



Welcome to the Pacific Parkinson's Research Centre

National Parkinson Foundation Centre of Excellence

The mission of the Pacific Parkinson's Research Centre (PPRC) is to act as a Centre of Excellence for the diagnosis and management of Parkinson's Disease and other related disorders. The PPRC also conducts a strong research program that spans pre-clinical, clinical and population studies.

Our multidisciplinary team includes neurologists, nurses as well as a physiotherapist and social worker, all working collaboratively to provide comprehensive, coordinated, patient-centered care to meet the various needs of patients and family members. The clinic is part of a teaching hospital and therefore patients are often seen by residents or fellows.

This package includes answers to some frequently asked questions about the clinic, contact information and provides general information on Parkinson's Disease. Our goal is to help you to live life well with Parkinson's Disease.

We are here for you,

The Team at the Pacific Parkinson's Research Centre

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1 The Value of the Health Care Team

Information and assistance from the right person at the right time makes treatment more successful. The team collaborates to provide guidance to patients to set realistic goals and achieve the best outcomes. In addition to the neurologist, the team includes the following health care professionals:

Nursing

The Nurse can help coordinate care for patients/care partners as follows:

- Provide educational support and advice regarding diagnosis and medications
- Provide a comfortable forum at clinic visits to express concerns regarding the changes
- Referral to other team members
- Under the direction of the neurologist, medication management includes the monitoring and adjustment of medications between clinic visits as needed
- Assist with competing forms for Canada Pension Plan and long term disability plans as well as disability tax credits
- Submit applications for Special Access Medications to Pharmacare and access compassionate supplies when possible

Physiotherapy

The Physiotherapist can help you manage the physical challenges of PD from diagnosis onwards in the following ways:

- Provide information on how Parkinson's symptoms can affect your movement and daily activities and how to best manage them
- Provide education on the benefits of appropriate regular exercise and activities, including provision of a home exercise program
- Improve walking difficulties, posture, rolling in bed, balance and reduce falls, relaxation techniques and safety awareness

- Advise partners and caregivers on how to best assist you
- Advise on appropriate equipment needs
- Refer to a Home Care Occupational therapist for a home safety assessment
- Liaise with your local physiotherapist as needed.

Social Work

The Social Worker can provide information, counseling and referral to help patients/family members understand, adjust and manage the emotional, social and practical concerns that may arise as a result of Parkinson's Disease.

- Issues may include impact of illness on the patient's work, family and lifestyle, loss of independence and grief, decision making, communication, impulse control issues, caregiver stress and advanced care planning
- Referral/Information topics may include finances/disability pensions, power of attorney/representation agreements, housing options, home support, respite care, and general resources
- Education/support in general for PD, stress/anxiety and coping strategies

2 Frequently Asked Questions

What should I do in between my clinic visits?

Please follow the new recommendations you have received at your clinic visit. Take your new prescription to your pharmacy to fill it or to have the medication labels on your old bottles updated. Your pharmacy can keep your new prescription on file until you are ready to fill it.

Your family physician will receive a letter from your clinic neurologist regarding your visit, along with any follow up recommendations including test results and investigations. This can take up to 2 weeks.

What should I do if I need to renew my Parkinson’s prescriptions before my next visit?

Please have your pharmacy fax a “Renewal Request” form to the clinic at 604-822-7866.

What should I do if I need to change my appointment date or time?

Please call your neurologist’s secretary. Telephone numbers are on our contact sheet attached.

What should I do if I notice a change in my symptoms or the way my medications are working?

First, make sure that you are taking your medications on time and as prescribed by your neurologist at your last clinic visit. Not all changes in your symptoms have to do with Parkinson’s, but some do. It can be helpful to notice of the time of day or the activities you were doing when your symptoms changed. Please call our clinic nurses for recommendations. See our contact sheet for our clinic nurses’ telephone numbers. If you are unable to reach a nurse, or if this is an urgent concern, please see your family physician.

Please do not email the clinic with your health concerns as online communications are not secure and we discouraged the use of email for personal or confidential information.

I’m having surgery . . . should I still take my Parkinson’s medications?

Please discuss your medications with your surgeon and anesthetist as they may allow you to take your movement disorders medications with sips of water early before and after your surgery as soon as it is safe to swallow. You can find more information and a list of medication to avoid while in hospital at www.parkinson.bc.ca, under “Hospitalization and Parkinson’s”.

Note that we cannot prescribe medications for patients while hospitalized and under the care of another physician.

Following Deep Brain Stimulation, you are welcome to call our clinic if you need medication adjustments.

How can I become involved in research?

We have several research projects ongoing and are always interested in volun-

teers to participate in our research program. Topics range from familial links (genetics), exercise, depression, apathy, vision, sleep disorders and impulse control disorders.

If you have questions about our research program or are interested in getting involved, please speak with any member of your clinical team or contact our research coordinators listed on our staff contact list or on our website.

I want to do some reading online about my movement disorder. Which website should I search?

The internet can be a helpful tool in learning more about your movement disorder. We do recommend the following reputable online resources:

Parkinson's Disease:

- www.parkinsons.ubc.ca
- www.parkinson.bc.ca
- www.parkinson.ca
- www.nph.org
- www.parkinson.org
- www.nwvf.org
- www.youngparkinsons.org
- www.michaeljfox.org

Restless leg syndrome:

- www.willis-ekbom.org

Dystonia:

- www.dystoniacanada.org

Multiple System Atrophy and Progressive Supranuclear Palsy:

- www.curepsp.org
- www.parkinson.ca select "What is Parkinson's" then "Parkinson-Plus Disorders" then "PSP"

3 Pacific Parkinson's Research Centre Contact List

Clinic

Secretaries (including booking of appointments)

Megan Schram (Dr. Cresswell) ☎ 604-822-7754

Jelena Cregg-Guinan (Dr. McKeown) ☎ 604-827-5136

Janita Gosal (Dr. Stoessl) ☎ 604-822-7967

Jelena Cregg-Guinan (Dr. Tsui) ☎ 604-822-7682

Nurses/nurse clinicians

Brandy Lachmann ☎ 604-827-1352

Skylla Burden ☎ 604-822-0392

Social Work

Elaine Book ☎ 604-822-7527

Research

Genetics

Christina Thompson ☎ 604-822-0322

PET imaging

Jess McKenzie

☎ 604-822-7764

Nicole Heffernan

☎ 604-822-7705

MRI studies

Christy Jones

☎ 604-822-9722

4 General Interest Reading

Living well with Parkinsons
By *Glenna Wotton Atwood*

The Little Book of Stress Relief
By *David Posen*

Anatomy of Hope: How People Prevail in the Face of Illness
By *Jerome Groopman*

Lucky Man
By *Michael J. Fox*

H.O.P.E.: Four keys to a better quality of life for Parkinson's people
By *Hal Newsom* through www.nwpf.org

Surviving Adversity: Living with Parkinson's Disease
By *Gord Carley* available through www.survivingadversity.com

Sex, Love and Chronic Illness
By *Lucile Carlton*

Positive Coping with Health Conditions: A self care workbook
Available through www.comh.ca

Feeling Good
By *David Burns*

Strong at the broken places: Voices of illness, chorus of hope
By *Richard Cohen*

Mastering the art of coping in good times and bad
By *Linda Edgar*

Parkinson's Disease: Mind, Mood and Memory
Available through the *National Parkinsons Foundation*

The Parkinson's Disease Treatment Book: Partnering with your doctor to the most of your medications

By *Dr. J. Eric Ahlskog*

Making the connection between Brain and Behavior: Coping with Parkinson's Disease

By *Joseph Friedman*

For Parents

How to Help Children Through a Parent's Serious Illness

By *Kathleen McCue*

We are not alone: Learning to live with Chronic Illness

By *Sefra Kobrin Pitzele*

For Children

When someone has a Very Serious Illness (for ages 3-8)

By *Marge Heegaard*

What's Wrong with Grandpa? (older elementary children)

My Mommy has PD...But It's okay! A guide for Young Children about Parkinson's Disease.

By *Jan Quist and available through www.youngparkinsons.org*

I'll Hold Your Hand So You Won't Fall: A child's guide to Parkinson's Disease

By *Rasheda Ali*

Who is Pee Dee? Explaining Parkinson's Disease to a Child.

By *Kay Mixson Jenkins and available through www.whoispeedee.com*

For Caregivers

Family Caregiver Alliance www.caregiver.org

National Alliance for Caregiving www.caregiving.org

Caregivers of People with Parkinson's www.pdcaregiver.org

Parkinson's Disease Caregivers Information www.parkinsonscare.com

Caregiving Online www.caregiving.com

Caregiver Blog <http://day2dayparkinsons.blogspot.com>