

ParkinsonPost

A quarterly magazine for Canadians living with Parkinson's



Reaching out:
An inside look at PSC's Community Outreach Programs

How to manage speech challenges

Gardening's many health benefits

PLUS:
Travelling with Parkinson's



Parkinson Society Canada
Soci t  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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Strengthening the Parkinson's network

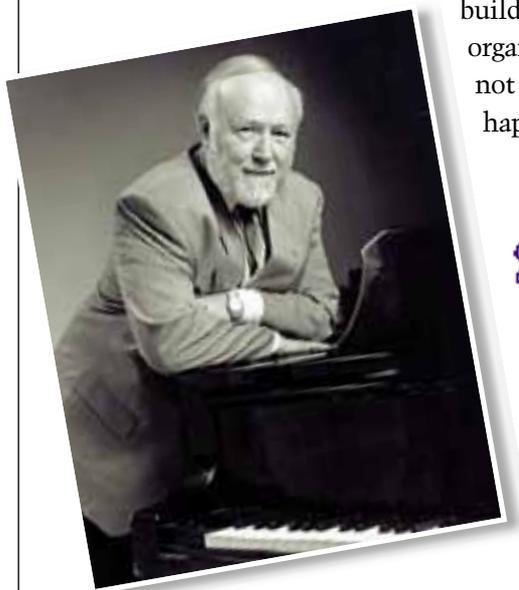
There is no one in my extended family who has Parkinson's, so how did I become involved? It is a long story. I became a friend of Dr. Ali Rajput and his family over 25 years ago. For a number of years, Dr. Rajput had asked me to join the Saskatchewan Parkinson's Disease Foundation (SPDF), a small foundation he had set up in 1972 after struggling with the fact that levodopa was not generally available to Parkinson's patients in Saskatchewan. In 1988 I agreed and I haven't looked back. Since that time, a number of close friends have developed Parkinson's.

In the 1970s, the SPDF made Parkinson's information in French and English available to people and organizations right across Canada. There was enthusiastic support locally with active chapters in Regina and Saskatoon who organized many activities. We now have eight active chapters with more on the horizon. The SPDF publishes a quarterly newsletter, takes countless phone calls, sends information packages across the province to people living with Parkinson's, and supports the chapters. We've sourced books, videos and other materials to ensure each chapter has its own library of local resources.

The Regina Chapter has two annual fund-raisers that have been going strong for the last ten years, the curling classic and the golf classic. Each now raises about \$50,000 per year, all of which goes to research. In 2002, Melba Grant in Saskatoon, whose husband Don has Parkinson's (both close friends of mine for nearly 40 years), led a team that organized our first SuperWalk for Parkinson's and raised over \$50,000 – a wonderful result.

Dr. Rajput continues to lead the way in research. He is currently establishing the Saskatchewan Centre for Parkinson's Disease and Movement Disorders that, amongst other things, will be analyzing the unique collection of human Parkinson's brains coupled with patient histories that exists in Saskatoon.

All of us at SPDF are now pleased and proud to be working with PSC and the regional partners across Canada. As we continue to work together, we will build a stronger, well-recognized national organization and hasten the day when we not only ease the burden, which is already happening, but also find a cure.



D. B. Russell

David Russell,
President, Saskatchewan Parkinson's
Disease Foundation,
National Board Member, PSC,
Saskatoon, SK

ON OUR COVER:
*Pharmacist Chee Chiu and
Ian Forrest discuss medications
at North York General's
LWWP Program (see page 16).*

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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
Soci t  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

- ▶ Fraser Valley regional conference held on February 28; Nanaimo regional conference on March 15; and Prince George conference on April 26.
- ▶ Dance party held on March 22.
- ▶ AGM held on April 12 with Dr. Trevor Hurwitz, Neurologist and Psychiatrist.
- ▶ Tulip Sale held April 23.

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

- ▶ 180 people attended recent popular sessions on 'Exercise', 'Speech/Swallowing Changes', 'Stress Management' and 'Medications.'
- ▶ Plans in place to launch a speech maintenance program in Fall 2003.
- ▶ Involved with a broad-based community initiative to develop better health/social services for seniors by avoiding duplication and filling gaps.
- ▶ February 'Hot Wings' event received significant media coverage and included 12 local MLA's and Mayors as judges.

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

- ▶ Another successful 'Hot Wing Eating Challenge for Parkinson's' was held on March 1.
- ▶ 30th Anniversary Celebration Open House held on March 13.
- ▶ Potted tulip sales held throughout Northern Alberta, April 10-12.
- ▶ The Parkinson's Society of Alberta AGM and 24th Annual Annie Wylie Memorial Lecture, with guest speaker Dr. Ali Rajput presenting 'New Aspects of Research in Parkinson's Disease', held on April 26.

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

- ▶ New support group in High River.
- ▶ Calgary Taoist Tai Chi Society celebrated the Year of the Sheep with a traditional Chinese New Year's dinner and entertainment with the proceeds to PSSA.
- ▶ SuperWalk final results showed Calgary, Medicine Hat and Red Deer doubling over last year and a solid increase for Lethbridge.
- ▶ AGM held April 5 with speaker Dr. Michael Trew, Psychiatrist, addressing the topic 'Coping with Emotional Changes and Depression in Parkinson's.'
- ▶ Hot Wing Eating Challenge held on May 31.

Saskatchewan Parkinson's Disease Foundation

Box 102, 103 Hospital Drive
Saskatoon, SK S7N 0W8
Ph: (306) 966-8160
Fax: (306) 966-8030

- ▶ Regina Curling Classic for Parkinson's Research was an overwhelming surprise, raising \$50,200.
- ▶ PW Golf Classic at Avonlea on Wednesday, August 27.
- ▶ Parkinson Week in Saskatchewan to be held September 21-27, 2003.
- ▶ SuperWalk 2003 scheduled for Sunday, September 21. To register, call Hilda at 306-934-1095

Parkinson Society Manitoba

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

- ▶ Successful launch of the first Regional Newsletter.
- ▶ Mordon chosen as Second SuperWalk location for Manitoba.
- ▶ Mailed new Regional brochures to 2,000 doctors and 900 pharmacies.
- ▶ April Awareness took us to rural Manitoba to bring more support to the rural Parkinson community.

PSC Central & Northern Ontario Region

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

- ▶ Toronto District Steering Committee welcomes Lucy DiCarlo on April 21 as the first-ever Toronto District Coordinator.

Continued on page 6



Parkinson Society Canada
Soci t  Parkinson Canada

- ▶ We have compiled a list of services and programs for seniors across the province. Call us for more information.
- ▶ Tulip sales blossomed across the region throughout April and now other volunteers are planning 19 SuperWalks for this year.
- ▶ Numerous Tea for Two fundraising events have taken place across the region, including a signature Tea for Two at the Old Mill in Toronto and three events at retirement homes in Kingston. Also hosting teas were the Millcroft Inn in Orangeville and the Hilton Inn in Mississauga.

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

- ▶ The Shamrock Charities of Kitchener raised over \$50,000 for Parkinson's in honour of Bobby Kuntz, a former CFL player who has Parkinson's. The evening featured numerous dignitaries, from former CFL players to Members of Provincial Parliament, including the Deputy Premier of Ontario, the Minister of Education and the Honourable Elizabeth Witmer. This was the first of many activities in Southwestern Ontario promising to bring new awareness of Parkinson's during the month of April!

Parkinson Society Ottawa

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

- ▶ Two new support groups set up in Ottawa South, in partnership with Bridlewood Retirement Home. One is our first French-speaking support group. Two more contract social workers hired to facilitate support groups.

- ▶ Several Parkinson's presentations given in rural communities.
- ▶ April Awareness activities launched at Ottawa City Hall on April 11 – the anniversary of James Parkinson's birthday. Celebrations included a Proclamation by the Mayor that April 11 is Parkinson's Awareness Day in the City of Ottawa.
- ▶ A student from Algonquin College's PR program helped develop ideas for our 25th Anniversary celebrations. We will showcase the 25 years of our organization over a 25-week period, launching June 16 at our Annual General Meeting.

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

- ▶ Planned and organized the next annual conference. This year, one day will be dedicated to health professionals and another to people living with Parkinson's.
- ▶ Created a scientific board made up of 10 leading Quebec neurologists in the Parkinson's field.
- ▶ Hosted a conference in the Quebec city region on April 8.
- ▶ Our internet site, www.infoparkinson.org, launched in April 2002 has been a huge success in its first year with nearly 77,650 visitors.

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

- ▶ Six 'Wing it for Parkinson's' Challenges were held in Dartmouth, Truro, and

Shelburne County, NS; Cornwall, PEI; and Saint John and Moncton, NB.

- ▶ Our website www.parkinsonsocietymaritimes.ca launched on April 11. Special thanks to Pavonis.
- ▶ Farmers Dairy generously donated the side panels of milk cartons to us, taking our April Awareness message throughout the Maritimes in April.
- ▶ Halifax Metro Transit generously donated advertising space on all their buses in April for a Parkinson's Awareness message.
- ▶ Fredericton hosted 'Porridge for Parkinson's' on April 12.
- ▶ In conjunction with our Chapters and Support Groups, we hosted speakers across the region to share information on Parkinson's. Dr. Bohn and Dr. Zacharias both gave wonderful presentations.
- ▶ Our AGM was held April 5. Once again the region met and exceeded its goals.

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

- ▶ 350 tickets sold to the first Porridge for Parkinson's event on April 5.
- ▶ Dr. Alan Goodridge hosted a videoconference presentation on Parkinson's for Labrador City, Goose Bay and St. Anthony on March 12.
- ▶ April Awareness municipal proclamations will be read across the entire province.
- ▶ Third SuperWalk will take place in NL in Conception Bay North in 2003.
- ▶ Regional Conference held May 2003 with guest speakers Dr. Mandar Jog and Dr. Alan Goodridge.



Parkinson Society Canada
 Société Parkinson Canada

Issues of interest to people with Parkinson's

Nominate outstanding people

Do you know an outstanding person in the Parkinson community who should be recognized for their efforts? We are now accepting nominations for three national recognition awards:

The **Mimi Feutl Award for Outstanding Patient Services**

is awarded to two people each year, a health care professional and a volunteer who have each made a significant contribution to patient services in their community.

The **Dr. Morton Shulman Award** is intended for an individual or organiza-



tion that, through fearless advocacy and an ability to make change, has made life better for Canadians with Parkinson's and their families.

The **David Simmonds Award** recognizes someone who has demonstrated extraordinary leadership skills, which have resulted in a significant contribution to the lives of people with Parkinson's.

Applications are available by calling Grace Meade at **1-800-565-3000, ext. 242**, or by visiting www.parkinson.ca and selecting 'Volunteering.'

Attend the AGM

Plan now to attend the Parkinson Society Canada Annual General Meeting in Montreal on Sunday November 16, 2003.

Don't miss the awards ceremony for our three national recognition awards (see details above). The day will also include the first annual Donald Calne Lecture, given by lectureship winner Dr. Yoshikuni Mizuno from Tokyo, Japan, a world-renowned leader in Parkinson's research. We encourage scientists, researchers, health care professionals and the public to attend.

For more information on the AGM, contact Rose Pillitteri at **1-800-565-3000, ext. 232** or visit our website at www.parkinson.ca.

PSC lends it voice

PSC is pleased to announce it has joined The Council for Health Research in Canada (CHRC). The CHRC's mission is to promote the health of Canadians by ensuring that Canada is a world leader in health research and to enhance and stabilize funding for quality health research. By joining other leading health organizations on this council, PSC will help to convey the message that investing in fundamental research is an investment in our economy and the future of all Canadians.



The latest Canadian research at your fingertips



If you are interested in the work of the Canadian Institutes of Health Research (CIHR), visit their website, and see the new section for the Institute of Neurosciences, Mental Health and Addiction, the institute that supports research into neurological health including Parkinson's. Visit http://www.cihr-irsc.gc.ca/institutes/inmha/index_e.shtml.

Ease the Burden; Find a Cure

Common questions answered by the Canadian Pharmacists Association:

Q *Should I keep a record of the medications that I am taking?*

It's a good idea to keep a written record of all medications you are taking, including nonprescription and herbal products. Bring it with you whenever you visit your doctor or pharmacist, and carry a copy with you at all times, in case of emergency. Your pharmacist will also keep a record of the medicines you take and how you have reacted to them. Remember to tell the pharmacist of all nonprescription or herbal products you take, since he or she will only know for sure about the prescription medications you have filled at the pharmacy.



Q *How do I store my medicines safely?*

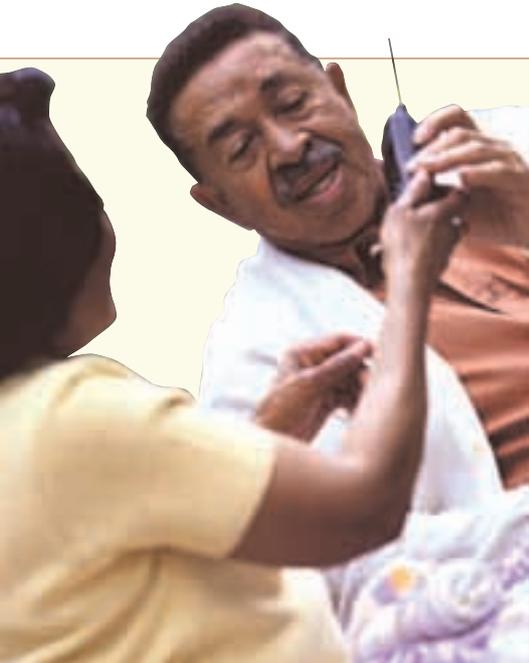
You should keep your medicines in the container that they came in. The bathroom cabinet is not a good place because it gets warm and damp. Always keep medicine out of a child's reach, and refrigerate medication only if it says to on the label.

Q *How do I get rid of my medications safely?*

You should take all outdated or unused medicines you have cleaned out to your pharmacy for safe disposal, including prescription and nonprescription. If you don't know if a medicine is good, ask your pharmacist. Medicine should not be flushed down the toilet: it's not friendly to the environment. Don't throw it in the garbage because children or animals may be able to get at it.

Source: www.pharmacists.ca

When words fail: Managing Parkinson's-related speech and voice problems



By Ian Corks

Because Parkinson's disease is a slowly progressive neurological condition, it can affect the coordination of the muscles used for speech and voice control. In many people, this can result in difficulties in speaking or controlling their voice.

In fact, as many as 75 per cent of individuals with Parkinson's will experience changes in their voice or speech at some point. A small percentage – less than five per cent – report changes in speech and voice as the first symptom noticed.

What changes can be expected?

Changes within the speech and voice system typically occur over an extended period of time. Often, the individual with Parkinson's is unaware of these changes because they are so gradual. In the same way that a close family member or friend may be the first to notice the physical symptoms of Parkinson's, the same is often true for changes in speech and voice.

The most common complaints are a soft or weak voice, hoarse voice, monotone voice, and slurred or mumbled speech (see *Signs of speech/voice problems*).

It is also important to note that Parkinson's can also seriously affect a person's ability to swallow (see *Safe swallowing*).

Why is speech affected?

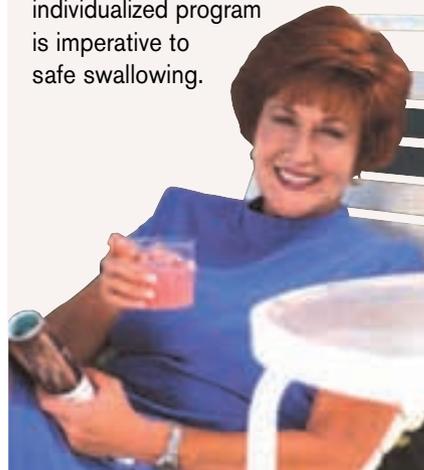
"Just as it disrupts other motor systems, Parkinson's can affect how

Safe swallowing

Difficulties with swallowing are also common complaints of people with Parkinson's disease. Common signs of swallowing problems include:

- Coughing or gagging while eating or drinking
- A 'wet' sounding voice following eating or drinking
- Constant throat clearing while eating or drinking
- Increased effort to eat or drink
- Weight loss or dehydration

An evaluation by a certified speech-language pathologist will help to determine the cause of swallowing problems, and allow for the development of customized and effective treatment approaches. Because no two people are alike, an individualized program is imperative to safe swallowing.



Signs of speech/voice problems

REDUCED VOLUME:

This is often the first change in speaking ability.

FADING VOICE:

The voice starts out strong but fades as you keep talking.

MONOTONE PITCH:

The voice lacks variation and expression.

VOICE QUALITY:

The voice sounds hoarse, breathy or tremulous. Indistinct articulation. Words are slurred and endings are unclear or omitted.

FAST RATE OF SPEAKING:

Words are run together without the usual pauses.

UNWANTED HESITATION:

The speaker has difficulty initiating speech.

we talk," explains Paula Coughlan, a BC-based Registered Speech-Language Pathologist who runs the VIP (Voice Intensive for Parkinson's) speech treatment program with Parkinson Society British Columbia. "Muscle movements in the speech system become stiffer, smaller, and more difficult to initiate. When this happens, the muscles of breathing do not supply enough power for a loud voice, the vocal folds do not meet well to vibrate, and the jaw and tongue movements are too restricted for maximum resonance and articulation. This can produce changes such as a quieter, rougher voice, reduced vocal inflections, less rate control and less clarity of speech."

Different people are affected in different ways. For example, changes in speech rate may occur, but these will vary from one person to another. Some may speak with short bursts of words, while others have slow, laboured speech.

The many ways that Parkinson's disease affects speech and voice ability impacts the overall ability to communicate with family members and loved ones. Adding to the frustration is the fact that these problems are frequently wrongly interpreted by the person.

"Parkinson's can disrupt the feedback mechanism so people may not be aware of how their speech really sounds," notes Paula.

Whose problem is it?

"My wife needs a hearing aid!"...or "Nobody pays attention to what I am saying anymore!" are heard all too frequently from people who don't realize that it is their own voice that has become softer and more difficult to understand. If not addressed, these problems can cause the person to withdraw, stop talking or limit social activities.

As soon as a person with

How a speech-language pathologist can help

By Bonnie Bereskin, MEd, Speech-Language Pathologist (Reg. CASLPO)

Speech-language pathologists (SLPs) can offer valuable support to people with Parkinson's and their families. It is important that work with the SLP begins soon after difficulties arise, so that effective strategies can be learned before problems become too hard to handle. However, even individuals who have had Parkinson's for many years can benefit from the skill of a SLP.

There are two important points to remember about Parkinson's speech difficulties. Firstly, it is never too early or too late to use the services of a speech-language pathologist. Secondly, there is a high likelihood of significant improvement.

Although each person with Parkinson's is unique, there are some common problems that arise with the disorder. One of these is the development of a quiet and monotonous voice. It happens so gradually that often the individual is unaware that there has been a change in their voice until it is pointed out by family members or friends. A second common difficulty is rapid speech, which affects articulation resulting in 'slurred' words.

Fortunately, there are a number of direct therapies that the SLP can use to address these and other problems. It is helpful to have a complete assessment by a SLP before deciding on or planning any therapy.

Another important role of the SLP is to provide education and support to the individual and his family. This can play a large role in helping people cope with the difficulties that arise. For example, some individuals have 'slowness of thought' or 'decreased initiation.' Occasionally, family members misinterpret these behaviours as laziness or stubbornness. It is easier to be tolerant and supportive of someone if you realize that these symptoms are, in fact, part of the disorder.

There are a number of ways to access the help of a SLP. These can include outpatient therapy at a hospital, home care speech therapy and private speech therapy. Some larger communities have specialized Parkinson's programs at local hospitals. The regional partners of Parkinson Society Canada (listed on pages 5 and 6) may be able to refer you to a program or a speech support group.

It is helpful to phone around and ask your doctor what is available. With the help of a SLP, individuals can learn and practise exercises to achieve a louder voice in their own home.

Exercises to improve breathing are very important. They increase the loudness of the voice and also help correct the respiratory problems that many patients experience. Other useful techniques include tongue, lip, and jaw exercises, and practice guides to improve pitch, articulation, and rate of speech. These are also useful if timely, regular access to a SLP is difficult.

The National Parkinson's Foundation in Miami publishes an excellent manual titled *Speaking Out*. (Available through Parkinson Society Canada by calling **1-800-565-3000, ext. 225**). In this brochure is a description of the speech and swallowing problems of Parkinson's and suggestions to help address these difficulties.



Help on-line

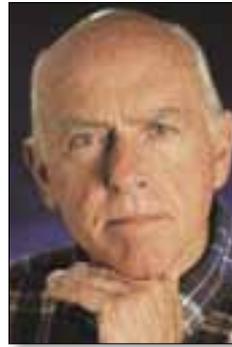
You can find the names of professionals in your area through the Canadian Association of Speech Language Pathologists and Audiologists (CASLPA) website at www.caslpa.ca.

Simply follow the links to 'Our Professions', then 'Find a Practitioner'. Association members are listed by province and territory. You can also contact the CASLPA toll-free at **1-800-259-8519**.



Parkinson's, a family member or caregiver notices changes in speech (or swallowing), it is time to seek referral to a speech-language pathologist – or SLP. These specialized health professionals can implement strategies and techniques that can help to maintain voice and speech function. In general, the earlier treatments are initiated, the more effective they will be. However, even in advanced cases, intervention by an SLP can

help restore function. Improvement following comprehensive speech-language therapy is frequently surprising and always rewarding.



For many people with Parkinson's, speech and voice problems go 'with the territory.' However, that doesn't mean that they, or their loved ones, need to take it 'quietly.'

On the contrary, if voice and speech problems are tackled as soon as they occur, everyone will still have plenty to talk about.

Take the partner test

Answer 'Yes' or 'No' to the following:

- | YES | NO | |
|--------------------------|--------------------------|--|
| <input type="checkbox"/> | <input type="checkbox"/> | I have difficulty hearing my Parkinson partner when s/he speaks. |
| <input type="checkbox"/> | <input type="checkbox"/> | I have difficulty understanding his or her speech. |
| <input type="checkbox"/> | <input type="checkbox"/> | My Parkinson partner does not talk as much as in the past. |
| <input type="checkbox"/> | <input type="checkbox"/> | My Parkinson partner does not attend social functions as frequently as in the past. |
| <input type="checkbox"/> | <input type="checkbox"/> | He or she often asks me to make phone calls or order from a menu for him or her. |
| <input type="checkbox"/> | <input type="checkbox"/> | My Parkinson partner clears his or her throat often. |
| <input type="checkbox"/> | <input type="checkbox"/> | My Parkinson partner often sounds as if s/he is running out of breath when speaking. |
| <input type="checkbox"/> | <input type="checkbox"/> | My Parkinson partner suspects that I need a hearing aid. |
| <input type="checkbox"/> | <input type="checkbox"/> | My Parkinson partner thinks I ignore what s/he has to say. |

Multiple 'yes' answers, or a 'yes' answer to even one issue that truly interferes with daily communication is sufficient basis for a complete speech and voice evaluation.

Source: National Parkinson Foundation, Inc.

Communication tips

Here are a few tips on how to improve communication in cases of speech or voice problems.

The speaker should:

- Stand or sit upright. Good posture is important to a strong voice.
- Exaggerate the loudness of your voice.
- Use short, concise phrases. They are easier to understand.
- If using long sentences, pause to give the listener time to understand.

The listener should:

- Face the speaker.
- Suggest the speaker raise his/her voice if it is too soft.
- Give the speaker time to start and finish a sentence without interrupting.
- Indicate understanding by nodding or saying 'yes.'
- If uncertain, repeat what you thought was said for confirmation.
- Reinforce any techniques provided by the SLP.



Plans underway for another record-breaking year

In 1990, seven volunteers in Ontario walked to raise funds for those with Parkinson's. In 2000, ten years later, SuperWalk for Parkinson's raised \$641,191. Just two years after that, this amount doubled: **SuperWalk for Parkinson's 2002 raised \$1,266,574!**

This year, plans are underway to make this the best SuperWalk ever. Over 70 communities across Canada will be uniting for SuperWalk 2003 to raise dollars to benefit those living with Parkinson's, their families and caregivers.

GET INVOLVED as a walker or volunteer and help make SuperWalk for Parkinson's 2003 the best! Contact your local Regional Partner for pledge forms (see pages 5 and 6 for contact information) or visit www.superwalk.com and see if online registration is available in your region.

Parkinson Society Canada was thrilled to have ElderTreks

Parkinson Society gratefully acknowledges the support of our sponsors

Diamond Sponsor: National Bank of Canada

Gold Sponsors: The Running Room and GlaxoSmithKline

Silver Sponsors: Draxis, ElderTreks, Air Canada and Hayhoe Mills

Bronze Sponsors: Bristol-Myers Squibb, Allison Canada, Astra Zeneca, RioCan and Central Park Lodges



join us as a sponsor for the first time in 2002, and we are delighted that ElderTreks will again be a SuperWalk Grand Prize sponsor in 2003. Doug and Annalee Bartlett, members of the Fredericton support group, were the winners of the 2002 Grand Prize – an ElderTreks trip to Costa Rica – and have already gone on their trip. Upon their return, Doug sent us pictures and wrote, "Costa Rica is a very beautiful country. The guide was excellent,

the travelling companions were great, the weather was beautiful, the itinerary was second to none, and the food and accommodations were excellent. Annalee and I are very thankful and deeply indebted to Parkinson Society Canada and ElderTreks for making this trip possible. Everything about the trip was a dream come true." (Don't forget to fill out the ElderTreks questionnaire inserted in this edition of the *Parkinson Post*.)

Last year, we also introduced our **National Team Challenge** and had over 150 teams compete to raise money across Canada. This year it will be even bigger! Any group of four to 10 people can enter – a family, corporation or group of friends or fellow employees can join together and register as team. In addition to being eligible as individuals for all of the prizes and incentives, the winning team wins a prize package for each member worth over \$300! Contact Sheri Rapp at **1-800-565-3000, ext. 236** or e-mail sheri.rapp@parkinson.ca for details.

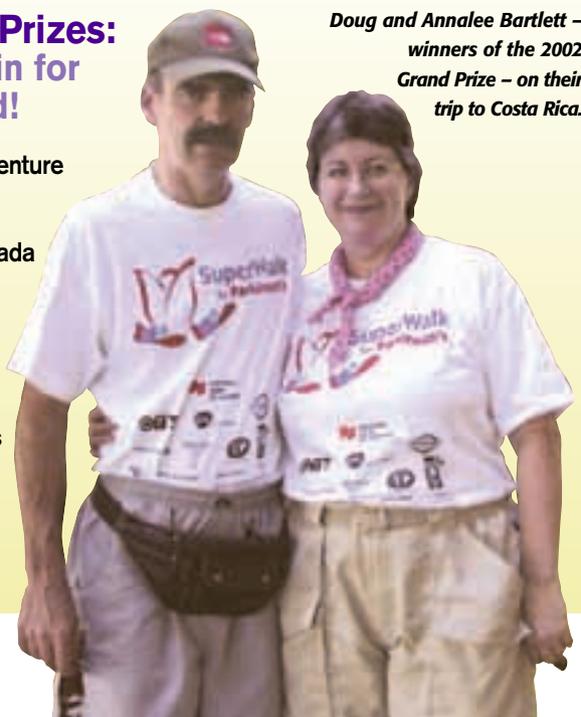
National Grand Prizes: One chance to win for every \$100 raised!

Costa Rica Rainforest Adventure
Courtesy of ElderTreks

**Two tickets to any Air Canada
scheduled destination**
Courtesy of Air Canada

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Plus! Earn **ROOTS gift
certificates** for every
\$100.00 raised.



*Doug and Annalee Bartlett –
winners of the 2002
Grand Prize – on their
trip to Costa Rica.*

A look at current Parkinson's research around the world

Research Editor: Dr. John Wherrett

Tracking Parkinson's progress

A landmark neuropathological study by German researchers has thrown more light on how Parkinson's disease progresses within the brain.

In a 125-person study, Professor Braak and his colleagues (well known for their work in Alzheimer's disease) showed that idiopathic Parkinson's disease involves multiple brain systems. Predisposed nerve cells in specific regions of the brain become progressively involved in a highly stereotyped manner.

Earliest changes affect the structures mediating the sense of smell and autonomic functions, but are not associated with obvious clinical symptoms. Later, the cells of the substantia nigra and other nerve cell stations in the brain stem become affected. It is during this stage that the typical features of Parkinson's first appear.

This process eventually extends to involve the cerebral cortex, ultimately affecting memory and other cognitive functions, as well as other functions. This evolving pattern of disease has analogies to Alzheimer's disease in that it further suggests a central role for abnormalities in protein (alpha-synuclein) processing. Researchers believe these could be therapeutically altered to delay progression of the disease.

Reference: *Neurobiology of Aging*

Clues to the cause of Parkinson's

Progress is being made in the characterization of gene mutations that

cause Parkinson's disease.

While occurrence of Parkinson's in more than one member of a family is uncommon, there are families where it runs through the generations (autosomal dominant inheritance), or where several members of a generation are affected (autosomal recessive inheritance).

The first gene mutation causing familial Parkinson's was discovered in 1997 in families with the autosomal dominant mode of inheritance. This mutation affected a small protein on the transmitting side of nerve connections (synapses) called alpha-synuclein, and first drew attention to the possibility that this protein could play a crucial role in the injury to nerve cells. Since this discovery, mutations have been demonstrated in families in which Parkinson's occurs before the age of 30 in an autosomal recessive manner. The affected gene encoded a previously unknown protein that has been called 'parkin'. It is believed that this mutation is the cause of half the cases of Parkinson's under the age of 40. Mutation in a gene that encodes for another protein called C-terminal ubiquitin hydrolase, also needed for breakdown of alpha-synuclein, has also been found in a Parkinson family.

Five other genes have now been implicated in the cause of Parkinson's and work is proceeding to identify them. The gene mutations discovered so far are rare absolute causes of Parkinson's disease. However, investigators are also looking into the possi-

bility that there are other mutations and normal gene variants that serve to increase susceptibility to Parkinson's in the more common forms of the condition, where environmental causes appear to be the primary cause.

Reference: *New England Journal of Medicine*

Infusion of protein protects nerve cells

A British-American collaborative study indicates that direct infusion of a specific protein directly into the brain may help protect dopamine cells, which are lost in Parkinson's disease.

A hormone-like protein called glial-derived neurotrophic factor (GDNF) that is known to assist in the development and maintenance of dopamine nerve cells, was continuously pumped into the brains of five individuals with Parkinson's through tiny tubes directed to the basal ganglia for a year. The subjects were assessed in detail before and after the treatment. Results were "favourable" in several areas.

These results are very preliminary. While the limited number of subjects, the lack of control subjects (individuals who had the tubes in place, but did not receive GDNF) and the lack of information about long term effects do not allow any conclusions about the ultimate efficacy of this procedure, the results were encouraging enough for the researchers to begin planning a more extensive study. In addition, this study is an example of how

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

international collaborations continue to yield valuable knowledge about Parkinson's disease.

Reference: *Nature Medicine* Online

Early detection of Parkinson's

A German team has reviewed a test that may help experts detect the existence of Parkinson's disease at an earlier, pre-clinical, stage.

It is now well accepted that changes in the brain caused by Parkinson's begin long before symptoms make the existence of the condition apparent. Since methods of delaying the progress of the disease are certain to be developed, it is important to be able to detect Parkinson's as early as possible.

This would allow doctors to initiate treatments, such as 'neuroprotective therapies', before clinical disability is established.

The researchers reviewed various laboratory tests, both simple and complicated, that might detect pre-



Focus on...

Dr. William Hutchison

**Division of Applied and Interventional Research,
Toronto Western Research Institute.**

"It's like being on a train going through Europe, listening to all the different languages and dialects," explains Dr. William Hutchison. "At each stop you hear something different.

And if you pay close attention and have the right amount of knowledge, you can pinpoint exactly where you are."

What Dr. Hutchison is describing is 'listening' to activity in the human brain with the help of a small electrode. And it is part of the important work, funded in part by Parkinson Society Canada, that he is doing at the Division of Applied and Interventional Research at the Toronto Western Research Institute.

A graduate of the University of Toronto, Dr. Hutchison earned his PhD in Australia, where he first became interested in neurophysiology. He spent time in Germany on a Humboldt Scholarship before returning to Canada. Back in Toronto, Dr. Hutchison earned a postdoctoral Fellowship through the PSC (then the Parkinson Foundation of Canada) and started working with Dr. Andres Lozano at Toronto Western in 1996.

He currently combines time in the operating room with research into the movement related neurons involved in Parkinson's and other disorders. That's where the 'listening' comes in.

The listening is, in fact, recordings made from the thalamus, subthalamic nucleus and globus pallidus in patients during deep brain stimulation surgery; a procedure used in Parkinson's and other movement disorders. These recordings provide a way to pinpoint the subcortical target for the implantation of the stimulating electrodes. They also provide important data for basic research into the responses and characteristics of movement-related neurons involved in movement disorders – research that could help point the way to more effective treatments.

clinical Parkinson's disease. This review included imaging techniques such as PET and SPECT, as well as testing of sense of smell and autonomic functions.

One simple imaging test, which uses an ultrasound to assess the sub-

stantia nigra area of the brain, showed particular promise. Studies so far suggest that this new non-invasive procedure, developed by Drs. Becker and Berg, could help to detect pre-clinical Parkinson's.

Reference: *Journal of Neurology*

WEBSITE HIGHLIGHTS

Visit Us Online: www.parkinson.ca

Some of the new content on our website includes:

- Parkinson Society Canada is pleased to announce the recipients of our 2003–2004 research program grants and fellowships. Read a full description of each of the new research projects or fellows. **(See Research/Current Awardees)**
- *Taking Charge: A Guide to Living with Parkinsonism* has recently been updated. The latest version of this popular resource is now available online for browsing or printing. **(See Parkinson's Disease/Brochures/Taking Charge)**
- PSC contributes funds to support Clinical Nurses working with neurologists at movement disorder clinics across the country and also supports unique Community Outreach Programs in certain communities. See a list of grant recipients for our Clinical Assistance and Community Outreach Grants Program for June 2003–May 2004. **(See Support/Clinics/Outreach)**
- If you know an outstanding person in the Parkinson community who should be recognized for their efforts, consider nominating them for one of PSC's three national recognition awards. Award descriptions, previous winners and nomination forms are all available on-line. **(See Volunteering/Recognition Awards)**

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



Flower power: Gardening and Parkinson's



By Ian Corks

Gardening, as one poet wrote, "is a way of showing you believe in tomorrow."

It is also a way of communing with nature, of enjoying the outdoors and of expressing our need to nurture and create. And to top it off, it is also good for you – physically, mentally and emotionally.

The benefits of gardening

Let's get physical: Researchers have found that gardening, a form of moderate exercise, is a viable substitute to a workout in the gym. Moderate exercise for around 30 minutes per day has been found to lower blood pressure and cholesterol levels. Gardening has also been found to help prevent type II diabetes, heart disease and strokes.

Mind games: Experts believe that gardening is an activity ideally suited for people with diseases or such as Parkinson's or physical limitations. It provides the opportunity to exercise the

mind as well as the hands. There's always something new to learn from your garden – new plants and flowers to discover, and new products to investigate.

Emotional rescue: Researchers at the University of Florida have found that just walking through a botanical garden lowered



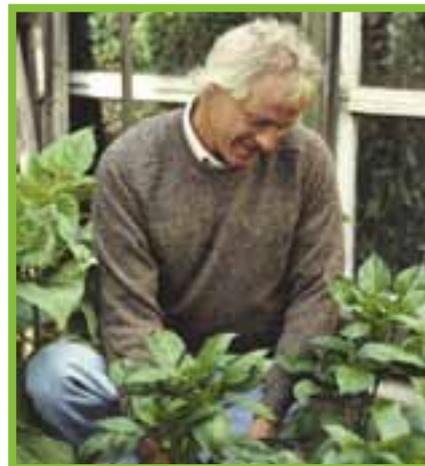
depressed, I didn't know which way was up, or even if there was an up. In my garden, I could lose myself and not think of Parkinson's or anything else. If that's what you mean by a healing garden, then I guess I do understand a little."

Caregiver's can also benefit from the restorative powers of the garden.

Joyce Humphries, of Corner Brook, Newfoundland, finds her garden relaxing. Her husband, Noel, has Parkinson's and is in long term care. "Our garden is quite large, and when all was well, Noel used to help with the heavy work," she notes. "Now, it's a little harder, but I still enjoy it. I can't wait to get into the garden. It is such an outlet for me."

In addition to relieving stress and improving coping skills, gardening can help to promote interest and enthusiasm for the future. It also offers the opportunity to be creative and self-expressive. Being able to watch things grow from just a tiny seed gives many gardeners a sense of achievement and raises self-esteem.

Vancouver's Paul Bradley gets a lot of satisfaction from his garden. A retired university professor, Paul was diagnosed with Parkinson's in



people's stress levels.

The garden is thought to have the same effects on stress as art therapy. And it isn't only doing gardening that reduces the stress. Just soaking up the colours, sounds and smells of your garden will also help.

Finding strength

Judith Richards, from London, Ontario, is one person with Parkinson's who credits gardening with helping her cope.

"As to understanding the healing powers of gardening, I'm not sure," Judith explains. "I do know that the year I had to leave my job because of Parkinson's, my garden saved me. I was so

Advice on-line

Dave's Garden is an on-line community of gardeners. Its chat group (available by subscription only) is frequented by a number of avid gardeners with Parkinson's who swap stories and advice. For more information visit www.davesgarden.com



fall 2002. He describes himself as a “long-time amateur” who started with a victory garden in World War II.

“Our home is on a small Vancouver lot, so space is limited,” Paul notes. “I have a few selected shrubs, various perennials, and a tiny salad garden. I also garden at our remote cabin by the ocean.

“For me, the satisfaction comes from noticing things that would otherwise pass you by. For example, a favourite flower of mine is *anemone blanda*. Its blossoms refuse to open on a dark day, but are joyous when the sun comes out.”

Parkinson’s hasn’t affected the 69-year-old’s devotion to gardening. “It’s a robust activity,” he explains. “I don’t foresee giving it up.”

The challenges of Parkinson’s

While Paul Bradley’s gardening abilities haven’t been affected by his condition, the physical realities of Parkinson’s can make things a bit more difficult for some. Luckily, there are ways to overcome most physical barriers.

Krysia Piorczynski, a professional landscaper, has helped people with Parkinson’s and other conditions keep on – or get started – gardening. Krysia runs Krystal Enterprises in the Blue Mountain region of Ontario and has spoken to local Parkinson’s groups on the subject.

“My mother and my sister are both disabled, and I know the challenges,” she notes. “Unfortunately, like it or not, most gardening is done on your hands and knees. It requires a lot of bending and good hand-eye coordination – things that can be problems for someone with Parkinson’s. But there are solutions to just about any problem.”

Krysia notes that the design of the garden and choice of plants

are important. Thought should be given to making the garden ergonomically efficient for someone with mobility or range of motion restrictions. (see *The Parkinson-friendly garden*).

She also suggests getting the right gardening tools, noting that there are specially designed products for the elderly or people with chronic conditions.

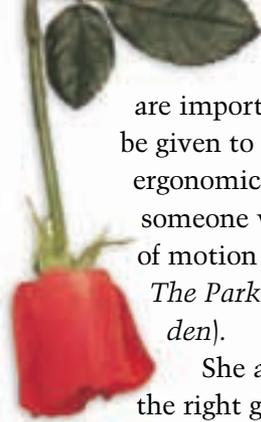
“There are a number of excellent specialty tools available,” Krysia explains. “You can buy tools with large, foam grips on the handles; extendable pruners, clippers or digging tools that eliminate bending or reaching; and mechanical devices like rototillers to reduce muscle power needed.

“The gardening industry was a bit slow at first, but now pretty much any good nursery will stock a variety of these tools. Home Hardware has a good selection, and even Canadian Tire carries some. They can be a bit more expensive than regular garden implements, but are well worth it.”

Krysia also recommends other labour saving tricks, like using slow release fertilizer that only needs one application.

For beginner gardeners, or those who might be facing a move to smaller premises (e.g. a care facility), Krysia suggests container gardening. “You don’t need a home with a large tract of land to enjoy the benefits of gardening,” she says. “A raised container is a terrific and easy place to grow flowers or even small vegetables,” she says. “And you can use it anywhere, even on an apartment balcony.”

As Krysia Piorczynski notes, with careful planning, a bit of homework and maybe even a little help from friends and family, Parkinson’s shouldn’t be an excuse



The Parkinson-friendly garden

Start small: The most important step is to acknowledge the abilities of the gardener. Start with a small area and increase the dimensions as necessary. People with Parkinson’s should not use heavy machinery, climb ladders, etc. Moderation is key.

Use containers: Containers or planters help to minimize bending and stooping. Ensure that they are moveable, so they can be easily relocated. Raised beds or planters can be put anywhere: in the front or back garden, on an apartment balcony or in the grounds of a retirement home.

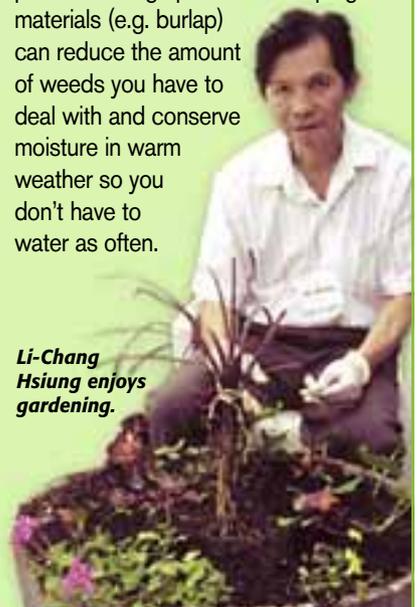
Consider terraces: A terraced garden is a series of small retaining walls or raised plantbeds forming steps. The lower levels of these steps can be adapted to provide easy access.

Select plants carefully: Choose plants according to your wants or needs. Consider the plant’s height, life span and the amount of attention it will require. If you have limited reach, choose plants or vegetables that grow less than two feet high.

Group plants: By grouping plants with similar requirements (e.g. acid soil, frequent watering, shade, etc.) together, you can reduce the amount of work (and travelling) needed.

Use mulch: Spreading mulch around plants or using special landscaping materials (e.g. burlap) can reduce the amount of weeds you have to deal with and conserve moisture in warm weather so you don’t have to water as often.

Li-Chang Hsiung enjoys gardening.



The multi-disciplinary team and volunteers at North York General help people with Parkinson's, like Li-Chang Hsiung (seated), improve their quality of life.

As part of its commitment to providing services to people with Parkinson's and their families across the country, Parkinson Society Canada (PSC) supports a Community Outreach Program.

This Program recognizes the expertise and dedicated efforts of health professionals and others involved in the fight against Parkinson's and provides funding to assist them in serving their communities. In 2002–2003, the PSC Community Outreach Program provided grants to six worthwhile organizations.

Reaching out PSC's Community Outreach Program 2003

Living Well With Parkinson's: North York General Hospital, North York, ON

The Living Well With Parkinson's (LWWP) program offers a variety of services to people with Parkinson's in the North York area. Its goal is to improve quality of life and maximize independence.

LWWP's multi-disciplinary team includes a neurologist, a pharmacist, a physiotherapist, an occupational therapist, a social worker, a recreation therapist, a speech language therapist and a dietitian.

A key component of the program is its eight-week-long exercise and education programs. Run twice a year (Spring and Fall), these programs focus on improving function through exercise, education and healthy living strategies.

People with Parkinson's are encouraged to attend with their

caregivers – a strategy that pays dividends, according to LWWP co-ordinator and pharmacist Chee Chiu. "Caregivers sometimes need to know just as much, if not more, than the person with Parkinson's," she notes.

Chee adds that a take-home 'maintenance' exercise program is currently under development.

Another major component of the LWWP program is its link to the North York General Senior Health Centre's Geriatric Day Hospital. Through the Day Hospital, individuals with advanced Parkinson's have access to personal treatment and counselling on issues ranging from medications to co-existing conditions, such as arthritis, diabetes or heart problems.

Access to LWWP is generally through a referral from the neurologist or family doctor.

"The doctor's referral is important, because it provides the medical information we need to help us match the right type of programs or services," Chee explains. "But if someone doesn't have a referral, they can call us and we will help them. We can fill out the forms and fax them to their doctor."

As Chee notes, LWWP helps people at all stages of the condition. And the services are constantly being improved with the help of client evaluations and feedback.

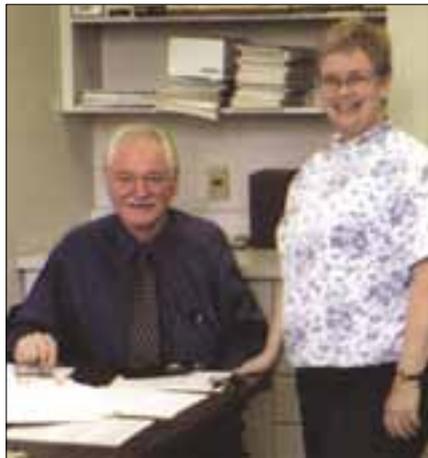
For more information on the Living Well With Parkinson's program, call **(416) 756-6050**.

The Maritime Parkinson Clinic: Dalhousie University School of Physiotherapy, Halifax, NS

The Maritime Parkinson Clinic provides non-medical support for people with Parkinson's living in

the Maritime provinces. The brain-child of Dr. George Turnbull, Assoc. Dean, Research and Academic Affairs at Dalhousie University, the primary focus of the Clinic is on physiotherapy, with a healthy amount of education and other support.

"The Maritimes has a lot of good neurologists and physicians," explains Janet Millar, who shares the physiotherapist duties with Dr. Turnbull. "But there are not a



Dr. George Turnbull and Janet Millar provide physiotherapy, education and support for those with Parkinson's.

lot of non-medical support services for people with Parkinson's. Our clinic helps fill this gap. We provide functional assessments, educate clients and their families, and prescribe exercise and treatment programs that address some of the physical manifestations of Parkinson's."

Programs are developed based on individual needs, interest and lifestyles. Janet and Dr. Turnbull also refer clients to other professionals if needed.

The Clinic is funded entirely by PSC and operates one-and-a-half days a week. Space is graciously provided by Dalhousie University. No referral is needed, but appointments are required.

Janet estimates that the Clinic sees about 25 clients per month. While referrals aren't mandatory, many clients come to the Clinic on a recommendation from their

neurologist or family physician and are from all parts of Eastern Canada.

"Our service area is the Maritimes, and we see people from all over," Janet notes. "We also try to reach out to other communities."

The Clinic may be only part-time and its staff small, but according to Janet, it has already made a big difference in the Maritimes.

For more information on the Maritime Parkinson Clinic, call **(902) 494-6484**, or toll-free **1-800-663-2468**.

VON Niagara Living With Parkinson's Program, Niagara Region, ON

The Victorian Order of Nurses (VON) Living With Parkinson's program turned 10 in April.

Originally conceived as a home visiting program, the program was launched with funding from PSC. Almost immediately, however, the need for additional services became apparent.

"We ran an ad in the local newspaper, and were inundated with calls," recalls Rita Talosi, RN. "I spent three days answering them."

Now the program offers a variety of services for people with Parkinson's, their caregivers and families throughout the 12 municipi-



VON Niagara Executive Director Roseann Norton (left) and Rita Talosi, mark Living with Parkinson's 10th Anniversary.

palities that make up the Niagara Region. The VON's traditional home visits are just one component.

Programs include home visits, weekly exercise/support groups spread throughout the region, a telephone support network and the successful *Newly Diagnosed* group – a 12-week session that runs twice a year and has had group sizes ranging from six to 27 people.

A new program is the *Lunch and Learn* sessions. "We've just introduced these sessions, which combine lunch with a speaker, a presentation or other educational aspect and the feedback has been great," Rita notes. "We've been averaging 50 to 70 people per session. And, like our other programs, we encourage everyone to attend."

The Living with Parkinson's program encourages volunteers (it currently has approximately 60 volunteers helping out by providing about 4,000 hours per year) and partners with local community centres, churches, care facilities and recently with Brock University.

"We have about 150 to 200 different individuals a month using our programs," Rita notes.

The Program is co-ordinated from the VON Niagara office in Thorold, with the support of resources at satellite offices in Fort Erie, Grimsby, Niagara Falls and Welland.

Programs – offered free of charge – are funded by PSC, other support organizations (e.g. The United Way of St. Catharine's and district) and local fund-raising activities.

For more information on the VON Niagara Living With Parkinson's Program please call **(905) 641-1077**.

Editor's Note: Watch for profiles of the three other PSC Community Outreach Programs 2003 in the next issue of Parkinson Post.

Travelling with Parkinson's

By Jill Pritchard

Aaahh...it's summer and you're starting to feel that familiar urge to venture a little further from home. Whether your plans include a trip to see the grand-kids in Saskatoon, a quiet week or two in a cottage on the edge of a peaceful lake, or a round-the-world cruise, we've got the information you need to help make your trip go smoothly.

The Canadian Transportation Agency has taken the lead role in ensuring that ALL Canadians have equal access to public transportation from coast-to-coast, whether by air, ferry, bus or rail.

Their Access to Travel website (www.accesstotravel.gc.ca) provides comprehensive information about travel services and transportation for people with special needs across the country.

Although the site caters to persons with disabilities, it also provides information that is rele-

vant to caregivers and families. For those of you without access to the internet, the agency can be reached by telephone, toll free, at **1-800-883-1813** (Canada only) or by fax at **(819) 953-6019**.

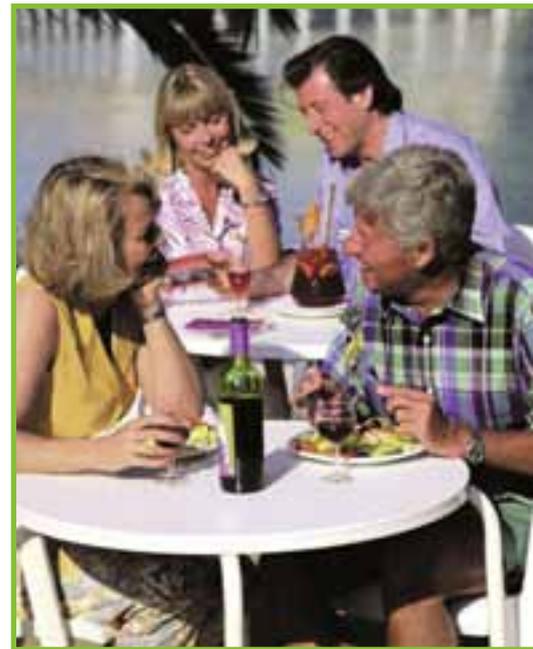
Travelling by air?

The Canadian Transportation Agency has two excellent booklets, available free of charge by calling the toll free number above.

Taking Charge of the Air Travel Experience – a Guide for Persons With Disabilities and *Fly Smart* will answer most of your questions about air travel in Canada, from arranging assistance to get you from the check-in counter to the aircraft; to travelling with an assistance animal, mobility aids, or a personal attendant.

Did you know on domestic flights, many Canadian charter and scheduled airlines voluntarily offer a 50% discounted fare for personal attendants? You may need a doctor's certificate to travel with an attendant at a reduced rate.

Remember, it's important to identify yourself as a trav-



eller with a disability or special need so that you can access the en-route assistance that you need. Requests for assistance must be made at least 48 hours before departure – and it's recommended that you make those arrangements at the time you book your flight. You can do this through your travel agent or by contacting the airline directly. Ask for written confirmation of the services to be provided.

Travellers with disabilities may make arrangements to obtain assistance with:

- Registering at the airline check-in counter
- Proceeding through security to the boarding area
- Boarding/deplaning the aircraft
- Storing and retrieving baggage
- Moving to and from an aircraft washroom (by wheelchair if necessary) *but not assistance in the washroom*
- Proceeding from the aircraft, on arrival, to the public areas of the terminal
- Proceeding to a representative of another airline for a connecting flight
- Transferring from a personal



Coming in the Fall 2003 issue of *Parkinson Post*

Community Outreach Programs – part two

If you enjoyed our article about outreach programs in this issue, don't miss the story about three more innovative Community Outreach Programs that are making a difference to people living with Parkinson's in various parts of Canada.

Cognitive changes

Many people with Parkinson's worry that their mental capabilities will be affected by the disease. Read about some of the problems that can occur and what can be done about them.

Writing as a coping strategy

The unpredictability of Parkinson's brings inevitable psychological stresses. One coping strategy that many people find helpful is writing. Learn how writing about your experiences, feelings and reactions can be a therapeutic and enjoyable outlet. Become inspired by reading how others have benefited from keeping a journal and by writing articles, stories and songs.

First person

Don't miss our story from a woman in British Columbia who was determined to keep a positive attitude when diagnosed with Parkinson's. Her key coping strategy was writing and resulted, two-and-a-half years later, in her self-published book that blends autobiography, inspiration and encouragement.

 Parkinson Society Canada
Société Parkinson Canada

mobility aid to the carrier's aid, and to a seat on board the aircraft

- Special meals and help with meals, e.g. by opening small packages and cutting food on meal trays, *but not with feeding*

TIP – When travelling outside Canada, never mix your medications in a daily pill organizer. All medication should be carried in the original container with the prescription label affixed to it, and on which your name, the drug's generic name, and the prescribing doctor's name appears. Always carry medication in your carry-on baggage. Always take more than you will need for your planned stay. A delayed flight could spell disaster if you run out of medication!

Travelling by rail?

The Code of Practice instituted by the Canadian Transportation Agency, applies to rail travel within Canada and to the U.S. on Amtrak.

Did you know free travel is offered to 'escorts' for passengers who are unable to attend to their personal needs (eating, medical, and personal hygiene such as toileting) throughout the journey? A service animal may also travel free of charge.

Travelling by ferry?

The Code applies to most

passenger ferries operated by Northumberland and Bay Ferries, Marine Atlantic, Northern Cruiser Limited, Owen Sound Transportation Company, Cooperative de transport maritime et arien (CTMA), Victoria Clipper Lines and some others within Canada, or between Canada and the U.S. Marine Atlantic, for example, offers adapted cabins for passengers with special needs. Assistance with wheelchairs is available from the crew. Passengers unable to travel independently may be entitled to have an attendant accompany them at no additional charge. Passengers are asked to identify themselves as requiring special assistance, to make arrangements well in advance, and to arrive at the terminal 90 minutes before sailing time.

Travelling by bus?

Greyhound, and many of its competitors, offer accessible buses (at certain times, on certain routes), pre-selection of seating, and free rides for adult attendants and service animals. The personal attendant is responsible for assisting special needs passengers on and off the bus. They ask that travel be booked 48 to 72 hours in advance to ensure availability.

Remember, the key to any good vacation is pre-planning.

Travel planning on-line

For more details about accessible travel around the world, check out the following sites:

 www.accesstotravel.gc.ca	Canadian, bilingual
www.gimponthego.com/links.htm	Excellent list of disability travel links
 www.pwd-online.ca	Canadian, bilingual
www.e-bility.com/travel	Australian site, good links
www.access-able.com	U.S.-based, cruise ships to cities
 www.enablelink.org/agc	Canadian, bilingual
 www.keroul.qc.ca	Quebec-based, French language

Let's talk about it: Support and open communication are key

By Lindsay Parkhurst, Midland, Ontario

I can't remember my Mom not having Parkinson's disease (PD). I've grown up with it and it's always talked about. Everyone at my Mom's work and in our community knows she has PD. We have nothing to hide and it's better because we always talk about it.

Mom was diagnosed with Parkinson's 11 years ago when I was in kindergarten. Now I'm in Grade 11 at Bethany Hills School. It's a small school of 100 students from Grades two to OAC. We know each other really well and everyone knows we are a family living with PD.

Keep a sense of humour

When I'm at home, we laugh a lot about Mom having PD: Like

when she tries to tease Dad by handing him a hot cup of coffee with her shaky hand. Or when we go skiing and we leave her behind at the baby hill. She has a hard time stuffing the cannelloni noodles for supper – they're slippery and she has trouble holding on to them. Dinner might be a little late that night!

Because Mom can laugh at herself, it makes it easier for all of us to cope. She does get frustrated sometimes because she can't do things as fast as she used to, but it works both ways. She does lots of things for me and I help her by carrying things up and down stairs, making sure she doesn't slip when we're out walking in the woods in winter, and stuffing those slippery noodles!

Live your own life

As a teenager living with PD, it's important to live your own life. I stay involved with community activities like music, dance classes and the Girl Guides of Canada. Along the way, my parents have been right beside me encouraging me. Mom was a Brownie leader and then a Guide leader – I'm sure I wouldn't have completed my Canada Cord (the highest award in Guiding) if Mom and Dad hadn't supported me.

My parents are also really involved with Parkinson Society Canada (PSC). Mom is on the National Board and she and Dad lead the support group in our community in Midland, Ontario.

For the past three years I've been the youth representative for PSC and my job is to communicate with other teens who live with someone with PD. My parents make sure I don't become over involved with PD (because that's not good either!).

Besides playing in the school band and the Star Fire Band, I'm playing this year in a band made up of students selected from across the province's independent schools. I play harp, and alto and baritone saxophone. My parents drive me to a lot of rehearsals and they always support me by attending my concerts. Because I now go to school away from home and my Mom is a member of the Parents' Association, they drive a lot to attend school events



Being open and honest about Parkinson's, both with family members and friends in the community, have helped Margot, John and Lindsay survive and thrive.

and to bring me home on weekends. Again it works both ways.

Because we're a family involved with PSC, we have a lot of support from everyone in the Ontario and National offices. We're always up-to-date on the latest treatment programs and research. Besides, it feels good to help other people. I would really suggest that if you aren't already a volunteer with PSC that you start now. I've met some really neat people.

Plan ahead

What does the future hold for us – a family living with PD? Sometimes when we go to conferences, I see people who are a lot worse than Mom and they've had their disease for a shorter time. Mom has had PD for 11 years and it seems to be progressing slowly. That's good because it allows us to make the changes gradually. We're also planning ahead by renovating our home and making it wheelchair accessible.

Mom and Dad have lots of friends and support in the com-



"We have lots of support which helps us live beyond the restrictions of Parkinson's disease."

munity. If they're out sailing, they watch out for Mom with her poor sense of balance. When her pills wear off and she starts to get shaky, they understand what's happening.

Being a family living with PD is like a big circle. We have lots of support, which helps us and lets us live beyond the restrictions of the disease. This gives me freedom to live my life, which then lets me feel good about volunteering with PSC, which supports us as a family.

Get involved!

The best way I can help is by continuing to be involved with Canadian youth who have someone they love living with PD. I attend conferences and speak

about the importance of involving youth in community activities. I phone and e-mail other teens who have parents or grandparents with PD. Lots of teens are embarrassed and don't want their friends or teachers to know they have a parent with PD. I'm helping them see that it's much easier for everyone if they talk openly. (PD is a very visible disease. Why not teach other people so they'll be able to help?) I'm also working with the office staff at PSC to develop a kids' web page with resources and information.

Youth and teens are the present and future strength of the PSC. We are the future group leaders and board members. We need to learn all we can about PD and share our feelings and ideas.

If you are, or know of, a youth living with someone with PD, please contact me at linds_pinsky@hotmail.com. Together, we can strengthen the youth section of PSC and help ease the burden and find a cure for Parkinson's disease.

Tips for Kids

Get involved: Volunteer with SuperWalk, sell tulips or attend Mall Days to raise awareness. It feels good to help others.

Live your own life: Keep your own friends and social activities. Don't become over-involved with caregiving. It's not healthy and you'll become a very boring person to be around.

Be honest: Don't hide the fact that a parent has PD. It's obvious anyway and it's easier if you're open about it.

Learn as much as you can about PD so you can teach others.

Connect with other youth who live with PD. Your needs, while different from the adults, and are just as important.

Laugh: Keep a sense of humor and focus on the positives.

Lindsay's school friends know more about Parkinson's disease thanks to her open attitude to discussing the condition.



Q *I find incontinence to be a problem. What coping strategies can you suggest?*

A Urinary incontinence – an involuntary loss of urine – is rare in Parkinson's disease. The most common complaints are polakiuria (frequent need for voiding), nycturia (getting up many times per night to void) and urinary urgency.

In case of urinary incontinence, consult your GP to assess and rule out any reason other than PD that could cause this problem.

If urinary incontinence persists after your doctor's assessment, there are several interventions to better control this condition:

Q *Is it true that people with Parkinson's have particular dental problems? What can we do to prevent them?*

A While there is very little literature pertaining to dental caries (a progressively destructive disease of the teeth), gum disease and Parkinson's, numerous neurologists and nurses have noted a reported higher incidence of oral hygiene problems. There seems to be a correlation between certain Parkinson medications, but there is no conclusive evidence.

The main reason behind dental problems relates directly to a diminished ability (because of rigidity, tremor and bradykinesia) to brush and floss adequately.

For this reason, the single biggest intervention is an electric toothbrush. Some even have timers so you can turn them on

General advice:

- Consult your Parkinson's doctor to optimize your medication. Remember to follow the schedule of medication prescribed: This may help lessen the *off* time, rigidity and or slowness; and improve your mobility and speed to reach the washroom on time.

A specific class of medication can be used for urinary incontinence; however, these can worsen memory problems and cause mouth dryness, constipation, urinary retention or confusion. They should be used cautiously and monitored closely.

- Reduce intake of diuretic liquids – coffee, tea, soft drinks and alcohol.
- Wear clothes that are easy to

undo. Try clothing that has an elastic band at the waist, and velcro or large zippers instead of small buttons.

- Use protective underwear or protective pads.

The environment:

- Have sufficient light in the bedroom and your way to the washroom. A nightlight could be useful.
- Be sure to have a clear pathway to the washroom.
- In case of reduced mobility, use a commode, bed pan or urinal.
- Install bars to help you to get out of bed and ease your way to the toilet. Your local occupational therapist can advise you about these modifications.

Since urinary incontinence in PD is often related to voiding urgency, improving accessibility to the toilet will help control incontinence.

Bladder training:

Even if you don't feel the need to void, follow a regular schedule:

- For a few days, empty the bladder every hour.
- For a few more days, empty the bladder every one-and-a-half hours.
- Then, empty the bladder every two hours.

It is also very important to maintain a good, general physical condition. It will help you to move with more facility and strength, and thus may help you to cope better with urinary urgency.

Marie-Josée Fortin, RN; Hélène Turcotte, RN; Jean Hall, RN; Michel Panisset, MD FRCPC;
Movement Disorders Clinic, McGill Centre for Studies in Aging; Montreal, Quebec.

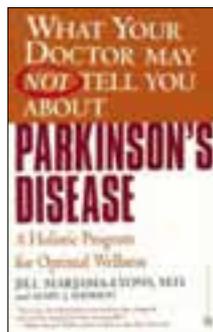


for a set time. The motion of the bristles cleans teeth, and stimulates the gums, decreasing the chances of gum disease. Electric toothbrushes also allow family members to help those who are unable to maintain good oral hygiene independently.

Regular visits to your dentist for professional cleaning, and drinking sufficient quantities of water throughout the day and with or following meals are also beneficial. Note: Schedule appointments when your medication is working well.

Jan Duff, RN

Chair, Parkinson Society Canada, Patient Services Committee



What Your Doctor May Not Tell You About Parkinson's Disease: A Holistic Program for Optimal Wellness

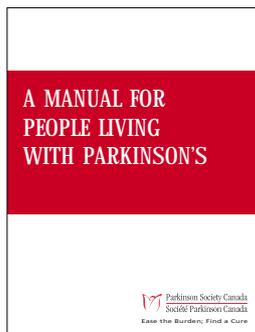
By Jill Marjama-Lyons, MD; and Mary J. Shomon
Reviewed by Ian McConnell

This book should be a standard reference work on the bookcase of every professional, person with Parkinson's and their caregiver. It gives a brief, clear description of every up-to-date treatment methodology from ancient Chinese and Indian medicine to the latest drug regimen: from surgery to spiritual to herbal and other forms of complementary medicine.

Refreshingly without bias, the author does warn readers that many of the treatments are unproven and warrant discussion with your doctor.

While American (many of the resources in the Appendices are U.S.-based), *What your doctor may not tell you...* is a valuable reference.

Available at your local bookstore for \$22.95.



A Manual for People Living with Parkinson's

Parkinson Society Canada

This was written to help the person with Parkinson's learn about PD and to highlight the many other printed resources available in Canada. Some of the topics covered include: Handling Your Diagnosis, Your Health Care Team, Medications, Surgery, Speech and Swallowing, Changes in Mental Status, Young Onset Parkinson's, Sexuality, Financial & Legal Issues, Long Term Care, Issues for Caregivers, etc.

PSC acknowledges the support of TD Bank Financial Group, RBC Financial Group through RBC Foundation, Scotiabank, CIBC and Allianz Canada in developing this resource.

Call the regional partner near you (see pages 5 and 6) or 1-800-565-3000 ext. 225 for a free copy of these three-hole punched pages, designed to go into a binder with other resources you collect.



Go For It! A Guide to Choosing and Using Assistive Devices

Government of Canada

An assistive device is any product that can be used to make the activities of daily life easier and enhance your independence. This guide is not Parkinson's-specific, but it will give people with Parkinson's some good ideas about how to clarify their needs and how to get assistance (for example, seeking the advice of an occupational therapist).

Go For It! also highlights some of the available assistive devices and how they can help with communications, cognition, personal care, personal mobility, housekeeping and recreation aids, and make simple changes to your home.

Organizations and provincial offices that offer assistance are also listed at the back.

Available for free by calling 613-952-7606 or by visiting www.hc-sc.gc.ca/seniors-aines.



Exercises for People with Parkinson's

Parkinson Society Canada

Studies clearly show that people with Parkinson's who exercise fare better in the long run than people with Parkinson's who do not exercise.

This new 12-page booklet explains how exercise can prevent the negative effects of inactivity and minimize secondary effects that may develop. It recommends doing a variety of activities that add up to 30 to 60 minutes each day. The three main sections are posture, flexibility or stretching exercises, and strengthening exercises.

Each section also includes clearly described, illustrated exercises that are appropriate for most people to do on their own.

Call 1-800-565-3000 ext. 225 for a free copy.

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.

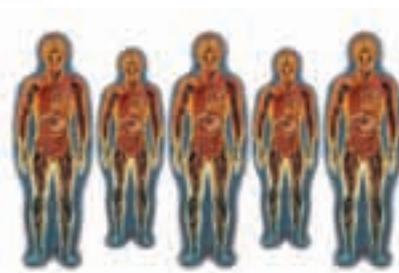
At Draxis, we're committed to the support system. Both inside and out.

Each person has a complex support system made up of bones, muscles and nerves. When Parkinson's disease (PD) affects this support system, medication can help by managing symptoms like stiffness and tremor.

Draxis Pharmaceutica was founded to provide PD medication. Today, we are proud to be one of Canada's leading pharmaceutical marketers of medication for all stages of PD, and we remain dedicated to helping patients make the most of each day.

That's why we are committed to another type of support system as well. Draxis supports Parkinson Society Canada in its activities, such as this magazine. We hope through this support you'll find useful information, motivation and inspiration.

Because even a support system needs a support system sometimes.



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