

Welcome to the Movement Disorders Clinic & the Pacific Parkinson's Research Centre

The mission of the Movement Disorders Clinic and 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 including tremor and dystonia.

Our multidisciplinary team includes neurologists, nurses, a physiotherapist, a social worker, a speech-language pathologist and an occupational therapist, all working collaboratively to provide comprehensive, coordinated, patient-centered care to meet the different needs of patients and family members.

The clinic is part of a teaching hospital therefore patients are often seen by residents or fellows.

The PPRC also conducts a strong research program that spans pre-clinical, clinical and population studies. Patients have the opportunity to participate in clinical trials, microbiome, and PET and MRI imaging studies.

This package includes:

- ✓ An Introduction to your Health Care Team
- ✓ Frequently Asked Questions
- ✓ A Contact List
- ✓ List of Resources for Now or for Later
- ✓ Information on PD Connect (we highly recommend asking your doctor or nurse for a referral)

Our goal is to help you live well with Parkinson's disease.

An Introduction to your Health Care Team

In addition to the neurologist, the team includes the following health care professionals:

Nursing 604-822-0392

The Nurse can help coordinate care for patients & family members as follows:

- Provide education regarding Parkinson's disease, medications and managing symptoms
- Encourage best self-management practices
- Assist with medication management (monitoring and adjusting medications between clinic visits as needed under the direction of the neurologist)
- Offer an opportunity for patients or family members to express any concerns or worries
- Refer to other team members and community resources
- Submit applications for Special Access Medications to Pharmacare & access compassionate supplies when possible

Nurse Practitioner 604-827-1352

The Nurse Practitioner acts as a complementary member of your health care team. The NP is accepting patients to be seen in clinic and offers consultation via phone.

- Provides comprehensive clinical care to patients with Parkinson's
- Diagnosis and manages motor and non-motor symptoms of Parkinson's (including depression, anxiety, constipation, sleep disturbances, memory difficulties, hallucinations)
- Offers medication management including monitoring, adjusting and refilling prescriptions
- Collaborates with the patient and their family to identify health concerns from a holistic perspective
- Provides education and counselling on healthy lifestyle, nutrition, exercise
- Provides ongoing support to patients and their families living with Parkinson's and other movement disorders
- Collaborates with the neurologist regarding your health care and refers care when deemed necessary

Physiotherapy 604-822-7695

The Physiotherapist can help you manage the physical challenges of Parkinson's disease from diagnosis onwards in the following ways:

- Provide information on how Parkinson's symptoms can affect your movement & daily activities & how best to manage them.
- Provide education on the benefits of appropriate regular exercise & activities, including provision of a home exercise program.

- Provide education on how to improve your walking pattern, including advice on the use of appropriate walking aids as needed.
- Provide education on how to improve your posture, ability to move in bed, your balance and discuss strategies to reduce your risk of falls and ensure safety.
- Provide referral to community partners and liaise with your local physiotherapist as needed.

Occupational Therapy 604-827-1644

- Provide education on the ways in which the meaningful activities and functional mobility may be impacted; analyze daily & desired activities to facilitate ongoing and safe management at home and in your community.
- Problem solve what may be limiting your function in your chosen activities, and find solutions along with you and your caregivers/family, through either a rehabilitative and/or compensatory approach.
- Encourage self-management and provide you with the required education and tools to achieve your desired goal and to continue being an active member of your health care team.
- Provide referral to other appropriate existing services (e.g. Home Health team, Neil Squire & etc.)

Social Worker 604-822-7527

The Social Worker can provide information, counselling and referrals 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 advance care planning
- Referral/information topics may include finances/disability pensions, power of attorney/representation agreements, housing options, home support, and respite care
- Assist with completing forms for Canada Pension Plan, Long Term Disability Plans, etc.
- Education/support in general for stress, anxiety, and coping strategies

Speech-Language Pathology 604-827-2799

The Speech-Language Pathologist can help you manage the swallowing and communication challenges of Parkinson's disease in the following ways:

- Provide education on how Parkinson's disease may impact your ability to swallow foods, as well as changes that may occur to your communication abilities
- Provide consultation on swallowing and/or communication difficulties
- Refer you to other available resources

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 doctor will receive a letter from your neurologist regarding your clinic visit and recommendations. 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 located on the last page.

Can I email the neurologist with my questions or concerns?

We do NOT encourage the use of email for patients & family members to communicate with their physicians for a variety of reasons.

What should I do if I notice a change in my Parkinson's 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 the time of day or the activities you were doing when your symptoms changed. Please call our clinic nurses for recommendations at 604-822-0392. If you are unable to reach a nurse, or if this is an urgent concern, please see your family doctor.

I am 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 Parkinson's medications with sips of water before the surgery and after the surgery once it is safe to swallow.

If you are going to be in hospital, please plan ahead and get an **Aware in Care** kit from the Parkinson's Society of BC. To order or purchase an **Aware in Care** kit, call 1-800-668-3330 or email info@parkinson.bc.ca

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

How can I become involved in research?

We have several research projects ongoing and are always interested in volunteers to participate in our research program. Topics range from microbiome to MRI and PET imaging.

If you have questions about our research program or are interested in getting involved, please speak with your doctor or nurse or contact our research coordinators. Telephone numbers are located on the last page.

I want to do some reading online about Parkinson's disease. Which websites should I use?

We recommend the following reputable online resources:

www.parkinson.bc.ca

www.parkinson.ca

www.parkinson.org

www.michaeljfox.org

I want to read about other people with Parkinson's disease. Which books should I read?

The New Parkinson's Disease Treatment Book: Partnering with Your Doctor To Get the Most from Your Medications by [J. Eric Ahlskog](#)

Lucky Man: A Memoir by Michael J. Fox

HOPE: Four Keys to a Better Quality of Life for Parkinson's People by [Mr. Hal Newsom](#)

A Parkinson's Primer: An Indispensable Guide to Parkinson's Disease for Patients and Their Families by [John M. Vine](#)

Shake, Rattle & Roll With It: Living and Laughing with Parkinson's by [Vikki Clafin](#)

Parkinson's? You're kidding me, right?: One woman's unshakeable belief in overcoming a shaky diagnosis! by [Sheryl Jedlinski](#)

I Am Rock Steady: Fighting Back Against Parkinson's Disease by [Julie Young](#)

Contact List

Neurologists

Dr. Silke Appel-Cresswell (Megan Schram)	604-822-7754
Dr. Melissa Mackenzie (Judy Tomaneng & Surena Ken)	604-822-7682
Dr. Martin McKeown (Jelena Majdanac)	604-827-5136
Dr. Tara Rastin (Judy Tomaneng & Surena Ken)	604-822-7682
Dr. Jon Stoessl (Janita Gosal)	604-822-7967
Dr. Jonathan Squires (Judy Tomaneng & Surena Ken)	604-822-7682
Dr. Joseph Tsui (Jelena Majdanac)	604-827-5136
Dr. Jason Valerio (Judy Tomaneng & Surena Ken)	604-822-7682
Dr. Christina Zhang (Judy Tomaneng & Surena Ken)	604-822-7682

Allied Health Team

Nurses (Laura Wong & Kate Chan)	604-822-0392
Nurse Practitioner (Joanna Davis)	604-827-1352
Physiotherapist (Michelle McCarthy)	604-822-7695
Occupational Therapist (Rosa Jafari)	604-827-1644
Social Worker (Elaine Book)	604-822-7527
Speech-Language Pathologist (Katy Chen)	604-827-2799

Research Coordinators

PET Imaging (Jess McKenzie)	604-822-7764
MRI Studies/Devices (Juana Ayala Castañeda)	604-822-5293
Microbiome (Dr. Samantha Schaffner)	604-822-3177
Clinical Trials (Annie Kuan)	604-827-0576

Resources for Now and for Later

PARKINSON'S INFORMATION & SUPPORT

Parkinson's Society of British Columbia

Information, education, counselling, support groups.

Call 604-662-3240 or 1-800-668-3330 or visit www.parkinson.bc.ca

Parkinson's Foundation

Information, education, webinars. Visit www.parkinson.org

Parkinson Canada

Information and education resources.

Visit www.parkinson.ca

EDUCATIONAL PROGRAMS

BC Brain Wellness Program – offers a variety of programs to improve and sustain quality of life for people living with brain disorders and their care partners, as well as to offer healthy agers the opportunity to enhance their wellness and engage in prevention lifestyle measures. For more information about free programs and events, visit www.bcbraintwellness.ca

Living a Healthy Life with Chronic Conditions

Sponsored by the BC Ministry of Health and University of Victoria, this program helps people learn skills to manage a chronic condition like Parkinson's. For more information about free workshops, visit www.selfmanagementbc.ca

CAREPARTNERING

Caregivers Association of BC

Find out about caregiver networks in your community.

Call 604-734-4812 or 1-800-833-1733 or visit www.familycaregiversbc.ca

Care Partner Program with the Parkinson's Foundation

Through this program, care partners will better understand their role in managing their loved one's care, create actionable strategies for self-care, develop clear networks for support and access relevant tools that will empower them in their role as care partner.

Visit www.parkinson.org/Summit

Vancouver Coastal Health (VCH) Caregiver Support Program

A service to give caregivers a break from the emotional and physical demands of caring for a relative or friend, including respite care at the home or outside of the home through short-term stays in a care facility or hospice.

Visit www.vch.ca/your-care/home-community-care/care-options/caregiver-support

ADVANCE CARE PLANNING

An Advance Care Plan is a written summary of your wishes to guide your substitute decision maker if you cannot make treatment decisions for yourself. Advance care planning begins by thinking about your beliefs, values and wishes regarding future health care treatment. It is about having conversations with your close family, friends and health care providers so that they know the treatment you would agree to if you become incapable of expressing your own decisions.

Visit www.gov.bc.ca/advancecare for a copy of the BC government's advance care planning guide called My Voice: Expressing My Wishes for Future Health Care Treatment.

Visit <http://www.speak-upinbc.ca/> for a free online workbook.

Email ce@vch.ca to find out about a free in-person workshop at VGH, Lions Gate or Richmond.

Or contact **Nidus Personal Planning Resource Centre and Registry**. Call 604-408-7414 or visit www.nidus.ca

FINANCIAL RESOURCES

Federal Benefits

Including disability tax credit, medical expense credits, GST credit, Old Age Security, Guaranteed Income Supplement, Canada Pension Plan.

Call Service Canada at 1-800-668-2642 or visit www.canada.ca and click on "BENEFITS".

Provincial Benefits

Including information on Medical Services Plan (MSP) and BC PharmaCare.

Call Service BC at 604-660-2421 (in Vancouver) or 1-800-663-7867 (elsewhere in BC) or visit www2.gov.bc.ca/gov/content/health/health-drug-coverage

Department of Veterans Affairs

Call 1-866-522-2122 or visit www.veterans.gc.ca

Senior's Supplement for BC Residents

Call 1-866-866-0800

Seniors First BC

Call 604-688-1927 or visit www.seniorsfirstbc.ca

Disability Alliance BC

Call 604-875-9227 (in Vancouver) or 1-800-663-1278 (elsewhere in BC) or visit www.disabilityalliancebc.org

Home Adaptations for Independence (HAFI)

A grant program for people with diminished physical abilities. It helps low-income households pay for modifications to their home for accessibility.

Call 604-433-2218 (in Vancouver) or 1-800-257-7756 (elsewhere in BC) or visit www.bchousing.org

Shelter Aid for Elderly Renters (SAFER)

Call 1-800-257-7756

HOUSING

BC Housing

Call 433-2218 (in Vancouver) or 1-800-257-7756 (elsewhere in BC) or visit www.bchousing.org

Seniors Services Society

Call 604-520-6621 or visit www.seniorsservicesociety.ca

Co-op Housing

Call 1-866-879-5111 or visit www.chf.bc.ca

LEGAL RESOURCES

Public Guardian and Trustee of BC

Call 1-800-663-7867 or visit www.trustee.bc.ca

UBC Legal Advice Program

Call 604-822-5791 or visit www.lslap.bc.ca

Lawyer Referral Service

Call 1-800-267-8860 or visit Canadian Bar Association at www.cba.org

Legal Services Society (Legal Aid)

Call 1-866-577-2525 or visit www.lss.bc.ca

The law firm of **Blakes, Cassels & Graydon** provide legal services free of charge to people with Parkinson's who have legal program related to PD. Contact PSBC Executive Director, Jean Blake, for more information at jblake@parkinson.bc.ca

TRANSPORTATION AND TRAVEL

Handicapped parking placard

Call 604-718-7744 or visit www.sparc.bc.ca

HandyDart/Taxi Savers

Call 604-953-3680 or visit www.translink.ca

Travel Assistance Program

Help with travel expenses due to out of town medical appointments. Call 604-683-7151 (in Vancouver) or 1-800-663-7100 (elsewhere in BC) or visit www.2.gov.bc.ca and search for TAP.

Access to Travel

Information on accessible transportation and travel across Canada.

Call 1-800-665-6478 or visit www.accesstotravel.gc.ca

EQUIPMENT

Red Cross Loan Cupboard

Lends basic equipment including canes, walkers, and wheelchairs on a short-term basis. Requires a referral from a physiotherapist, occupational therapist, nurse or doctor.

Call the Vancouver Short Term Loan Program at 604-301-2566 or visit www.redcross.ca

SAFETY

Lifeline

A personal response service that lets you summon for help any time of the day or night.

Call 1-866-387-1548 or visit www.lifeline.ca

Medic Alert Bracelet

Tells first responders that about your diagnosis and health needs.

Call 1-800-668-1507 or visit www.medicalert.ca

Crisis Centre

Help is available 24 hours a day, 7 days a week if you or someone you know is having thoughts of suicide. Call 1-800-784-2433 or visit www.crisiscentre.bc.ca

Senior's Distress Line

Call 604-872-1234

HEALTH SERVICES

Better at Home

A program through the United Way. Call 604-268-1312 or visit www.betterathome.ca

Wellness Pharmacy/Naz's Pharmacy

Daily home monitoring for medications and/or use of a smart dispenser (automated medication dispenser) is available to people who are clients of the pharmacy. Call 604-880-2340 or visit

www.wellnesspharmacy.com or email care@wellnesspharmacy.com

BC Seniors Guide

A great resource for information on government programs for health, housing, transportation, finances, etc. Call 1-877-952-3181 or visit www.seniorsadvocatebc.ca

For information on **Medical Services Plan** (MSP) and **BC PharmaCare**, call 604-683-7151 (in the Lower Mainland) or toll free 1-800-663-7100 (elsewhere in BC) or visit www.health.gov.bc.ca

For **general health information** and access to general health professionals including a dietitian and pharmacist, call 8-1-1 or visit www.healthlinkbc.ca

For information and referrals regarding community, government and social services in BC, call 2-1-1 or visit www.bc211.ca.

HOME AND COMMUNITY CARE SERVICES

Each health authority offers care and services in your home and community. These services can include, but are not limited to the following:

- Home care nursing
- Home support
- Residential care
- Assisted living
- Adult day programs
- Physical and occupational therapy
- Caregiver support
- Convalescent/Respite care
- End-of-life care

To access these services, you can refer yourself or have a family member call for you.

Vancouver Coastal Health:

Vancouver Central Intake for Home and Community Care - Phone: 604-263-7377

North Shore Community Health - Phone: 604-986-7111

Richmond Community Health - Phone: 604-278-3361

Fraser Health:

Phone: 1-855-412-2121

Island Health:

Victoria Community Access Centre (for South Island): All communities south of Mill Bay, including Greater Victoria, the Southern Gulf Islands and west to Port Renfrew. Phone: 250-388-2273 or 1-888-533-2737

Nanaimo Community Access Centre (for Central Island): All communities from Mill Bay to Deep Bay, including Gabriola Island, and from Parksville on the east coast to beyond Tofino/Ucluelet on the west coast. Phone: 250-739-5749 or 1-877-734-4101

North Island Central Intake: All communities north of Deep Bay including the Mt. Waddington Regional District and the mainland area adjacent to it. Phone: 250-331-8570 or 1-866-928-4988

Interior Health:

Phone: 250-469-7070

Please note, the message will say you have reached Kelowna Health Services.

Press "3" for Clinical Services, then press "1" for Home Health.

From the Home Health menu, press "2" to make a new referral for home health services.

Northern Health:

There are over 20 community health centers within Northern Health. Please speak to your nurse for contact information. Or go to: <https://www.northernhealth.ca/services/home-community-care>

Ask your Nurse or Neurologist for a REFERRAL to PD CONNECT.

PD Connect



Who is Parkinson Society British Columbia?

Parkinson Society British Columbia (PSBC) is the voice of British Columbians living with Parkinson's. Our purpose is to ease the burden through advocacy, education and support services, while pursuing the search for a cure by investing in promising research. We believe that every person touched by Parkinson's deserves to know that they are not alone in their journey. *You are not alone. We are here to help.*

Our friendly and knowledgeable staff is committed to offering support, sharing reliable information and raising funds for programs and research. We are part of a strong community united in our dedication to improve the lives of those affected by Parkinson's.

What is PD Connect?

PD Connect is a referral program intended to help healthcare professionals connect individuals diagnosed with Parkinson's disease, and their carepartners, to Parkinson Society British Columbia's support services at the time of diagnosis or at any point in the disease's progression.

Why is there a need for PD Connect?

The number of those diagnosed with PD increases every year. To date there are approximately 13,000 British Columbians living with PD; this number is predicted to double by 2040 ([Dorsey & Bloem, 2018](#)). With the increasing number of patients diagnosed with PD, greater pressure is placed on our healthcare system, specifically on the limited number of movement disorder specialists. The lack of available resources results in longer waitlists, leaving more patients without adequate care.

PSBC is the leading provincial organization supporting people with Parkinson's (PwP) and their carepartners at every stage of the disease. In a 2017 survey for PwP and for those caring for PwP, PSBC was ranked the number one resource for education and support on Parkinson's disease, followed by the Internet and movement disorder specialists. The Society is a valued resource for those affected by the disease; however, only 23% of PwP and carepartners were made aware of PSBC through a healthcare professional.

Feedback from our fifty support groups across the province indicates that individuals would have preferred to be informed of the Society at the time of diagnosis. Being connected with the Society earlier on has helped individuals increase their knowledge of the disease, gain access to reliable PD literature and resources, obtain free counselling services, join a support group and grow their network of allied healthcare professionals, such as physiotherapists, occupational therapists, speech-language pathologists and trained exercise professionals.

The PD Connect program provides people with Parkinson's, and their carepartners, the support services they need, want and deserve earlier in the disease's progression. Ultimately, PD Connect bridges the gap in the system and aims to help patients (and support healthcare professionals) by connecting them to support and learning opportunities.

Parkinson Society British Columbia 1-800-668-3330 • info@parkinson.bc.ca • www.parkinson.bc.ca

PD Connect is an initiative developed by Parkinson Society British Columbia.