Fall 2003 ▪ Volume 3 ▪ Issue 3
$4.50

ParkinsonPost

A quarterly magazine for Canadians living with Parkinson's

The healing power of writing

Author Pauline Neck and others find the 'write' stuff

Understanding cognitive changes

Community Outreach Programs 2003

PLUS: The latest Parkinson's research

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

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If you would like more information about Parkinson's and its management, you can discuss treatment options with your physician or call Bristol-Myers Squibb for medical information at **1-800-267-1088** extension 4302 or 2078.

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Pharmaceutical Group

Letter from Parkinson Society Canada

Parkinson Society Canada
Société Parkinson Canada

ON OUR COVER:
Writing helped Pauline Neck cope with her Parkinson's diagnosis, and eventually led her to become a published author.

Lending our support to the Parkinson's family

From the vision of a few people with Parkinson's, their families and neurologists, The Parkinson's Society of Alberta (PSA) began 30 years ago in Edmonton, soon joined by its partner, The Parkinson's Society of Southern Alberta (PSSA), in Calgary, to form a network of information and support services to reach across Alberta. That network now includes support groups, including young onset, Parkinson's Plus syndromes and caregiver groups, counselling, monthly newsletters, toll-free information and support lines, print materials, resource libraries and educational presentations. Specialized exercise programs are held in several major centres. PSSA has a physiotherapist providing individual advice and outreach.

PSSA has partnered with Calgary Health Services Speech-Language Department to provide speech improvement classes. In Edmonton, a partnership with University of Alberta (Rehab Medicine-Speech) provides an innovative 'Speech Education in Action' program.

In addition, PSSA has established outreach offices in Lethbridge and Red Deer. We work closely with the two Movement Disorder Clinics in the province. 'Flying doctor' neurology clinics are provided in Lethbridge and Medicine Hat several times a year.

Both Societies hold a variety of fundraising events during the year, including six SuperWalks across the province in September, which help us to increase awareness and raise crucial funds to help meet the needs of our large Parkinson's population. We are also committed to supporting research in Alberta and nationally through the PSC research program.

New preliminary data from Alberta Health and Wellness is sobering: Approximately 17,000 Albertans have Parkinson's, more than double the number 10 years ago. The implications for provision of information, education and support services now and in the future are substantial. Together, we are working to meet the anticipated needs of Albertans living with Parkinson's, their caregivers and families.

We're proud of our accomplishments and would like to recognize the dedicated, innovative and caring staff in our respective Societies, and the many wonderful volunteers and Board members who keep things moving forward. We commend and encourage all the individuals and families who cope with Parkinson's daily – they are the inspiration behind all that we do. As David Simmonds, Past Chair, Parkinson Society Canada wrote in his song about living with Parkinson's, "I Won't" (give up).

We won't either!

Mary Chibuk,
Executive Director,
The Parkinson's Society
of Alberta
Edmonton, AB

Judy Axelson,
Executive Director
The Parkinson's Society
of Southern Alberta
Calgary, AB

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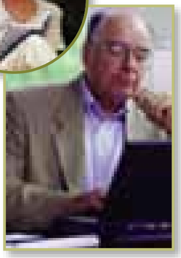
FEATURES



COLUMNS

ParkinsonPost
A quarterly magazine for Canadians living with Parkinson's

Parkinson Post Vol. 3, Issue 3, Fall 2003

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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

Regional Partners/Roundup

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

- Annual fresh tulip sale was held April 23 in Vancouver and Kamloops.
- For the fourth year in a row we partnered with Ballet BC for a most successful Annual Golf Tournament.
- Spring regional conferences took place in Abbotsford, Nanaimo, Prince George, Vernon, Kamloops, Sechelt and Nelson.

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

- Opthalmologist Dr. Margaret Kilshaw's presentation was well attended.
- A $10,000 media award has been received to help us publicize upcoming services and events.
- Expansion of fundraising events and the planned giving program are underway.
- Fall plans include education events on nutrition and a research and treatment update with Dr. Jon Stoessl, Director of the Pacific Parkinson's Research Center, University of British Columbia.

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

- Held AGM on April 27 with 24th annual Annie Wylie Memorial Lecture presented by Dr. Wayne Martin on 'Recent developments in the treatments of Parkinson's disease.'
- SuperWalks in Grande Prairie on September 21 and Edmonton on September 27.
- Four beautiful quilts donated by members for a raffle in recognition of our 30th Anniversary.
- New support group started in Stony Plain/Spruce Grove.
- Third Annual Speech Educational Program scheduled for Fall 2003.
- Planning underway for June 2004 Parkinson Golf Classic.

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

- Held three sold-out 'Spring into Wellness' June workshops in Calgary, covering meditation, good nutrition, and family and social relationships.
- Parkinson's display at Brain Awareness Day at Foothills Hospital. Staff and volunteers on hand.
- Parkinson's presentation at Assembly of Health Care Providers to Seniors.
- Held 12th Annual Parkinson's Tulip Tournament on July 3rd at Cottonwood Golf Club with 144 golfers.
- Lethbridge Chapter raised over $3,000 through Hot Wing Eating Challenge to support 'satellite' movement disorders clinic.
- Various April awareness activities were held in Medicine Hat, Red Deer, Lethbridge and Calgary.

Saskatchewan Parkinson's Disease Foundation
3502 Taylor St. E., Suite 108B
Saskatoon, SK S7H 5H9
Ph: (306) 477-4242
Fax: (306) 477-4243

- Regina Curling Classic for Parkinson's Research raised just over $50,000.
- PW Golf Classic for Parkinson's Research is being held August 27 in Avonlea.
- Tulip bulbs arrive early September.
- SuperWalk 2003: September 21. Contact Hilda at 306-934-1095.
- Saskatchewan Parkinson's Awareness Week is September 21-27.
- Dr. Jon Stoessl from Vancouver will be guest speaker in Regina on September 24, and in Saskatoon on September 25.

Parkinson Society Manitoba
171 Donald Street, Suite 302
Winnipeg, MB R3C 1M4
Ph: (204) 786-2637
Toll-Free: (866) 999-5558
Fax: (204) 975-3027

- Please note our new address! We have more space for meetings, volunteers and information.
- We now have two full-time people

Continued on page 6

Parkinson Society Canada
Société Parkinson Canada

on staff in the regional office.

- The annual Golf Tournament was a success. The event was well attended and the weather was perfect for a day on the links.

PSC Central and 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

- On June 10, the sixth annual Granite Ridge Charity Classic raised approximately $15,000.
- Derek Curwen and his team had another successful soccer tournament on June 15, raising $17,630 for research.
- June 26 was the 14th annual ‘Pitch In’ for Parkinson’s. This baseball extravaganza raised $8,000 with Mary Martin throwing out the first pitch.
- Tulip bulbs will be available the first week in September (10 bulbs for $5.00).
- The development of a new Toronto Chapter is well underway with a newly-elected Executive Committee.

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

- Launched Parkinson Legacy Program resulting in a $15,000 annuity for local services. Thanks to Roger Ali for his help!
- Successful April Awareness campaign included: media coverage, special presentations, workshops, mall displays, Tea’s for Two, Casual Days, Cut-A-Thon, Tulip Benefit, Tulip sale and raffle. Thanks to staff and volunteers.
- Introduced new initiatives, including a Cut-A-Thon in Windsor and a new Chatham SuperWalk Committee.
- Attracted 240 people to our popular regional conference.

Parkinson Society Ottawa

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

- Began a celebration of our 25th anniversary at our AGM on June 16th. ‘25 weeks for 25 years’ includes a variety of events. Details are on our website!
- Held second annual Dr. J. David Grimes Memorial Golf Tournament June 11, raising over $30,000.
- Lynn Hunt, occupational therapist and Certified Driver Rehabilitation Specialist, addressed ‘Safe driving and Parkinson’s, the evaluation process’ at the annual AGM/Strawberry Social. Call us for a synopsis of her speech.

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

- Created public service ads and distributed them to Quebec print media in April.
- Expanded the Scientific Board to a total of 16 neurologists. They will provide written information and tips for PSQ’s newsletter and website.
- Created three new support groups: Two in the Montreal area and one in Rivière-du-Loup.
- PSQ welcomes Johanne Langlois as our New Director of Support Services, Information and Continued Education.
- Raised over $12,000 through the sale of Dream Home raffle tickets.

PSC Maritime Region

5991 Spring Garden Road, Suite 290
Halifax, NS B3H 1Y6
Ph: (902) 422-3656
Toll Free (NS, NB & PEI):
(800) 663-2468
Fax: (902) 422-3797
www.parkinsonsocietymaritimes.ca

- Fourteen SuperWalks are being hosted throughout the Maritimes with tai chi demonstrations and local entertainment onsite.
- Hosted second annual New Brunswick Parkinson Picnic in Saint John on June 21.
- Golfing for Parkinson’s moved to its new venue at the Truro Golf and Country Club.
- Welcome to our three summer students – Stephanie Grace, Stephanie LeBlanc and Stephen Boudreau – hired to assist the region with SuperWalk and the Maritime Parkinson Clinic.
- Plans underway for a Maritime Region Early Onset Forum.

Parkinson Society Newfoundland and Labrador

The Ashley Building
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

- Held a very successful Regional Conference in May with over 100 registrants and National Board Chair Meredith Saunderson.
- Three SuperWalks planned for St. John’s, Carbonear and Grand Falls-Windsor. Also, Norma Dutot is organizing a small walk of family and friends in Stephenville Crossing.
- Parkinson Society NL will be highlighted in the newsletter for the provincial electric company, Newfoundland Power, in September.
- Almost 20,000 tulip bulbs will be sold in the Province again this Fall.

Parkinson Society Canada
Société Parkinson Canada

The Advocate

Issues of interest to people with Parkinson's

New statistics now available

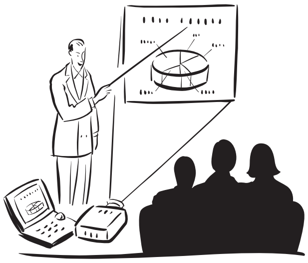
According to recently released information by Health Canada, the total cost of Parkinson's disease to the Canadian economy is $558.1 million per year. That figure includes direct costs (like hospital care, drugs, physician care and research) and indirect costs (lost production due to disability and premature death). It is estimated that 56.3% of Canadians with Parkinson's are men and 43.4% are women. This is the first time that these economic statistics are available about Parkinson's. For more information or to order the *Parkinson's Disease: Social and Economic Impact report*, see Resources on page 23.

PSC does not canvass door-to-door

Just a reminder that Parkinson Society Canada is not affiliated in any way with Parkinson's Support and Research Society (PSRS). We have received many calls and complaints about PSRS and its activities. Individuals in various cities and towns across Canada have contacted Parkinson Society Canada to advise that PSRS has solicited donations for Parkinson's through door-to-door canvassers, telemarketers and people collecting donations outside retail establishments. Parkinson Society Canada does not engage in any of these fundraising techniques.

If you'd like to donate to PSC, please call **1-800-565-3000**, or any of the offices on pages 5 and 6.

Learn about current research and treatments



Plan now to attend the lecture on the latest in Parkinson's research and treatments by world-renowned researcher Dr. Yoshikuni Mizuno from Tokyo, Japan. The lecture is open to the public and will be held as part of Parkinson Society Canada's Annual General Meeting from 9:00 a.m. to 12:30 p.m. on Sunday, November 16, 2003 at the Crown Plaza Montreal Centre Hotel. For more information, please contact Rose Pillitteri at **1-800-565-3000, ext. 232** or **rose.pillitteri@parkinson.ca**.

Reintroduced Government Act may help Parkinson's research

Stay tuned for the *Assisted Human Reproduction Act* to be re-introduced in the House of Commons later this fall. There are some important clauses in the proposed bill that will significantly enhance opportunities for stem cell research into Parkinson's and into many other diseases and health conditions. Watch our website – **www.parkinson.ca** – for details on how you can get involved.

Ease the Burden; Find a Cure

Health Tips

Q Thinking about getting a flu shot?

Are you deciding on whether or not to get a flu shot this fall? People with Parkinson's often see their symptoms worsen for the duration of the infection and take longer to recover.

Health Canada's informative website can help you make your decision. Here's an excerpt:

Influenza (or flu) is a common illness affecting millions of Canadians each year. A flu vaccine administered every year can help prevent the infection or reduce the severity of the illness.

Influenza or 'the flu' is a viral infection affecting between one in four and one in 10 Canadians each year. Between 500 and 1,500 Canadians, mostly seniors, die from influenza-related complications every year. The symptoms typically start with a headache, chills and cough, and are rapidly followed by fever, loss of appetite, muscle aches and fatigue, runny nose, sneezing, watery eyes and throat irritation. Nausea, vomiting and diarrhea may also occur, especially in children.

After vaccination, your immune system will produce antibodies against the virus strains in the vaccine. When you are exposed to the flu virus, the antibodies circulating in your body will help to either eliminate the virus or destroy virus infected cells. This will prevent the infection or reduce the severity of the flu.

Flu vaccinations are especially important for:

- People with chronic heart and lung disease, diabetes, anemia, cancer, immune suppression, HIV or kidney disease.
- Anyone living in a nursing home or chronic care facility.
- People 65 years of age and older.

For more information, visit **www.hc-sc.gc.ca/english/iyh/medical/flu_shots.html**

UNDERSTANDING COGNITIVE CHANGES

By Ian Corks

IS IT Old Age OR IS IT Parkinson's?

"Now what was I meant to pick up at the store, again? And where did I leave my keys anyway?"

Most of us have experienced this sort of memory lapse. As we age, we begin to notice subtle changes in memory – usually having trouble remembering things that happened in the last few hours or minutes, while events that took place 25 years ago are clear in our minds!

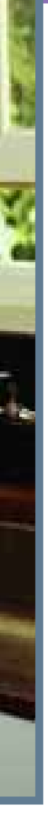
People with Parkinson's disease naturally experience these challenges, but often report that they seem more severe or happen more frequently than 'normal.'

The fact is that, while the primary symptoms of Parkinson's centre around movement, a variety of other problems can occur as well; specifically, changes in *cognition* – a person's ability to think, reason and remember.

"To use a computing analogy, the speed of your central processing system is slowed down," explains Dr. Michael Trew, a Calgary-based psychiatrist who has studied the link between physical and psychological problems in Parkinson's and other conditions. "It doesn't mean the

person can't process information, it's just that they do it more slowly."

In Parkinson's disease, subtle cognitive changes can appear at any stage, but dementia is more likely to be experienced by individuals who have had the disease for many years, according to Dr. Anthony E. Lang, Director of the Movement Disorders Clinic at Toronto Western Hospital.



While he points out that many people with Parkinson's disease will not notice any significant changes in their ability to think clearly, process information and make decisions, Dr. Lang emphasizes that the possibility is real. "Studies have shown that many people with Parkinson's experience trouble with executive functions." Slowed executive function refers to the inability to process new information quickly, particularly when trying to carry out a physical task at the same time or in stressful circumstances (crowds, strangers etc.) "Very often these are barely perceptible and don't disrupt a person's life. In some cases, however, these impairments can progress."

Common cognitive changes

The most common forms of cognitive impairment include:

Thought processing: Bradyphrenia, or a slowing of the ability to think, can occur. Just as it takes longer to get up from a chair, more time may be needed to respond quickly to even quite simple questions or to participate in complex conversations with other people. A person with Parkinson's may be so slow to respond or to describe things that the listener may not realize what they are saying or that it relates to an earlier part of the conversation.

Abstract reasoning: The performance of complex activities – especially those that require analysis, prioritizing and organization – become more difficult. This can affect a variety of functions, ranging from mathematical calculations to taking the initiative and even understanding jokes.

Memory: Short-term memory may suffer. Such tasks as remembering names, birthdays and shopping lists can be the most difficult. Studies suggest that a person with Parkinson's can recognize and store information, but that problems occur when they are asked to recall it.

Language: Significant cognitive-related language changes are relatively uncommon, however, some subtle ones may occur. For example, speech often becomes slower and spontaneous speech is reduced. People with PD may not initiate conversations as often as they used to. It is important not to misinterpret this as apathy.

Visual orientation: People may occasionally find it difficult to read a map, comprehend graphic diagrams or follow illustrated assembly instructions.

Attention and concentration: Individuals may become more easily distracted, losing their chain of thought. Tasks that require concentration, like reading and comprehending difficult instructions, or filling out complex forms can be problematic. Multi-tasking can also be very difficult.

Naturally, many things on this list are common problems of aging that all of us may experience, Parkinson's or not.

Medication side effects

In some cases, cognitive changes may actually be caused by the Parkinson's medication the person is taking. "Many people can be managed on levels of medications that will never cause any problems at all," notes Susan Calne of the Pacific Parkinson's Research Centre. "However some will experience confusion, hallucinations or even psychosis under certain circumstances."

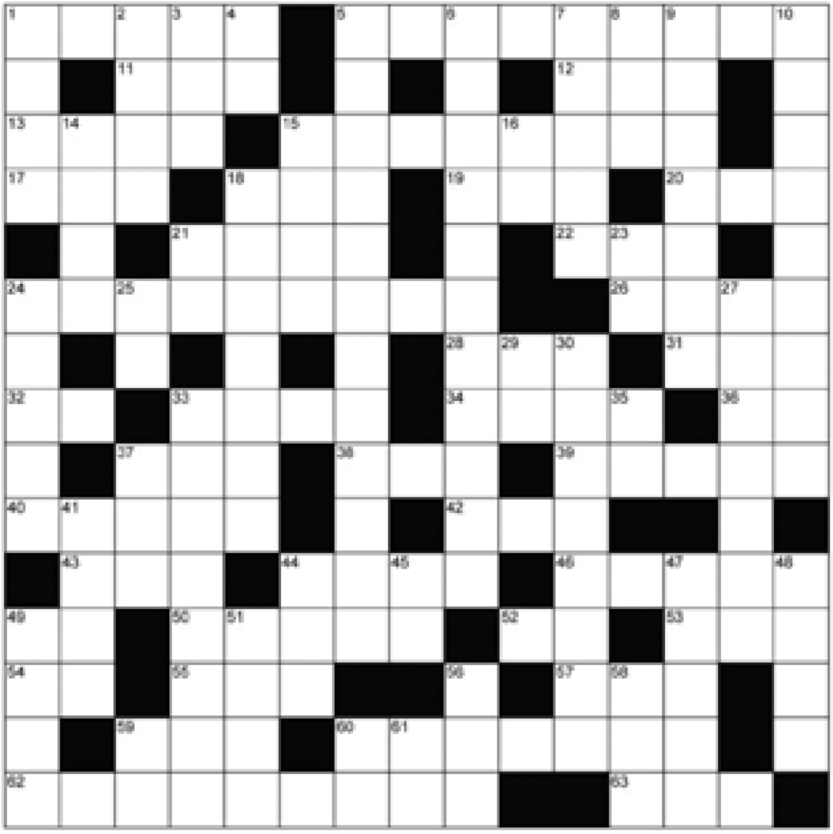
As Susan explains, the hallucinations are usually mild, such as seeing small items, like animals or children. Often they don't bother the person at all, but can be worrying to the family. Some people learn to live with these, especially if the medication is working well. She laughingly tells the story of one patient whose claims of seeing a mouse in her room were dismissed as hallucinations by family members, until she walked into the kitchen with the mouse in a trap.

If the hallucinations are worrisome or develop into frank psychosis, the medications may need to be reviewed. However, other factors first need to be ruled out. "People who are doing well on their medications can suddenly experience psychotic symptoms that are triggered by independent physical or other factors," explains Susan. She offers this checklist of things to watch for:

○ Incorrect use of antiparkinson drugs over the last few days
○ Side effects from, or interactions with, other prescriptions, over-the-counter medications or supplements.
○ Recent general anesthesia for surgery.
○ Recent fever, with or without a known infection (e.g., chest, bladder, abscess, etc).
○ Recent travel involving time and dosing changes.
○ Dehydration.
○ Constipation.

If these can be excluded, the doctor may need to adjust the dose and/or type of medication.

Autumn reflections by Myles Mellor



Answers on page 22

Across

1 Autumn colour
5 White and black mix overhead?
11 Tub
12 _____ Deighton: spy writer
13 Pitter patter sound maker
15 Stylish clothes
17 Sunset colour
18 Agreement indication
19 Cereal
20 Conditions
21 Chic women's clothes supplier
22 Clairvoyance
24 Chill makers
26 Lizard monster
28 Website name
31 Caulk maker
32 Approve
33 Put on
34 Medieval honey drink
36 Compass point
37 Battery type
38 Point
39 Romantic poet
40 Garment
42 Just before
43 It cost an _____ and a leg
44 Tragic king
46 Neck warmer
49 Spanish agreement
50 Large meal
52 Two
53 African antelope
54 Serpico's Pacino
55 Scamp
57 Spanish day
59 Spoon bender
60 Produce celebration
62 Leaf losers
63 French sea

Down

1 Cold expression!
2 Roman writer
3 Pale
4 Nortel trading symbol
5 Autumn sights
6 Autumn starts here
7 Grey hue
8 Drink container
9 Jejune
10 Ocean paintings
14 Aviation prefix
15 Mongolian desert
16 Royal Academy
18 Autumn need?
21 Bank draft
23 Solicitor General
24 Autumn weather action
25 The French...
27 Darkness penetrator
29 Concerning
30 Romantic poet setting
33 Place to go to warm up
35 Fleur _____ Lys
37 Atmosphere
41 Call a cab
44 _____ top
45 Near
47 Precious stone
48 Autumn night woman's clothes
49 Swedish car
51 Send out
56 Stumbling expressions
58 Philosophy
59 _____ of the Chaldees
60 Guy
61 Mysteries here on TV?

What to do

But if you do suspect that these problems may be due to more than just age, what should you do? To a great extent, that depends on the severity. As Susan Calne, CM, RN, Coordinator of the Pacific Parkinson's Research Centre in Vancouver, notes, "It's one thing to forget where you put your keys, but when you forget what the keys are for, that's another story."

If the cognitive impairments are serious and worrisome (either for the person with Parkinson's or those who care for them), a doctor should be consulted. There are two important things to consider in these cases.

The first is that the changes may not be caused by Parkinson's disease itself. Cognitive impairments can result from treatable conditions such as a vitamin B12 deficiency, hypothyroidism or stroke. They can also be linked to Parkinson's drugs (see *Medication side effects*). Secondly, there is a chance that the impairments may be early signs of dementia (see *Parkinson's and dementia*).

Even if the cognitive changes are not severe, consultation with a health professional is a good idea. There are a number of useful strategies for helping families to cope.

"The best overall approach is to use patience, understanding and a sense of humour," claims Dr. Trew. "It's frustrating for the person and often irritating for the family. But getting upset is only going to make things worse. Stress can aggravate the symptoms."

Coping strategies

Dr. Trew offers the following tips for coping with the more common cognitive changes, especially slowed thinking, memory loss and lack of concentration.

Be aware of the situation: Don't misinterpret what's going on as intentional behaviour, a lack of interest or even stubbornness.

Pace yourself: If you are the one experiencing the problem, don't rush. Don't try to accomplish too much, too fast. Take the time you need to process the information.

Don't force information: Whether you are trying to give or receive instructions, remember that you can't force understanding. Be patient.

Avoid information overload: Don't give the person with Parkinson's too much information at once, and don't expect them to multi-task.

Brain boosters

- Read and discuss articles in the newspaper or magazines.
- Do crossword and word search puzzles (see page 10).
- Take up a hobby that requires some study, like bird watching.
- Make memory books for your children and grandchildren with old photos and keepsakes.
- Exercise daily, including outside activity, such as short walks in the neighborhood.
- Plan a small job or household chore to do everyday.

If you are having the problem, don't be afraid to point out that you are being overloaded and ask people to slow down.

Avoid 'busy' situations: Some people are confused by too much sensory input. For example, when a lot of things are going on or many people are speaking at once.

Write things down: You may not be able to rely on verbal instructions anymore. Keep a notebook handy and jot things down.

Make lists: A daily to-do list or a list of items to pick up from the store can help make life easier. And the lists don't have to be too detailed. Sometimes a hint will do. Studies have shown that people with Parkinson's recall information much better when given clues.

Use memory aids and 'brain boosters': These have been shown to help people remember and think more clearly. Some samples are provided in this article.

Finally, learn to accept things the way they are. Don't worry about what other people think and become frustrated. As Dr. Trew concludes, "It's not as if the person has suddenly become stupid or doesn't know how to think any more. It's just a new way or style of thinking that we can all learn to live with."

Memory aids

- Keep a detailed diary of daily events and review it every day.
- Keep a calendar of appointments and engagements and review it daily.
- Keep paper and pen handy to write down information to be remembered.
- Organize lists in categories to stimulate memories.
- Review upcoming activities for the day every morning.

Parkinson's and dementia

More significant changes in memory, reasoning ability, language and attention may develop over a long period of time in people with Parkinson's. It is not possible to determine who will or won't develop dementia before it begins. Studies so far do not show that dementia is an inevitable part of Parkinson's; however, they do show that there is a higher incidence of dementia than in the general population. If an individual develops dementia, he/she will need increased care and supervision. Clinical trials using a number of newer medications have shown promise in treating Parkinson's-related dementia.

Research Report

A look at current Parkinson's research arou

Research Editor: Dr. John Wherrett

Weight loss and Parkinson's

Many people with Parkinson's disease tend to be thin – a fact that has raised concerns about their caloric intake and nutrition – even to the point of speculation that increased calories consumed may be linked to Parkinson's.

A recently published Harvard-led study, which began in the 1970s and looked at the status, weight and energy intake of a large number of health professionals, has provided some insight into weight and caloric intake in individuals developing Parkinson's disease.

Among 165,000 individuals followed-up every two years, from 1988 to 2000, 468 persons with Parkinson's were identified. Weight and caloric intake were looked at pre-diagnosis and every two years (from 1988 to 2000) in 96 men and 78 women who developed Parkinson's during the study. The study subjects lost an average of 8.5 lbs before diagnosis (most of it in the four years before the diagnosis was made). Weight loss continued after diagnosis, when the average loss was 7.7 lbs in eight years.

The question of whether this could be accounted for by decreased caloric intake or by increased energy expenditure was addressed through analysis of the participant's dietary questionnaires. Data showed actually that increased caloric intake began at about the same time as weight began to decrease, and continued to increase with weight loss. Increased energy expenditure has been demonstrated in people with Parkinson's and has been attributed to excess muscle activity and dyskinesias. In addition, improvement in the symptoms resulting from surgical treatment has been associated with weight gain.

While these observations might suggest that increased caloric intake might be linked to Parkinson's disease, it is more plausible that the decrease in weight and increase in energy expenditure are consequences rather than cause of the condition.

Reference: Annals of Neurology

A perplexing form of Parkinson's

A recent review has listed 54 different conditions in which the syndrome of parkinsonism occurs, including an important and perplexing form of Parkinson's – *dementia with Lewy bodies*.

This form of Parkinson's is now considered to be the second most common form of dementia after Alzheimer's and could also be one of the most common forms of Parkinson's. Unfortunately, the clinical diagnosis of dementia with Lewy bodies is surprisingly inaccurate. In fact, about 50% of patients are incorrectly diagnosed, possibly because of the prominence of dementia symptoms. Even with a correct diagnosis, there is debate about treatment of the parkinsonian symptoms because it is generally thought that it will aggravate the other symptoms, specifically hallucinations and cognitive fluctuations.

A recent study at a California memory clinic looked at 98 patients who were found to have the findings of dementia with Lewy bodies at postmortem examination. An important finding was that virtually all of the patients had the changes of Alzheimer's disease. In those in which these changes were severe enough to diagnose both dementia with Lewy bodies and Alzheimer's disease, the clinical diagnosis of dementia with Lewy bodies was much less likely to be made. An interesting possibility arising from this and earlier studies is that the cellular changes in Alzheimer's disease could promote or even cause those occurring in Parkinson's disease.

Reference: Journal of Neurology, Neurology

Improving levodopa therapy

Efforts are continuing to improve response to treatment with levodopa, still the most potent Parkinson's therapy available.

These efforts include attempts to prolong the treatment response after a dose to prevent early wearing off, and to delay or ameliorate side effects such as dyskinesias, the excessive movements that commonly develop with prolonged treatment.

French and German researchers have just reported experiments in which they used monkeys in which Parkinson's was induced (by use of MPTP, a synthetic narcotic analogue). Dopamine derived from levodopa is a neurotransmitter and like all neurotransmitters has been found to bind to several receptors on nerve cells. In these experiments, the investigators

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.

nd the world

found that the development of dyskinesias following treatment of the affected monkeys with levodopa was associated with an increase in the number of one class of dopamine receptors, designated D_3. When they tried drugs that blocked the effect of levodopa on the D_3 receptor, the Parkinson symptoms returned. However, when they tried drugs with a mild stimulating effect on the receptor called partial agonists, the beneficial effect of levodopa was retained and the dyskinesias were greatly reduced.

These studies may be useful in the potential development of drugs that normalize D_3 receptor function and correct the dyskinesias resulting from prolonged levodopa therapy.

Reference: Nature Medicine

Focus on…

Dr. Jackalina Van Kampen

Parkinson Society Canada Research Fellowship

It was a very close family connection that first sparked Jackalina Van Kampen's interest in Parkinson's disease. "My father has had Parkinson's for more than 20 years now," explains Dr. Van Kampen, a native of Charlottetown, PEI. "So naturally it was a subject close to my heart. I learned more about the disease during my undergraduate work at McGill and decided to focus on research into various aspects of Parkinson's."

After McGill, Dr. Van Kampen earned her MSc and PhD in Neuroscience doing research with Dr. Jon Stoessl, first at the University of Western Ontario and subsequently at the University of British Columbia. Then in 2000, the opportunity came to work with Dr. Theo Hagg and Harold Robertson at Dalhousie University. "It was a great chance to get back to my Maritime roots," Dr. Van Kampen notes. "Plus my Dad wasn't doing that well at the time and it let me be closer to home."

Dr. Van Kampen's current research at Dalhousie, funded by PSC, is looking at ways of 'activating' endogenous stem cells in the brain into viable dopaminergic neurons. "In essence, instead of implanting embryonic stem cells into the brain, we are trying to activate stem cells that are already there," she explains. She is also involved in studying the potential role of ginseng as a 'neuroprotector' in some forms of Parkinson's disease.

While these studies are currently in rodent models, the results are promising and she hopes to advance them to the next stage. "In the ginseng studies, we are hoping to organize clinical trials with a group in Calgary and are discussing doing some advanced work with researchers at Yale," she notes.

And things have also gone well on her family side. "My Dad underwent deep brain stimulation surgery and the results were amazing," Dr. Van Kampen recounts. "Almost immediately, for the first time in nearly 20 years he was without tremors. I felt great, even better than I did when I graduated."

Occupational link to Parkinson's?

Studies are examining the link between environmental factors, including occupations, and the occurrence of Parkinson's in various patient populations.

Although genetic factors may influence susceptibility to develop Parkinson's, it is generally agreed that environmental exposures must play an important role in the majority of patients. At the recent meeting of the American Academy of Neurology, seven papers were presented on the epidemiology of Parkinson's disease. These studies looked at specific associations for the development of Parkinson's, including: occupation, head injury (increased risk), alcohol consumption (did not affect risk), consumption of tropical fruit but not vitamin C (increased risk), use of anti-inflammatory drugs (decreases risk), smoking (decreases risk as previously shown) and coffee (did not affect risk).

Of particular interest was the study of occupation. This was conducted in a large group of twins, one of whom in each set had Parkinson's disease. In the pairs of twins who shared identical genetics (identical or monozygotic twins), there was a strong association of Parkinson's disease with the occupations of teacher and health care worker. This association was first detected in a study directed by Dr. Joseph Tsui from the Movement Disorders Clinic at the University of British Columbia reported in 1999. It has been suggested that these occupations could be at increased risk because of excessive exposure to viral infections. The possibility that patients with these occupations are more likely to be seen in movement disorder clinics, than individuals with other occupations will be examined in future studies.

Reference: Neurology

Renowned Japanese scientist receives inaugural Donald Calne Lectureship

Dr. Yoshikuni Mizuno of Japan has been awarded the first annual Donald Calne Lectureship by Parkinson Society Canada (PSC).

Dr. Mizuno is head of the Department of Neurology at Juntendo University Medical School in Tokyo, Japan. One of the foremost clinical experts in the world on Parkinson's disease, his department spearheaded the discovery of a genetic abnormality in a variant of Parkinson's disease. Dr. Mizuno's lab also identified the function of the abnormal gene, thus providing major insight into gene mechanisms, impacting not only genetics work in Parkinson's disease but also in other neuro-degenerative disorders.

Dr. Mizuno will deliver a lecture to the Parkinson community at the Annual General Meeting of PSC in Montreal on Sunday, November 16, 2003 (See page 7 for details).

Research Report

Research Program Awards for 2003–2005 cycle

Granting period July 1, 2003 – June 30, 2005.

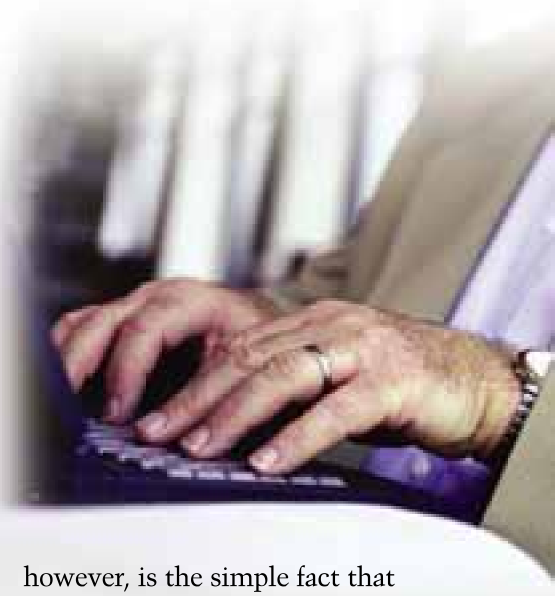
Parkinson Society Canada (PSC) is pleased to announce the recipients of its 2003–2005 Funding Awards for the National Research Program.

This is the first cycle of our newly revitalized research program, developed after extensive consultation with scientists and laypersons from across the country. PSC is refocusing its investment with two new grant categories, the Pilot Project and New Investigator Grants, which aim to encourage development of new ideas and emerging researchers. This, we believe, will enhance our support for the best Parkinson's research and researchers across Canada.

Researcher	Project name	Institution	Total award over two years
Pilot Project Grants (one year grant)			
Friedman Grant David Park	Pathways by which DJ-1, a gene linked to familial PD, mediate dopaminergic loss.	Ottawa Hospital	$45,000
Michael Rathbone and Eva Werstiuk	Protection against MPP+-induced apoptosis by non-adenine based purines.	McMaster University	$22,000
Anatol Feldman	Virtual reality for gait initiation and control in Parkinson patients.	University of Montreal	$45,000
Lennard P. Niles	Neuroprotection by neural stem cells and Melatonin in a model of Parkinson's disease.	McMaster University	$45,000
New Investigator Grant			
Christian Duval	Tri-dimensional Kinematic characterization of drug-induced dyskinesia: A study of young-onset versus elderly patients.	Brock University	$49,800
Francesca Cicchetti	Anti-inflammatory drug treatment in animal models of Parkinson's disease: A novel therapeutic approach.	Laval University	$80,000
Operating Grants			
Anurag Tandon	Organization and disassembly of alpha-synuclein complexes in human cells.	Centre for Research in Neurodegenerative Diseases, University of Toronto	$100,000
Daniel Lévesque, Drs. Rouillard, Bedard and DiPaolo	The transcription factors Nur77 and Retinoid X Receptor (RXR): Putative new players involved in motor dysfunctions associated with Parkinson's disease and L-DOPA therapy.	Neuroscience Research Center, Laval University	$100,000
David Grimes	Parkinson's genetics in a Canadian cohort.	Ottawa Hospital	$100,000

Fellow	Field of training	Institution	Total award over two years
Basic Research Fellowships			
Jeff Biernaskie	Therapeutic potential of skin-derived precursor cells for cell replacement in Parkinson's disease.	Toronto Hospital for Sick Children	$90,000
Ratan Bhardwaj	The role of endogenous neural stem cells in mammalian adult CNS neurogenesis towards a potential cure for Parkinson's disease.	Karolinska Institute, Sweden	$90,000
Trent Anderson	Cellular mechanisms of deep brain stimulation for Parkinson's disease.	University of Calgary	$90,000
Clinical Research Fellowship			
Connie Marras	Parkinson's disease prognosis.	University of Toronto	$90,000
Clinical Movement Disorders Fellowship (one year fellowship)			
Boehringer Ingelheim Clinical Movement Disorders Fellowship Cindy Zadikoff	Clinical studies in Parkinson's disease	University of Toronto	$45,000
		Total funds awarded	**$991,800**

For full descriptions of these and other current PSC funded research awards, please visit **www.parkinson.ca/research**.



THE WRITE STUFF:

The healing POWER of WRITING

By Ian Corks

There are many forms of writing and there are many styles, from keeping a diary to writing stories, songs or poetry. We have different ways of expressing ourselves, just as we have varied reasons for doing so.

But writing can offer more than just a form of expression. It can be therapeutic and can help people come to grips with the issues in their lives, including the challenges of Parkinson's disease.

Help yourself to personal growth

Writing therapy simply involves transferring thoughts, feelings and emotions into words – whether it is by taking pen to paper or working at a computer keyboard. It is based on the theory that releasing your deepest feelings, fears, concerns, and/or problems by recording them can help relieve stress, promote health and well-being, and lead to personal growth.

By encouraging people to put difficult emotions and memories into words, writing therapy provides therapeutic release. For this reason, it has been shown to be particularly beneficial for those who tend to internalize their feelings. After a writing session, many people say they feel calmer and more in control.

For some, writing is a form of meditation that helps settle the mind. For others it is a de-stressor, helping to release tension. It can be a secret 'confessor' that lets us reveal our secret thoughts.

Writing can be creative, cathartic and curative. No wonder that so many psychiatrists, therapists and counselors recommend it.

Your way to physical and emotional health

And there is a strong scientific basis to support writing therapy. It has been shown to be beneficial in combating low self-esteem, depression and stress-related ailments. It has been used effectively to help people with a number of physical and emotional problems, including chronic medical conditions, like Parkinson's disease. It has also been employed to help people cope with traumatic events. For example, poetry therapy was used by the students of Columbine High School following the 1999 shooting tragedy.

Beyond the scientific benefits, however, is the simple fact that writing can be fun. While it may not be for everyone, many people, including those with Parkinson's, have gained so much from it. Just read the accompanying stories, and you'll get an idea of the power of writing.

So, if the idea of writing appeals to you, remember these rules.

1) Anyone can write.
2) When you're writing for yourself, there's no such thing as bad writing.
3) Choose the style and format that suits you. Consider keeping a journal where you express your emotions and what is on your mind. Write personal letters to people real or imaginary, living or dead, etc.
4) Write when you feel like it – don't make it a chore.
5) Write at your own pace.
6) Write about what you want to – don't hold back.
7) Don't worry about what other people think of your writing.
8) Stick with it – don't be discouraged.

With these rules in mind, put pen to paper or fingers to keyboard. If the experts and the 'writers' profiled in this article are right – you may just end up feeling better about yourself and your life.

Jim's story

"My name is Jim Forbes and I was born in St. Joseph's Hospital, Port Arthur, Ontario in 1940."

With that line, Jim Forbes started to write. Exactly what Jim, a 33-year veteran of the local police force who was diagnosed with Parkinson's at age 56, expected at that moment he doesn't know. That was back in November 2002. Six month later, Jim had cranked out over 200 type-written pages of an informal memoir.

Jim had no formal training as a writer, although years of writing crime reports had given him some practise and he is a self-described natural storyteller.

"I had a hard time staying focused on things. I was retired and my condition was beginning to affect me a bit more," Jim recalls. "I started to write and just couldn't stop. And I felt good about it."

He calls writing a cathartic experience. "I had a lot of issues to deal with in my childhood, and I found that when I put them down on paper, a lot of my negative feelings were released."

His writing has become a family affair. "My wife, Elaine, is my critic, censor and editor," Jim laughs. "She tells me what I can and can't put in."

Jim has recently added poetry to his writing repertoire. As for his memoirs, they are continuing, and some day will arrive at the point when he came face to face with Parkinson's.

"I haven't quite got to that stage yet," he notes. "Either mentally or on the word processor."

But when he does, Jim is sure his writing will help him out.

Beth's story

Writing wasn't exactly new for Beth Holloway. A high school English teacher in St. John's, Newfoundland, Beth had 'dabbled' with writing before she found out she had Parkinson's.

However, her diagnosis seemed to awaken something inside her. "Suddenly, I just had to do it," she explains. "I had to write. I'd get up at three in the morning and put my thoughts down."

Beth wrote anything and everything, from journal-like entries to scenes from plays. Before long she was writing an online journal for the People Living with Parkinson's website (www.plwp.org) and contributing articles and a humour column to the Newfoundland Parkinson newsletter, *The Prattle*.

"It's hard to explain why I do it," she notes. "It's just something I have to do. I guess I have to admit that I like the pat on the back when people say they like my writing. Of course, I force them to read it so they have to say they like it! All in all, it just gives me a lot of satisfaction."

Next up for Beth is song writing. "I've written a few songs, and even come up with some melodies for them. I don't know how I managed that because I don't have a tune in my body! I don't know where that will go, but like the rest of my writing, it's just something I had to try."

Beth's two-and-a-half cents

(an excerpt)

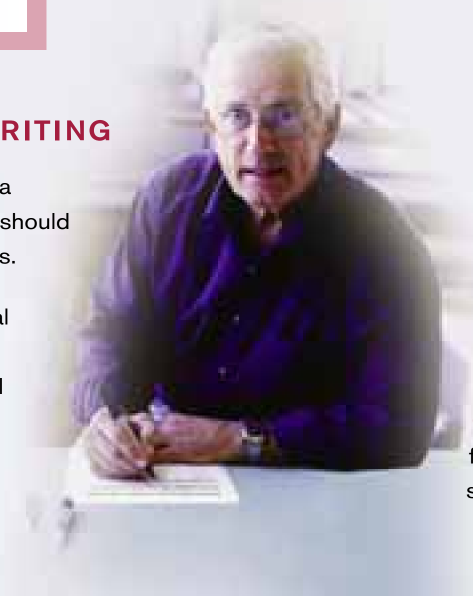
By Beth Holloway

As I write, snow whitens our land once more, and we are close to breaking the snowfall record set two years ago. Although snow shoveling is one of my most adored hobbies, I look forward to the five warm days we call summer. I am hoping this year they fall in early July, anytime will do as long as we get them.

I did get some relaxation in last summer. My friend invited me to use her camper at a provincial park on the Southern Shore. We spent many of the early evenings by the fire on our campsite or visiting other camper neighbours. These ranged from young families with two small children to families whose teenage son and girlfriend visited when they needed gas money to older couples in huge RVs with tiny dogs with tiny high-pitched barks who protected their campsite from well within the confines of the RV.

But there was one neighbour who caused more than a little discomfort. I have no problems with people having different tastes in music than I do, but I often wonder if it was just me, or was someone three sites down also having problems with Tammy Wynette at 7:00 a.m. loudly expelling the hardships of a D-I-V-O-R-C-E over a 35-year-old sound system that could only be an eight-track.

TYPES OF THERAPEUTIC WRITING



Journal: This involves more than keeping a diary-style log of daily events. The journal should focus on expressing emotions and feelings.

Letters: This involves writing very personal letters to people. These letters don't have to be sent, and they can be to people real or imaginary, living or dead. They are intended to express the writer's most candid thoughts and feelings.

Poetry/songs: The writer creates original verses that draw upon their experiences and emotions or to write responses to someone else's poems as way of expressing their feelings.

Other: The list is almost endless, from articles for Parkinson's-specific or other newsletters to short stories, memoirs or even jokes.

What Nerve!

By Ellen Alban

To think she wanted the best possible life,
As a mother, a daughter, a friend and a wife.

To think that she didn't know anything,
Until it arrived, unannounced, one spring.

To think that she was told to go soon,
To a neurologist, the next day at noon.

To think that she first couldn't comprehend,
Where it came from, or when it would end.

To be told to bring her spouse that same week,
To discuss her treatment, she was unable to speak.

To take one little pill, three times a day,
In hopes of keeping the tremor at bay.

But alas! After six years her life's not the same,
Now she's facing the challenge, with no blame.

To think that before all these events occurred,
She was too shy to share her thoughts or her words.

To know that she's changed so much since that day,
She now writes, and enjoys life in every way.

Ellen's story

Ellen Alban was teaching high school in Toronto when she was diagnosed with Parkinson's. Eventually she decided to take a six-week leave of absence. That became a four-month leave and is now up to seven years. She just never went back.

"I really didn't know what to do with my life," she explains. "Then one day I came across a pretty little spiral bound notebook and decided to try my hand at a journal. I soon filled it up, and not just with typical journal stuff, but also with poems, random thoughts, etc. So I bought another. Six books later, my husband introduced me to the computer – and away I went."

Ellen started with poetry, mixing straightforward descriptive poems with more abstract verses that were open to personal interpretation. "Poetry is like art, it shouldn't be judged," she notes. "It should just evoke feelings and emotions."

Discovering writing was, in Ellen's words, "an epiphany."

"It allowed me to really search my soul for the first time," she explains. "It was very emotional and cleansing."

It also gave Ellen a purpose she had been lacking since leaving her teaching job. She joined a writers' group – something she heartily endorses for would-be writers. Soon she started writing poems as gifts for friends. She then added 'pet poetry' – verses about her own and friends' pets, followed by writing speeches for weddings. Now Ellen is in the process of publishing her first collection of verse, entitled *Mirrors of My Soul* and will be running her own writers' group.

She offers this advice to others. "Don't be afraid to give it a try," she says. "And remember to write from your heart. Then it's sure to be good."

Henry's story

Henry Guenter's father had Parkinson's disease. So did four of his uncles and two cousins. In fact, the Guenter family of Saskatoon is well known in Parkinson's circles, and is being studied by researchers looking for clues into the genetic factors of the disease.

Henry was diagnosed with Parkinson's at age 50. A traveling representative for the Massey-Ferguson farm equipment company, he had to accept long term disability when the side effects of his medication started making driving dangerous.

He began writing for purely personal reasons, keeping a journal. "I would just write, sometimes without thinking," he notes. "I'd just write what I felt. Put it all down on paper. Then I'd read it later and be surprised by what I saw. I'd say to myself, did I really think that? But I guess I did."

Writing was a release for Henry. "It's a way of letting some strong emotions out," he explains. "If I keep it inside, it troubles me. If I write it down, I release them. It melts away the stress. And at this stage of my life, the less stress the better. Stress can aggravate my symptoms and I just don't need it."

Before long, Henry started writing about his experiences for the Saskatoon Parkinson Disease Foundation newsletter. He also writes letters of encouragement to other people with Parkinson's. A long-time Sunday school teacher, Henry has written down some of his lessons in book form and has even produced an unofficial manual on the Massey combine for his old clients.

Me and my Shadow *(an excerpt)*

By Henry Guenter

Right now I am coping quite well with my shadow. I am not afraid to talk about it, nor do I try to hide it. This helps to put me at ease. I am experimenting with different things to overcome difficulties that arise. The better I feel because of eating healthy foods, exercising and maintaining a regular schedule, the less my shadow bothers me. In fact, sometimes it seems like my shadow disappears.

"Don't worry about how well you can write," he advises people. "Just do it. Write it down, and worry about it later."

Community

The Community Outreach Program is a key component of Parkinson Society Canada's (PSC) commitment to people with Parkinson's disease.

This program provides funding for vital local programs and services which ensures that dedicated health professionals, and others involved in the fight against Parkinson's, can serve their communities.

In this issue we continue our look at the six worthwhile organizations that received PSC Community Outreach Program grants for 2002–2003.

These three women are just a few of the participants benefiting from St. Peter's Hospital Parkinson's Exercise Class, which is supported by funding from Parkinson Society Canada.

Reaching out: PART TWO

PSC's Community Outreach Program 2003

Movement Disorders Clinic and Thunder Bay Outreach Clinic: London Health Sciences Centre London, ON

For the London Health Sciences Centre (LHSC) and people with Parkinson's in the region, the Movement Disorder Clinic represents something of a 'circle.'

People who attend the clinic benefit from the research and experience of neurologist Dr. Mandar S. Jog and his team. In return, they provide important data on issues such as gait and cognition that helps fuel that important research.

"It's certainly a mutually beneficial system," explains registered nurse Linda Grantier, the MDC's nurse specialist. "Dr. Jog is involved in research with the University of Western Ontario and the University of Waterloo. We often ask our clients to fill in questionnaires or participate in surveys. The data is very useful."

Clients are usually happy to comply while they receive the services of the MDC.

But the two-day-a-week clinic isn't the only service the LHSC provides to people with Parkinson's. Three times a year, Dr. Jog, Linda and a clinical fellow attached to the MDC climb aboard a small plane and fly north to Thunder Bay. There they conduct an intensive three-day outreach Parkinson clinic. This unique 'clinic on the move' is supported by PSC's Community Outreach Program, with the help of funds raised by Cullis, Gibbs, Kenny and Wells – four students from B.C. who cycled across Canada in 2002.

"The Thunder Bay clinic is very popular," states Linda. "It's a busy time when we are there. We start the clinic immediately on arrival on Sunday and run until about 7:00 p.m. Then we are open Monday from 8:00 a.m. to 7:00 p.m. and Tuesday from 8:00 a.m. until 4:00 p.m. During our stay we'll see between 60 and 68 clients with a variety of needs."

In addition, the team frequently provides evening educational sessions and participates in hospital and nursing home visits in conjunction with local physicians.

Thunder Bay itself has a population of 150,000 and the clinic also serves the surrounding communities.

"People often travel for hours to attend," Linda adds. "People with Parkinson's in the area don't really have access to a neurologist, let alone a movement disorder specialist. Even though it's only a few times a year, I think we make a valuable contribution. The number of people we see each time is witness to that. And the responses we receive from

A unique three-day outreach program in Thunder Bay is just one way in which Dr. Mandar S. Jog (left) and Linda Grantier help those with Parkinson's.

local physicians and, most importantly, the people we see indicate that the program is very successful."

St. Peter's Hospital Parkinson's Program: Hamilton, ON

Michelle Shilton and Laura Jewell run St. Peter's popular Early Intervention Program, an eight to ten week program consisting of weekly, 90 minute sessions.

The St. Peter's Hospital Parkinson's program officially serves Ontario's greater Hamilton region, but as Bonnie McInnes, Program Director, Rehabilitation and Community Services says, they are not "terribly strict" about who attends their clinic or classes.

Run by St. Peter's Hospital Rehabilitation and Community Services department, the program consists of three components: the Parkinson's Exercise Class, the Movement Disorders Clinic and the Early Intervention Program. The latter two are funded by Parkinson Society Canada's (PSC) Community Outreach Program.

The Movement Disorders Clinic (MDC), which operates one afternoon a month, is co-ordinated by registered nurse Laura Jewell. "We see about six to eight clients a month," notes Bonnie. "That generally includes two new clients, plus a few returning for follow-up. How often a person comes to the MDC depends upon their individual needs."

People with Parkinson's who are assessed through the MDC are frequently referred to St. Peter's Outpatient Services or Day Hospital for intervention and follow-up as needed.

The MDC has been in operation since 1995.

On the other hand, the second PSC-funded service, the Early Intervention Program (EIP), is quite new. "We only started this program last year," Bonnie explains. "And it has become very popular."

Michelle Shilton (left) and Laura Jewell run St. Peter's popular Early Intervention Program, an eight to ten week program consisting of weekly, 90 minute sessions.

The goal of the EIP is to provide education and fitness programs to people newly-diagnosed with Parkinson's or in the early stages of the condition. These are provided through an eight to 10 week program consisting of weekly 90 minute sessions. These sessions are run by Laura, along with physiotherapist Michelle Shilton. Each program is limited to a maximum of 10 people to ensure personal attention. And, a home exercise program is provided at the end.

The new EIP nicely rounds off the services offered by St. Peter's Parkinson Program – a program that has become a mainstay for the Parkinson community of the Greater Hamilton area (and slightly beyond).

Parkinson's Resource Nurse Program: VON St. John, St. John, NB

Sheree Trecartin, RN, has been involved with the VON's St. John Parkinson Resource Nurse Program for the last three years. In fact, Sheree is the Parkinson's resource nurse!

Once a week, Sheree visits people with Parkinson's disease in the St. John area in their homes. "My primary focus as the Parkinson resource nurse is to provide assessments, education and counselling to clients and their families. I also coordinate support services. We don't have a neurologist in our area, so I help out by acting as a kind of resource."

The Parkinson's Resource Nurse Program was established in the fall of 1992. It is currently supported by the PSC Community Outreach Program, through the generous support of RBC Foundation. It serves approximately 35 to 40 people with Parkinson's in St. John and the surrounding area. The program also provides its services elsewhere in New Brunswick, with Sheree participating in health fairs and speaking at regional meetings throughout the province.

In addition to in-home visits and educational speaking engagements, the VON program has been active in other Parkinson-specific initiatives. "We've recently revived the St. John support group," Sheree notes. "That has been very well received – attendance has almost doubled since we started. We've also worked to raise awareness of Parkinson's disease and the PSC here in St. John. For example, we held St. John's first SuperWalk last fall, with 20 dedicated walkers braving the rain. We also raised funds through a Chicken Wing Challenge and were involved in other activities."

This fall, the plan is to introduce a weekly exercise and wellness program for people with Parkinson's. But it will always be the home visits by a caring, dedicated nurse that is the heart of the program. "You can get information through books or online, but its not the same. And some older people are not comfortable with computers," Sheree Trecartin explains. "People welcome the one-on-one contact and the personal touch."

CREATING SMALL VICTORIES:

Therapeutic writing creates new

By Pauline J. Neck, Port Coquitlam, BC

When I retired from my secretarial job in 1998, vague symptoms of fatigue and muscle stiffness had been troubling me for years. I was definitely looking forward to a lighter work schedule. After setting up a home office, I was fully equipped to join other home-based entrepreneurs providing word processing services. Now I could type and create to my heart's content in my own living room.

A typical weekday included typing, running errands and providing after school care for my granddaughter. At first glance, my carefully thought out retirement plan appeared to be working perfectly. As the months passed, however, painful muscle cramps and problems with balance added to the growing list of 'odd' things happening to my body. Just standing briefly in a grocery store lineup produced feelings of lightheadedness and panic.

Family members also noticed an obvious slowness in my movements and communicated their concerns to my doctor. Within two weeks, I had an appointment to see a neurologist.

Author Pauline J. Neck takes a break from writing to enjoy the mid-day sun on her patio.

A life in transition

My Parkinson's disease diagnosis in September 1999 came as a great shock. I expected life as I had previously known it to change drastically. I hadn't counted on the positive aspects of living with a serious illness – the outpouring of love from my family, the caring support of friends and the strengthening of my faith.

As my family and friends prayed, a deep sense of peace settled over me and I was able to view the future with increased confidence and hope. I had been given a wake-up call – a gift if you like, to help me cherish my world and the people in it.

A search for purpose

My friend Josie offered some excellent advice. "Keep up with your writing," she told me firmly. "It will be a good outlet for self-expression." I had joined a writing group the previous year but wasn't taking it too seriously. However, with my diagnosis came the realization that life can be incredibly short and it was up to me to make the rest of my days totally meaningful.

I started jotting down ideas for keeping a positive attitude. I wrote about the benefits of support groups, pet ownership and maintaining hope for the future. I listed coping strategies, enjoyable activities and everything I could possibly think of to help me appreciate life.

This therapeutic exercise was done not just for myself, but with the idea that somehow I would be able to help other people facing similar situations.

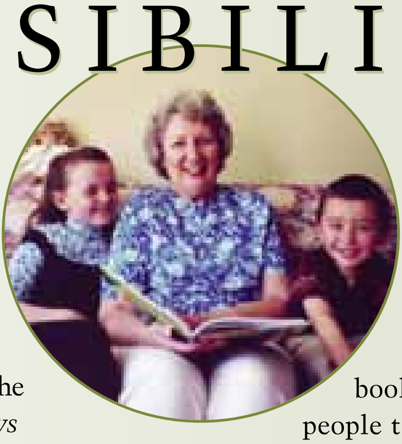
A moment of kindness

One of the first small victories involved learning a lesson in basic human kindness. Early one morning I decided the time had come to tell the local grocery store cashier about the reason for my awkwardness in retrieving money from my purse. It was hard to swallow my pride. Thankfully, there were only a few people in the store. Approaching the checkout I explained to the cashier that my lack of coordination was due to Parkinson's disease. To my surprise, she came around the counter and gave me a hug. This woman's simple act of kindness boosted my morale tremendously. From that moment on I found it much easier to talk (and write) about my own experiences with Parkinson's.

For the next two years I hibernated – compiling stories, poetry, prayers and humour to form a blend of autobiography, inspiration and encouragement. Surveying the stacks of written material now taking up most of the space on my dining table, I told myself, "There must be enough here to write a book." And so I did...

Removing the Sting actually began with one inspirational poem, originally written to encourage the members of my Bible study group. On a

POSSIBILITIES



Pauline shares her love of words by reading to grandchildren Hayley and Maxwell.

personal level, the words of this poem became my own Parkinsonian's prayer. To-date, the poem *All our days belong to the Lord* has appeared in numerous magazines, newsletters and church bulletins, with more than 1,000 copies in bookmark format distributed world-wide.

It's been more than a year since I excitedly took possession of the first shipment of my self-published book. The transition from book writing to promotion has definitely nudged me out of my comfort zone – to developing an assertiveness and determination I certainly never had before.

When I learned the book was actually helping people talk about Parkinson's disease more openly, I knew all the effort had been worthwhile.

A great reward

A most enjoyable event took place recently. I was invited to visit my granddaughter Hayley's grade three class to read a children's story and some poetry I had written. The children sat quietly and listened attentively. The thoughtful questions they asked afterwards touched my heart. It was a morning I will never forget for as long as I live. To be able to bring a smile to the face of a child is a blessing beyond description.

I'm sure the days ahead will hold many more small victories and moments of pure joy. Like the other day when Hayley came bounding into the kitchen to tell me, "Grandma, it's five o'clock – time to take your pill!"

All our days belong to the Lord: A parkinsonian's prayer

By Pauline J. Neck ©2000

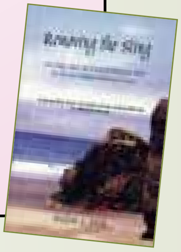
Please give to me good length of days
in which to do your will.
Some days for singing songs of praise,
some days to just be still.

Lord, grant me courage to go on
and willing hands to serve.
Be patient with my anxious thoughts
and fill my heart with love.

When trouble comes upon me
and life's an uphill climb;
Help me surrender to your love
and feel your hand in mine.

For there's no doubt I need you,
without you I am lost.
Help me to lay my burdens
upon your rugged cross.

And when at last I see you,
and look into your face,
I'll lift my hands up to the one
who saved me by His grace.



Editor's note: Some excerpts taken from the book Removing the Sting *by Pauline J. Neck, published in March 2002 by Trafford Publishing, Victoria, BC (CAD $20.00, USD $12.50). To order call 1-888-232-4444 (Canada & U.S. toll free), or 250-383-6864, or visit www.trafford.com/robots/02-0036.html*

DON'T MISS AN ISSUE!

Coming in the Winter 2003 issue of *Parkinson Post*

Support groups and how they can help

There are numerous support groups across Canada and one may be just right for you. Find out what's available and learn how people with Parkinson's and their caregivers gain information, inspiration and friendship. If you are motivated to start a support group of your own, we'll give you tips and first-hand advice from people who've done it successfully.

Eye problems

Visual complaints are common in patients with Parkinson's. We'll explain why and tell you what can be done to address the problems.

SuperWalk review

Don't miss our annual review of SuperWalk for Parkinson's! We'll share photos, results and success stories that prove we are a community of Canadians walking towards a cure. Happening once again across Canada this September, you can learn more about SuperWalk by visiting **www.superwalk.com**.

First person

Read our story from a woman in New Brunswick about how she copes with Parkinson's. She reluctantly quit the nursing job she loved and now relies more on the help of her supportive husband, but she asserts that "there is life after Parkinson's!"

Parkinson Society Canada
Société Parkinson Canada

Ask the Experts

Q *What is Progressive Supranuclear Palsy (PSP) and how is it different from Parkinson's?*

A PSP is an uncommon neurodegenerative disorder which causes problems with gait and balance, abnormality of voluntary eye movements, bradykinesia (slowness of movement) and mental changes.

The incidence is estimated at seven per 100,000 and usually affects adults in mid to late life. PSP is listed under the umbrella of Parkinsonian syndromes because it resembles Parkinson's disease (PD) in the initial stages (see table). The disease progresses slowly over a period of five to 10 years.

A common first symptom is loss of balance while walking, with unexplained falls. Typically the patient has an erect posture with the head tilted back and a tendency to lean backwards. Bradykinesia, shuffling and freezing become apparent.

Visual problems initially are described as 'blurring.' This is due to the inability to look downwards. Eventually, upward and horizontal gaze is also affected. Abnormal eyelid movements such as blepharospasm (forceful involuntary closing of the eyes), difficulty opening the eyes or reduced blinking may occur.

	PSP	PD
Tremor at rest	rare	common
Posture	Erect, head may be tilted back. May have tendency to lean backwards	stooped or bent forwards
Rigidity	increased stiffness in the trunk	increased stiffness in the limbs
Facial expression	'astonished'	masked or immobile
Balance problems	occur in early stages	occur in later stages
Response to treatment with levodopa	little response	good response
Problems with vision, speech and swallowing	common	less common
Incidence	7/100,000	1/1,000

Speech can become slurred or have a 'drunken' quality. The voice becomes low in volume and has a strained quality to it. Swallowing problems occur in later stages.

Mood changes include increased irritability, changes in personality, difficulty making decisions and inattentiveness. Dementia, which develops in later stages, is characterized by slowness of thought and the inability to comprehend new ideas or plans.

PSP is caused by a gradual deterioration of brain cells in parts of the brainstem and the substantia nigra. The cause is unknown, although several theories are being investigated including hereditary and environmental factors.

Currently, treatment involves supportive care to maintain function and quality of life. Patients may be started on levodopa, though response is typically minimal. Research is underway to find improved medical and neuroprotective therapies.

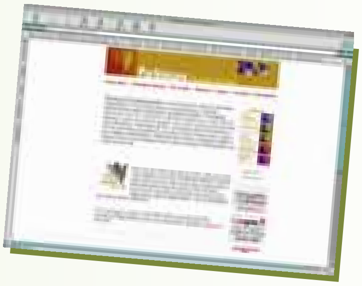
Lorelei Derwent, RN
Oksana Suchowersky, MD, FRCPC
Movement Disorders Program
University of Calgary, Foothills Medical Centre

WEBSITE HIGHLIGHTS

Visit Us Online: www.parkinson.ca

Our website is constantly being updated. Here are some highlights of what you'll find:

- Even young people write to ease the effects of Parkinson's. Don't miss the poem written by a 13-year-old girl who has two grandmothers with Parkinson's. **(See Parkinson's Disease/For Kids)**
- We've streamlined our Research section to make it easier for you to find what you are looking for. **(See Research)**
- If you are interested in an in-depth overview of current research into Parkinson's, check out the detailed article that has been added to our site. **(See Parkinson's Disease/Brochures/ Parkinson's Research Update)**
- If you have friends who are considering subscribing to *Parkinson Post*, send them to our website where they can read sample articles and obtain information on how to subscribe. **(See Parkinson's Disease/*Parkinson Post*)**

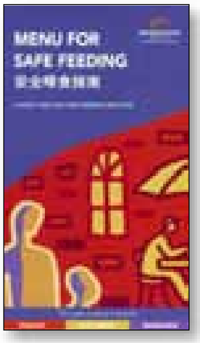


Send your comments and suggestions for our website to general.info@parkinson.ca

ANSWERS TO Autumn reflections by Myles Mellor

Full Crossword is on page 10.

Resources



A Menu for Safe Feeding: A Video Teaching Safe Feeding Practices

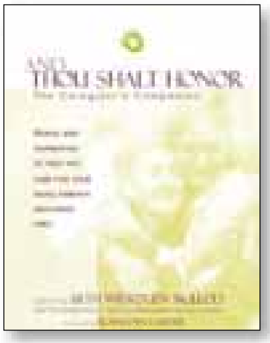
Produced by Bridgepoint Health

Reviewed by Stephen Wolters

This 19-minute video helps caregivers understand how to safely feed a person who is having feeding/swallowing problems. Clearly narrated, the video illustrates the fundamentals of safe feeding: positioning and set-up, verbal cueing, hand-over-hand techniques and danger signs. *A Menu for Safe Feeding* also contains three versions of the same material, narrated in English, Cantonese and Mandarin.

Also available is the *Mealtime Assistance Handbook: A Resource for Families, Personal Attendants and Volunteers*, a 22-page, illustrated guide with English and Cantonese/ Mandarin text. It covers a variety of feeding issues including how we swallow, the role of a mealtime assistants and various mealtime strategies.

Available for: $30 (Video), $6 (Handbook), or $35 (both), including shipping in Canada. To order, call 416-461-8252, ext. 2167.



And Thou Shalt Honor – The Caregiver's Companion

Edited by Beth Witrogen Mcleod

Reviewed by Isabel Ward

Today, caregiving is an inevitable part of our lives. Many of us become caregivers for family, friends or neighbours while still caring for children. This book provides valuable information for both new and experienced caregivers.

Real life experiences, advice from the experts and particularly useful checklists cover such topics as recognizing the need, preparing for, giving and getting help and the legal aspects of caregiving. The needs and health of the caregiver are also well covered.

Information about contacts, agencies, laws and policies are American, but it gives the reader insight into the kinds of sources to look for and the problems one might encounter. A number of websites are described. The companion website is www.thoushalthonor.org.

Available at most bookstores for $36.95 hardcover or $23.95 paperback (fall 2003).

Parkinson's Training for Caregivers website

Northwest Parkinson's Foundation

Reviewed by Suzanne Tobin

This free, on-line course was developed to train para-professional caregivers in long term care settings including skilled nursing facilities, assisted living communities, adult family homes and in-home settings. In fact, it is so understandable and easy to follow that it might be helpful to caregivers/ family members or people looking to learn more about PD. It covers characteristics and stages of PD, treatment basics, activities of daily living, mobility and safety, digestion and bladder problems, communication, sleep, mood and thinking problems. Users can go through the eight lessons at their own pace. Short video clips and definitions are included throughout.

Visit www.parkinsonseducator.com

Parkinson's Disease: Social and Economic Impact

Parkinson Society Canada and Health Canada

Parkinson Society Canada collaborated with Health Canada to produce this report. Information was drawn from the Economic Burden of Illness in Canada, 1998 (EBIC), released by Health Canada in late 2002. This is the first time the EBIC publication, based on census and other national data, has isolated information on Parkinson's.

This six-page report presents the PD-specific statistics from EBIC 1998, including direct and indirect costs of PD on individuals, their families and the health system in Canada.

The information is intended for people with Parkinson's, their families, health professionals and policy makers in hopes that it will lead to awareness, discussion, improved policies and increased funding.

For a free copy, call PSC at 1-800-565-3000, ext. 225.

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.