, Parkinson's disease is just something they have heard about or seen on TV. My reality is different. I am one of thousands of Canadians who knew and loved someone with Parkinson's disease.

For most of my life, my grandpa fought a disease that slowly took over his life. For five years prior to his death, I watched with great sadness as his condition deteriorated. He went from the active grandpa I knew and loved so much to being unable to eat or move or to write or speak clearly. Yet his mind was as sharp as ever, and he still amazed me in a way only a grandfather could. He died in 1996 with Parkinson's disease when I was 13.



Many fond memories

I have fond memories of him, but very few are before this disease slowly stole pieces of him. One day we were setting up his new computer, and everything seemed to be fine except there was no sound. As we made every attempt to fix the problem, my grandfather was trying to tell me what he thought it was, but I couldn't make out what he was trying to say. Eventually I got him his typewriter, and he typed: "Is it muted?" I was so proud of him. It was a moment I will never forget.

When I think back to the special times I had with my grandfather, I also think about what could have been if he did not have Parkinson's—the memories that we could have had; the memories that were stolen from both of us.

When I was eight years old, it was hard for me to grasp what was going on. By the time I was old enough to appreciate the man for who he was and all he overcame, he was gone.

An idea is born

Last year I went on a 1,000 kilometre bike trip, cycling southern Vancouver Island and the Sunshine Coast. On one of the first few days of that trip, I met a friendly woman as I was having a drink of water while taking a break. She asked if my trip was dedicated to any cause. I replied no, but later I soon realized how great an idea a Parkinon's-related trip was.

That is why I decided to embark on a 17-day journey to bike 1,700 kilometres from Regina to Vancouver—it was my personal vendetta against Parkinson's disease. My motivation was my grandfather, and my goal was to raise money and awareness for a disease that has taken so much away from so many.

I began my journey on August 8, 2007. No one could deter me from my goal. I prepared myself mentally for the obstacles that I would face, obstacles that included torrential rains and wind, extreme heat and the unavailability of a hot shower when I needed it. Some days were tough, and I experienced nights where I really just wanted to give up. However, I drew inspiration from my grandfather who had to live with his limitations 24/7, and from the well-wishers who believed in me and my journey.

Everyday heroes

The definition of a hero is different for everyone: it could be the firefighter who rescues the cat in the tree, the person who gives up their seat on the bus to an elderly lady, or the seven-year-old girl who comforts her baby brother who skinned his knee.

Many people have called me a hero and an inspiration, but I did what I had to for my grandfather who is my hero. He was a man who never let Parkinson's control his life and continued to live in spite of it.

Taking action: Care partners as advocates *continued from page 7*

kind of support is available in your community (home care, disability, CPP, etc.) and whether you qualify.

9. Befriend another care partner. Having someone who understands your situation can be invaluable. Over 235 support groups operate coast-to-coast. To find the group best suited to you, simply contact your PSC regional office. (See pages 5 and 6.)

Walking for a cure

By Gina Collymore

During the early morning of July 27, before sunrise, and before most people get their first whiff of brewing coffee, 19-year-old Justin Smith set out on a 106-kilometre walk from Trenton, Ontario, to Kingston, Ontario, to raise awareness for Parkinson's disease. The motivation for his walk was simple: two members of his family were diagnosed with the disease.

Accompanied by two childhood friends, Justin set out on his journey in memory of his grandmother who died with Parkinson's a few short months ago. More recently, his aunt has been diagnosed with the disease.

The idea for the walk began while he was on a five-month high-school exchange program in China. While there, he walked along the Great Wall of China, and after hearing of his grandmother's death, decided that a walk was the best way to honour her memory while raising the profile of Parkinson's disease in Canada. Through the support of family members and with the help of Parkinson Society Canada, Smith began planning his walk when he returned to Canada in May.

"My grandmother suffered for over 10 years with Parkinson's, and my aunt was recently diagnosed," says Smith. "I am walking to help raise awareness among Canadians on just how prevalent this disease really is."

Smith arrived at the Hotel Dieu Hospital in Kingston after 11:00 p.m. and attracted the media attention of local newspapers the *Trentonian* and the Belleville *Intelligencer* as well as local radio station 98.3 FLY FM.

Both newspapers featured in-depth profiles of his walk, and his goal to educate Canadians about Parkinson's. Justin's perseverance also assisted Parkinson Society Canada in promoting SuperWalk during the month of September.

With support from family and friends, Justin met his goal to increase awareness about Parkinson's. Asked if he would do it again, he responds without hesitation, "In a heartbeat!"

Celebrity and Stanley Cup help raise funds for PD

The Stanley Cup made a brief appearance in the greater Toronto area this summer and lent a helping hand to the Durham Region chapter of Parkinson Society Canada (PSC).

On August 14, Shawn Thornton of the NHL championship team, Anaheim Ducks, paraded into town with Lord Stanley's cup to help raise funds for Parkinson's disease. Shawn's grandmother, Maureen, has Parkinson's, and his personal connection to the disease prompted him to do something for people like her.

Shawn hosted a special event at the Waltzing Weasel in his hometown of Oshawa, Ontario, where patrons had their photo taken with the cup. All proceeds went to PSC.

"My grandmother has PD and I wanted to do something special to bring awareness of the disease and to raise funds for Parkinson Society Canada. With the help of the amazing staff at the Waltzing Weasel and PSC, this event was a great success," says Shawn.

Maureen Mills hoists the Stanley Cup over her head with the help of her grandson, Shawn Thornton.

The impromptu fundraising event raised more than $3,000, money that will help fund vital research, education and support for people living with Parkinson's and their families.

MedicAlert speaks for you in an emergency

With Parkinson's influencing muscle control, your movement, speech or posture may be affected. But tremors or movement disorders may have other causes (stroke, head injury, hypoglycemia, Alzheimer's, alcohol intoxication, etc.) and it is important for emergency responders to know that in your case, they are caused by Parkinson's disease. You may have an implanted deep brain stimulator, a pacemaker-like device to help control tremors and chronic movement disorders, or you may be on medications known for their adverse effects and for interacting with other drugs or with certain foods.

MedicAlert identification immediately gives paramedics and other health professionals critical information about your medical condition.

If you have difficulty communicating—your voice may be very soft or start off strong but fade—or have difficulty pronouncing your words, being unable to quickly and accurately convey your needs during an emergency can put you at unnecessary risk.

Avoid the risk, and give yourself and your loved ones peace of mind by allowing MedicAlert to speak for you.

MedicAlert identification immediately gives paramedics and other health professionals critical information about your medical condition, medications and implants. A quick glance at the MedicAlert identification and a call to the MedicAlert 24-hour Emergency Hotline for detailed medical information saves time for confirming diagnosis and determining emergency treatment, thus giving a clear voice to anyone who is medically at risk.

For more information or to become a member, contact MedicAlert. Phone 1-866-679-2709 (Monday-Saturday, 9:00 a.m. to 5:00 p.m. EST) or visit www.medicalert.ca.

WEBSITE HIGHLIGHTS

Visit us on-line: www.parkinson.ca

Our website is being updated regularly! Please watch for more changes in the months ahead.

- **The PSC website** has been averaging 37,423 unique visits since its official launch in April 2007.
- **Click on the Legacy Fund** to find out how you can donate to PSC in honour of a loved one.
- **Visit Parkinson's in the News** for the latest stories and issues on Parkinson's disease.
- Learn what's happening in your region under the **In Your Community** banner to find out about events and updates.

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

Ask the Expert

Care partners often feel a responsibility to assist in maintaining the person's independence. We asked several health care professionals to provide helpful hints for the care partner.

From Speech-language Pathologist Bonnie Bereskin, MEd, SLP

- One of the most common areas needing support is voice. Many people with Parkinson's disease (PD) have an excessively quiet voice that becomes quieter over time. Another common difficulty is in controlling the rate of speaking. Some people with PD speak excessively fast.
- Have the person assessed by a speech-language pathologist experienced with Parkinson's.
- Set aside time (about four times per week) to practise the voice and speech exercises. These can be done during TV commercials or while preparing dinner.
- Use positive cues that are short and simple, such as "Speak louder." Have a few periods during the day when the expectation is to speak loudly and clearly.

From Clinical Pharmacist Chee Ying Chiu, BSc Pharm, RPH

- Learn all you can about Parkinson's and about the medications the person is taking. Why was the person prescribed a particular medication? How does it affect the Parkinson's symptom? What are the side effects? In Ontario, if the person is taking more than three medications, you and the person are eligible to have an appointment with your pharmacist for a free counselling session to learn about his or her medication regimen.
- Ensure the person takes medication on time by following a schedule. Consider using a "reminder" such as a beeper.
- Organize the medications in a weekly or daily pill box.
- Watch for side effects such as hallucination, dizziness, frequent falls, etc. Make note of these side effects so you can discuss them with the doctor or pharmacist.
- Watch for symptoms of depression, which can often be treated.
- Always keep an updated medication card in the person's wallet. The card should list all medications (with timing), any allergies and family doctor's phone number. See the PSC Medication Card at www.parkinson.ca.

From Physiotherapist Caroline El-Tantawy, pht

- Once the person with Parkinson's has been evaluated, the physiotherapist may ask the caregiver to help. Both the client and their caregiver are taught how to perform all the activities indicated, in a safe and appropriate manner.
- If exercises are needed, the caregiver can help the person with Parkinson's with an individualized home program of exercises.
- If there are problems with mobility, the caregiver may be asked to help the person with such activities as
  - getting in and out of bed, a car or a chair
  - walking or climbing stairs
- No matter which activity the caregiver is helping with, it should be done in a safe manner.

From Occupational Therapist Robert Campos, erg

- Occupational therapists (OTs) can evaluate how well the person with Parkinson's can manage activities of daily living such as banking, finances, cooking, driving, and the medication schedule. Each individual will be different and should be assessed by an OT.
- Caregivers can learn about adaptive equipment to make hygiene, dressing and grooming easier. They can also learn what tools and equipment may help with activities such as cleaning, meal preparation and driving.
- Ask for fall prevention guidelines.
- Help with exercises to strengthen fine motor movements and to maintain or improve hand function and flexibility.
- Learn how to safely assist with bed mobility, transfers, dressing, exercises.

From Social Worker Joan Buhr, BSW, RSW

- Continue to communicate your thoughts, feelings and needs to the person with Parkinson's.
- Allow the person living with Parkinson's disease to do what they can for him or herself.
- Continue to be a spouse—continue to pursue the shared interests and activities with the person with Parkinson's.
- Encourage the person with Parkinson's to continue with friendships and participation in hobbies and activities.
- Talk to the person about his or her caregiving needs and, when possible, talk about sharing the responsibilities with other family members, friends and professionals.
- Ask for help sooner, rather than later.

SuperWalk 2008

mark your calendar...

September 13/14

Watch for exciting new information about SuperWalk 2008 in the new year.

www.superwalk.com

SuperWalk for Parkinson's

Parkinson Society Canada
Société Parkinson Canada