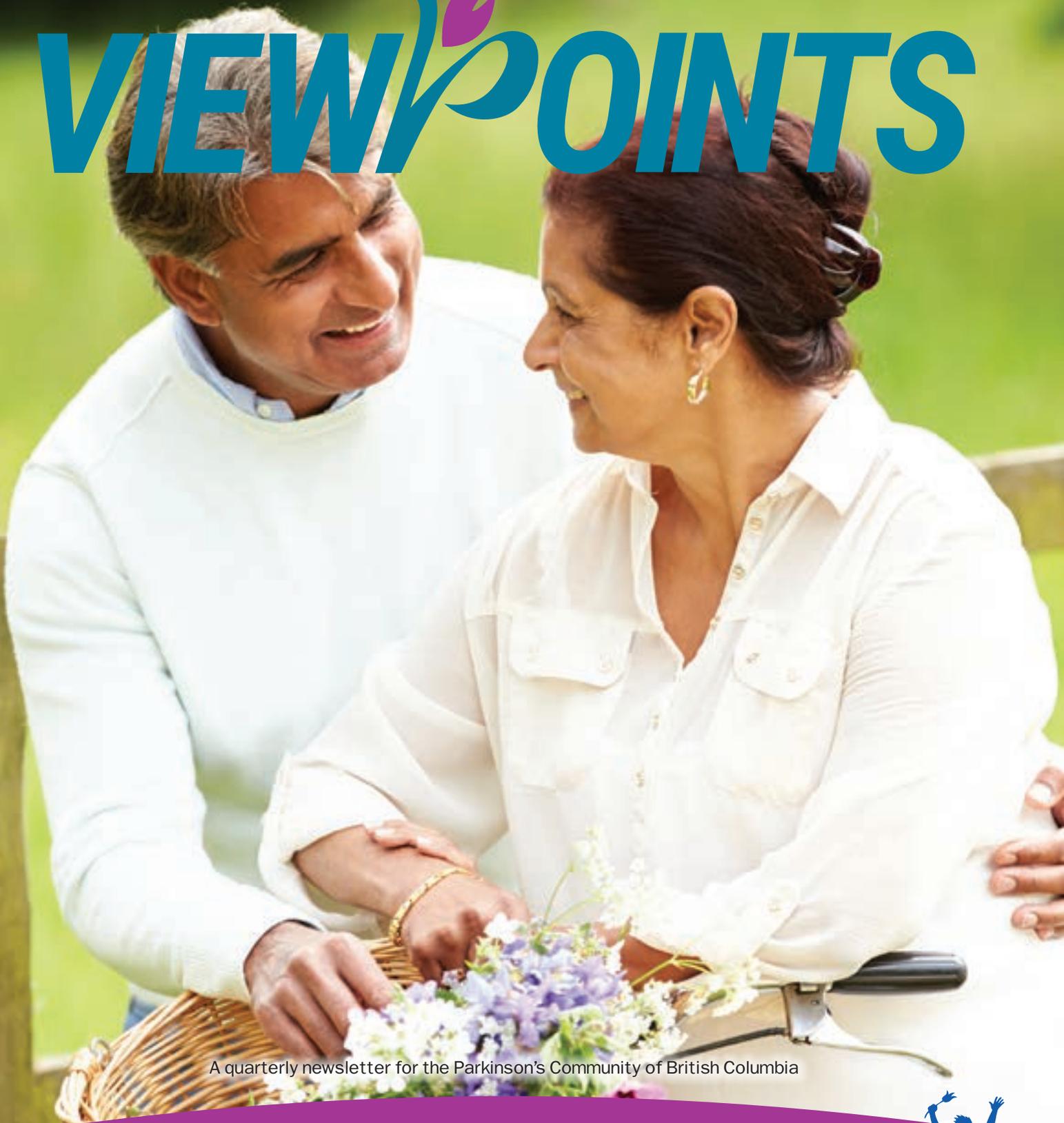


VIEWPOINTS



A quarterly newsletter for the Parkinson's Community of British Columbia

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PSBC would not exist without the generosity of its members, donors and volunteers since it receives no government support.

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Your participation in our special events makes a difference

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Editorial Statement

The views and opinions expressed within the pages of *Viewpoints* are not necessarily those of Parkinson Society British Columbia. The intention is to provide the reader with a wide range of material. Parkinson Society British Columbia welcomes submissions for the newsletter. The editor reserves the right to edit material and to withhold material from publication.

Articles contained in *Viewpoints* are for information only. PSBC does not guarantee nor endorse any product or claim made by an author. In matters of medical treatment or therapy, patients should consult their physicians.

End-of-Life Care Planning: Removing the onus from the patient

When clinical ethicist Kim Jameson was interviewing patients for a project involving supportive decision-making, several people with Parkinson’s disease raised the issue of end-of-life care.

To Jameson’s surprise, they told her neither their family doctors nor their neurologists had discussed planning for their long-term or end-of-life care.

“Some talked about wanting to initiate these discussions with their clinicians to partner with them in planning for future end-of-life care needs,” Jameson says.

So Jameson decided to talk to more people with Parkinson’s disease about their advance care planning needs. She plans to develop best practice guides to help doctors talk to their patients about these critical and sensitive issues, and to recommend ways to start the conversation.



Jameson, a PhD candidate at the University of British Columbia, wants to find out what the barriers are that keep doctors from raising end-of-life care planning with their patients. She hopes her report will support health care professionals and the patients as they make these important decisions about medical intervention, pain management, artificial nutrition and hydration and other end-of-life needs that align with people’s values, beliefs and wishes.

RESEARCH PROJECT



Parkinson’s disease patients’, family caregivers’, and clinicians’ perspectives of advance care planning for end-of-life care.

RESEARCH PROFILE

Kim Jameson

PILOT PROJECT GRANT

\$105,000 over three years

DESCRIPTION

“There’s a lot of uncertainty about when to initiate these end-of-life care discussions and when it is the most appropriate.”

Having these conversations in advance, “can really help families and the patients themselves to relieve the stress and uncertainty they may have,” says Jameson. “The real outcome is to generate patient-centred guidelines on how and when to engage people with Parkinson’s disease and their caregivers in advance care planning.”

Jameson plans to publish her work in academic journals, and hold workshops and educational lunch sessions in health care settings to inform doctors and other health care providers about appropriate ways to engage their patients and begin these conversations.

She hopes her research will relieve people with Parkinson’s from feeling that the onus is on them to bring this difficult subject up with their doctors. Instead, she wants the health care professionals to feel comfortable and to have the right tools to initiate the conversations.

Jameson, who had family friends with Parkinson’s disease, says that personal experience helps to inspire her to continue with her work. She hopes her guide will not only help people with Parkinson’s disease and their doctors, but will also guide clinicians and patients who have other kinds of neurodegenerative diseases as well.

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ask an expert

Ask the Expert with Sherri K. Zelazny,

MA RSLP, LSVT® CERTIFIED CLINICIAN



Sherri Zelazny, MA RSLP, is a speech-language pathologist with extensive specialized experience in evaluation and treatment of voice disorders. She is LSVT® certified and has more than 25 years of clinical experience. Sherri

also volunteers her time to facilitate Parkinson Society British Columbia's Communication & Swallow Workshops and serves on the Board of Directors.



What is a Registered Speech-Language Pathologist, and where do I find one?

A Registered Speech-Language Pathologist (RSLP) has a minimum of a Master's level education and has met the highest standard of knowledge and skills as established by the College of Speech and Hearing Health Professionals BC (CSHHPBC). Like many other health care professions, RSLPs are required to study a breadth of topics including neuroanatomy, genetics, human and language development, linguistics, psychology, acoustics and more, which is why they are qualified to evaluate, diagnose and treat:

- Speech delays and disorders including articulation, phonology and motor speech disorders.
- Language delays and disorders, including expression and comprehension in oral and non-verbal contexts.
- Fluency disorders, including stuttering.
- Voice and resonance disorders.
- Swallowing and feeding disorders in adults, children and infants.
- Cognitive-communicative disorders including social communication skills, reasoning, problem solving and executive functions.

- Pre-literacy and literacy skills including phonological awareness, decoding, reading comprehension and writing.
- Communication and swallowing disorders related to other issues. For example, hearing impairments, traumatic brain injury, dementia, developmental, intellectual or genetic disorders and neurological impairments.

(Speech-Language & Audiology Canada, 2016)

In order to provide speech-language evaluation and treatment in BC, a speech-language pathologist must be registered with the College.  If you're looking for a RSLP in BC, you can review the directory on the College's website at: <http://www.cshhpbcc.org/>



What percentage of people with Parkinson's experience issues with communication and swallowing?

90% of people with Parkinson's experience changes in voice and communication, and up to 100% can experience some degree of swallowing problems. Communication and swallowing problems can be mild to severe, and are not necessarily progressive in nature. As with Parkinson's disease (PD), the symptoms, severity and progression may differ from person to person.



How do I know if I'm experiencing issues with communication and swallowing? What are the "first signs" if any?

Voice and swallowing problems can sometimes occur prior to a formal diagnosis, at the onset of Parkinson's disease or any time along the progression of the disease. Problems can be mild, moderate or severe and don't necessarily start the same for everyone, or progress the same as other symptoms of PD.



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A very common, and often first, sign of voice and communication changes is softer voice. Family members, friends or co-workers might tell you they are having trouble hearing you. You might find yourself needing to repeat more often or pulling away from social activities. Hoarseness, voice tremor and rate of speech changes may also be noticed.

Swallowing problems can be present in a variety of different ways from taking noticeably longer to eat, drooling, avoiding certain foods or coughing/choking during or after meals.

? *What causes issues with communication and swallowing?*

The acts of communication and swallowing involve movement of muscles and motor programming. The muscles that are active in communicating and swallowing can be affected by the same decline in movement that impacts walking and other motor activity. Stiffness, rigidity, slowness of movement, decreased amplitude of movement and tremor bring on the characteristics of communication and swallowing problems in the breathing, voice and speech muscles.

? *Can the Communication & Swallow Workshops offered by Parkinson Society British Columbia help me? How?*

Yes! Parkinson Society British Columbia's (PSBC's) Communication and Swallow Workshops are designed to help people with Parkinson's and carepartners/caregivers understand and recognize symptoms of PD-related communication and swallowing disorders. Early identification of symptoms can help start conversations about treatment with health care providers. In addition to education about the signs and symptoms, the workshops introduce practical exercises and strategies to help improve and maintain quality of life.

? *I am already losing my voice and experiencing issues with communication & swallowing. Can my symptoms be improved?*

Absolutely. There is research evidence for exercises and therapy programs for communication and swallowing. A Registered Speech-Language Pathologist will evaluate and provide specific recommendations based on your results.

? *What is LSVT® Loud?*

The Lee Silverman Voice Treatment (LSVT) LOUD®, is the gold standard for improving communication changes in Parkinson's disease. It is an intensive 1:1 voice therapy program provided by a LSVT® certified Registered Speech-Language Pathologist. There is a large body of research supporting the benefits of LSVT® LOUD including improved loudness, vocal quality, articulation and lip movement, facial expression, creation of new motor pathways in the brain and in some cases, improved management



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Constipation and Parkinson's disease



A Parkinson's diagnosis is a life changing event. Suddenly, the most basic functions can become more difficult. Bowel movements are no exception. Constipation is estimated to occur in approximately 50-60% of Parkinson's patients, and may manifest long before other motor symptoms appear (Abbott, 2003). What complicates the discussion and diagnosis is that every individual's bowel movements vary in everything from frequency to consistency. In terms of timing, what may be irregular or slow for one person may be another person's normal. This is why it is important to avoid comparing your experiences to those around you, especially if something seems unusual or uncomfortable to you.

Most people will experience occasional constipation for various reasons at some point in their lifetime, but chronic constipation is a more serious concern. The main diagnostic criteria of chronic constipation involves at least two of the following symptoms for a minimum of twelve weeks within a year:

- Straining to pass stool more than 25% of the time
- More than 25% of stools are lumpy or hard
- Sensation of incomplete evacuation more than 25% of the time
- Sensation of anorectal blockage for more than 25% of the time

- More than 25% are facilitated by manual maneuvers (e.g. digital evacuation or support of the pelvic floor)
- Fewer than 3 bowel movements per week (Gastrointestinal Society, 2014)

As evident from the diagnostic criteria, two people may both be experiencing constipation yet have very different symptoms.

What causes constipation?

Your large intestine's primary role is to absorb water and sodium from food before creating stool. Muscles in the large intestine work to move the stool along to be eliminated—hence the term bowel movement. When insufficient water or fibre is consumed, stools may appear lumpy or hard and be excreted as small pellets or one hard piece. The longer a stool remains in the large intestine, the more pressure is exerted on the bowels. This often causes rectal pressure/fullness, sensation of incomplete evacuation, bloating and abdominal pain. It can also cause malaise, loss of appetite and back pain. Further complications, such as hemorrhoids and rectal bleeding, are typically due to strain when passing stools (Healthline, n.d.).

According to Dr. Duncan Forsyth, a consultant geriatrician who specializes in constipation in Parkinson's, constipation often has several causes:

- Poor fluid intake
- Reduced activity levels
- Reduced food intake
- Effects of drugs
- Direct effects of Parkinson's on the nerves that control bowel function, which leads to a slowing of bowel transit time (Parkinson's UK, 2011)

Some of the medications in your regimen may contribute to constipation. Anticholinergics—which block involuntary movements of the muscles—can have the dual effect of decreasing appetite as well as slowing bowel movement (State of Victoria, 2015).

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Levodopa, dopamine agonists and amantadine can also contribute to constipation (Parkinson's Disease Foundation, n.d.). Other contributing drugs include narcotics, sedatives, antacids, antispasmodics and iron supplements (Okun, 2011). For people with Parkinson's the benefits of continuing to take a drug such as levodopa outweighs a side effect like constipation, however, chronic constipation may be a good reason to re-evaluate dosage for painkillers and supplements. This is just one reason why it is important to mention whether or not you are experiencing constipation to your doctor, so you can help identify a medication regimen that works for you.

You may have heard that constipation can be counted as an early sign of Parkinson's disease. In 2009, a study led by Dr. Walter A. Rocca at the Mayo Clinic in Rochester, Minnesota discovered that individuals with Parkinson's are approximately twice as likely to have a history of constipation as those without. While the study does suggest that Parkinson's disease typically has a long preclinical period, the many causes of constipation mean that it cannot be understood as a specific marker of Parkinson's disease (Hendry, 2009).

Constipation Prevention and Management

Whether you experience constipation or would like to avoid it, making some lifestyle changes can help you manage digestion as well as increase your overall health.

- Incorporate more whole grains, fruits and vegetables into your diet, avoid processed foods and ensure that you drink 6 to 8 glasses of fluids daily.
- Avoid diuretics such as caffeine and alcohol.
- Have set meal times as well as establish a regular time of day for bowel movements (Carter, n.d.).

- Warm foods and beverages at breakfast can encourage bowel movements in the morning—not a bad reason to reach for that herbal tea or oatmeal!
- Exercise. Exercise accelerates breathing and heart function which encourages movements in other parts of your body while toning and strengthening the walls of your large intestine. Aerobic exercise—also known as cardio—stimulates heart rate and encourages the pumping of oxygenated blood to muscles. Common aerobic exercises include walking, running and cycling. A brisk 10–20 minute walk is one of the best exercises for constipation relief. Yoga can also have its benefits. Some yogis believe that certain positions strengthen stomach muscles, help with digestion and relieve constipation (Orenstein, 2009). If you plan on increasing your activity level to help manage your health, it is important to first consult with a health care professional. Remember to start off with the easiest exercises and incorporate more difficult ones as your fitness level increases. As with most activities, moderation is key; extreme exercise can sometimes cause diarrhea.



Laxatives

You may be tempted to use laxatives or stool softeners to help manage constipation. This may be a viable alternative only after attempting to modify your diet or incorporating more exercise into your routine. Speaking with a physician as well as avoiding the use of any type of laxative or stool softener for longer than a two week period is advisable. If you

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CONSTIPATION AND PARKINSON'S DISEASE

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are considering using these products, it is important to know the different types available to you.

Bulk-forming laxatives or fibre supplements are widely considered the safest type of laxative you can take. Fibre laxatives absorb liquid in the intestines to soften stool. The increased bulk leads to bowel stimulation, triggering movement. Stool softeners or emollients on the other hand, do not cause bowel movement but can help reduce straining. Stimulant, saline, hyperosmotic laxatives or combination products should only be taken upon advice from your physician. Homeopathic supplements are another option, however keep in mind that research and regulation of these products are minimal (American Parkinson Disease Association, 2013).

The Bottom Line

It may be tempting to ignore symptoms of constipation out of embarrassment, but this condition should not persist unaddressed. If you experience a sudden change in bowel movements, see your physician or neurologist. They should be able to assess your condition and make recommendations while considering your current medication regimen as well as your medical history. They may be able to refer you to a dietician or physiotherapist who can help recommend food and exercises that will be beneficial for you. The good news is that many of the life changes recommended for Parkinson's disease double as excellent ways to manage or prevent constipation.

Please note that this article is intended as a general guide. If you would like more information about gastrointestinal disorders, The Gastrointestinal Society is an excellent BC-based resource.  You can reach out to them by calling 1-866-600-4975 or visit their website at www.badgut.org. The Gastrointestinal Society as well as Parkinson Society British Columbia are unable to answer specific, urgent medical questions. The best advice will come from an expert who knows your medical history.

References:

- Abbott RD, Ross GW, White LR, Sanderson WT, Burchfiel CM, Kashon M, Sharp DS, Masaki KH, Curb JD, Petrovitch H. (2003). *Environmental, life-style, and physical precursors of clinical Parkinson's disease: recent findings from the Honolulu-Asia Aging Study*. Accessed April 30, 2016 from <http://www.ncbi.nlm.nih.gov/pubmed/14579122>
- American Parkinson Disease Association. (2013). *Constipation & PD*. Retrieved April 29, 2016, from <http://www.parkinsonassociation.org/wp-content/uploads/2013/06/APDA-Constipation-and-PD.pdf>
- Carter, Julie. (n.d.) *Constipation in Parkinson's Disease*. Retrieved April 28, 2016, from <http://www.parkinson.org/sites/default/files/Constipation%20in%20Parkinson%27s%20Disease.pdf>
- Gastrointestinal Society. (2014). *Constipation*. Retrieved April 26, 2016, from <http://www.badgut.org/wp-content/uploads/GIS-PIH-CO.pdf>
- Healthline. (n.d.) *What causes constipation?* Retrieved April 28, 2016 from <http://www.healthline.com/symptom/constipation>
- Hendry, Joene. (2009). *Constipation: an early sign of Parkinson's?* Retrieved April 28, 2016, from <http://www.reuters.com/article/us-constipation-parkinsons-s-idUSTRE5B04R520091202>
- Okun, Michael. (2011). *Parkinson's Treatment Tips for Constipation*. Retrieved April 28, 2016, from <http://movementdisorders.ufhealth.org/2011/09/12/parkinsons-treatment-tips-for-constipation/>
- Orenstein, Beth. (2009). *Exercising Constipation Out of Your Life*. Retrieved April 29, 2016 from <http://www.everydayhealth.com/digestive-health/exercise-and-constipation.aspx>
- Parkinson's Disease Foundation. (n.d.). *Gastrointestinal Issues*. Retrieved April 26, 2016 from http://www.pdf.org/en/gastrointestinal_problems_pd
- Parkinson's UK. (2011). *Q&A: Bladder and Bowel Problems in Parkinson's*. Retrieved April 26, 2016, from <http://www.parkinsons.org.uk/content/qa-bladder-and-bowel-problems-parkinsons>
- State of Victoria. (n.d.). *Parkinson's disease and constipation*. Retrieved April 26, 2016, from <https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/parkinsons-disease-and-constipation>

Dementia & Cognition Issues

Like other serious chronic conditions, Parkinson's disease (PD) is an unwelcome guest that is here to stay. If you are caring for a person with PD, coping with this new role can be challenging. As a family member or friend, it is natural to wonder what is needed and how to be supportive and respond to that need. It is also normal to be confused about what you can do. Feelings of sadness, worry and guilt are all common reactions to adopting a new role as a carepartner/caregiver. This can be especially tricky when faced with the non-motor symptoms of PD, such as cognitive decline and dementia.

While about 50% of people with PD will experience some cognitive decline as the disease advances, only ~30% of those with cognitive decline will go on to develop dementia in the later stages. The progression of PD is thus different for each person. As a carepartner/caregiver, this can add to the ambiguity of caring for the person with PD, as well as the challenge of dealing with it because there is no way to know for sure what will happen in the future.

Some symptoms of advanced cognitive decline and/or dementia that can pose everyday challenges, like getting in the way of interactions and communication, are:

- Difficulty concentrating
- Difficulty with planning and sequencing tasks
- Changes in perception
- Altered judgment
- Slowness of thought and in expressing thoughts
- Problems with word-finding
- Difficulty following conversations in large groups
- Difficulty understanding the emotional meaning of a conversation



- Difficulty changing topics quickly, or losing 'train of thought' when talking
- Visuospatial difficulties (such as conceptualizing things in 3D)
- Forgetfulness and difficulty with retrieval of learned information
- Behavioural changes (such as aggression)
- Language deficits (including finding words, articulation, volume and tone)

The skill that is often impaired first is the ability to think of the right word. People may struggle to put thoughts together and require more time to organize and communicate their thoughts.

Another skill that may be impaired early on is the ability to understand complex sentences and concepts. A person's contributions to conversations are often affected. In the early stages, the person may not try to explain original thoughts or insights and their breadth of topics for conversation may be narrower. As PD advances, these communication skills may begin to worsen.

Cognitive decline and/or dementia can change how a person thinks, acts and/or feels. These changes often present special challenges for families and carepartners/caregivers. An ordinary conversation, for example, can be quite frustrating when your loved one has difficulty remembering from one moment to the next what has been said.

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Ten Tips for Communicating with a Person with Cognitive Impairment

We aren't born knowing how to communicate with a person with cognitive decline and/or dementia—but we can learn. The Family Caregiver Alliance® states that: “improving your communication skills will help make caregiving less stressful and will likely improve the quality of your relationship with your loved one. Good communication skills will also enhance your ability to handle the difficult behavior you may encounter as you care for a person with a dementing illness” (2016).

- 1 Set a positive mood for interaction.** Your attitude and body language communicate your feelings and thoughts stronger than your words. Set a positive mood by speaking to your loved one in a pleasant and respectful manner. Use facial expressions, tone of voice and physical touch to help convey your message and show your feelings of affection.
- 2 Get the person's attention.** Limit distractions and noise—turn off the radio or TV, close the curtains or shut the door, or move to quieter surroundings. Before speaking, make sure you have their attention; address them by name, identify yourself by name and relation, and use nonverbal cues and touch to help keep the person focused. If he/she is seated, get down to their level and maintain eye contact.
- 3 Speak slowly, clearly and carefully.** Use simple words and sentences. Speak slowly, distinctly and in a reassuring tone. Refrain from raising your voice higher or louder; instead, pitch your voice lower. If he/she doesn't understand the first time, use the same wording to repeat your message or question. If the person still doesn't understand, wait a few minutes and rephrase the question.
- 4 Ask short, simple questions.** Ask one question at a time; those with yes or no answers work best. Refrain from asking open-ended questions or giving too many choices. For example, ask, “Would you like to wear your white shirt or your blue shirt?” Better still, show him/her the choices—visual prompts and cues also help clarify your question and can guide their response.

- 5 Listen with your ears, eyes and heart.** Be patient in waiting for your loved one's reply. If they are struggling for an answer, it's okay to suggest words. Watch for nonverbal cues and body language, and respond appropriately. *Always strive to listen for the meaning and feelings that underlie the words.*
- 6 Break down activities into a series of steps.** This makes many tasks much more manageable. You can encourage your loved one to do what he/she can, gently remind them of steps they tend to forget, and assist with steps he/she is no longer able to accomplish on their own. Using visual cues, such as showing them with your hand where to place the dinner plate, can be very helpful.
- 7 When the going gets tough, distract and redirect.** If your loved one becomes upset or agitated, try changing the subject or the environment. For example, ask her/him for help or suggest going for a walk. *It is important to connect with the person on a feeling level, before you redirect.* You might say, “I see you're feeling sad—I'm sorry you're upset. Let's go get something to eat.”



- 8 Respond with affection and reassurance.** People with dementia often feel confused, anxious and unsure of themselves. Further, they often get reality confused and may recall

continued on next page...

things that never really occurred. Avoid trying to convince them they are wrong. Stay focused on the feelings they are demonstrating (which are real) and respond with verbal and physical expressions of comfort, support and reassurance. Sometimes holding hands, touching, hugging and praise will get the person to respond when all else fails.

9 Remember the good old days. Remembering the past is often a soothing and affirming activity. Many people with dementia may not remember what happened 45 minutes ago, but they can clearly recall their lives 45 years earlier. Therefore, *avoid asking questions that rely on short-term memory*, such as asking the person what they had for lunch. Instead, try asking general questions about the person's distant past—this information is more likely to be retained.

10 Maintain your sense of humour. Use humour whenever possible, though not at the person's expense. People with dementia tend to retain their social skills and are usually delighted to laugh along with you.

Caring for someone with PD who is having cognitive impairments is challenging. You may often feel like you are trying to hit a moving target; not knowing exactly what your loved one is wanting or needing. Building strong communication patterns can be helpful to maintaining a loving and supportive partnership with them. This being said, you may also want to share your experience with other carepartners/caregivers; those also caring for someone with PD, just like yourself. Finding a group of individuals that can relate to how you are feeling is extremely important to your own self-care.

Community Resources:

- British Columbia Government—Caring for the Caregiver
- Family Caregivers of BC
- The Family Caregiver.com

Parkinson Society British Columbia can help you find caregiving support groups in your area. Call us 1 800 668 3330 or email us info@parkinson.bc.ca to find a group near you.

References:

Family Caregiver Alliance® National Center on Caregiving. (2016). *Caregiver's Guide to Understanding Dementia Behaviors*. Retrieved from <https://www.caregiver.org/caregivers-guide-understanding-dementia-behaviors>

Portions of this article were reprinted with permission of Family Caregiver Alliance®. For more information, visit www.caregiver.org.



West Coast College of Massage Therapy

West Coast College of Massage Therapy holds a special massage clinic for people with Parkinson's, caregivers and support workers.



The clinic is on **Thursdays from 4:00 pm to 7:45 pm**. The cost is \$13 for people with Parkinson's and \$22 for carepartners and support workers.

We have received excellent feedback from those who have attended the clinic. If you are interested, please call the clinic receptionist at **604 520 1830**.

Access is through the back entrance on Clarkson Street and is wheelchair accessible.

613 Columbia Street
New Westminster, BC

(Near 6th Street, one block from
Columbia Skytrain Station)



Special Thanks



A big thank you to **Melanie Galloway** and **everyone who participated** in aqua fitness classes as part of The Parkinson's Movement. Melanie surpassed her goal and raised \$1,850 to help support exercise programs & services for people with PD.

Kudos to **Sherri and Julian Zelazny** and **Becks D'Angelo** for organizing the 3rd Annual Beer & Chocolate Tasting fundraiser. The event took place on March 13, 2016 and raised over \$1,400. Special thanks to the Donnelly Group's Clough Club and chocolatier, Take a Fancy, for helping to make the event successful.

Thank you to **Shoppers Drug Mart, Shaughnessy Station** who raised \$3,373. Their support allowed PSBC to host a full day Communication & Swallow Workshop in Coquitlam led by Sherri K. Zelazny, MA RSLP.



Our **Holt Renfrew April Awareness** event generated \$1,700 in donations. A big thank you to our volunteers, without whom this would not have been possible: Peg, Alex, Jessica, Mischa, Bree, Susan, Lori and Ryan.

Notice our new look?

As announced in December 2015, as a result of the dissolution of the Parkinson Canada Federation, Parkinson Society British Columbia (PSBC) has implemented a new look. Although we are not a part of the new national organization, we will continue to collaborate with complementary Parkinson's organizations with the aim of achieving the greatest impact possible. We remain focused on increasing and strengthening the delivery of programs and services across BC.



Do you have Parkinson's related legal issues?

Blakes

Through a partnership with PSBC, the law firm of **Blake, Cassels & Graydon LLP** offers free of charge legal services to people with Parkinson's in British Columbia.

The Litigation Support Program from Blakes addresses legal issues such as discrimination against individuals with Parkinson's in the workplace; discrimination in accommodations, services or facilities that are generally available to the public; and, wrongful denial of disability insurance or denial of government services.

If you have a legal problem relating to Parkinson's disease, please contact **Jean Blake, CEO** at jblake@parkinson.bc.ca for more information.

END-OF-LIFE CARE PLANNING

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Biography

Kim Jameson earned a Master of Arts in philosophy with a specialization in applied ethics from the University of British Columbia in 2009. Her Masters dissertation, supervised by Dr. Michael McDonald, focused on the ethical conduct of health research involving human subjects.

Jameson has worked as a graduate research assistant on a number of qualitative health research projects for over eight years and is currently working as a graduate research assistant on the ongoing CIHR funded project *Supportive Decision Making for Diverse Populations*. Jameson was an ethics fellow at Providence Health Care between September 2011 and May 2014, and has been working as a part-time clinical ethicist at Vancouver Coastal Health since August 2013. She has also been a volunteer ethicist on the UBC behavioural research ethics board since February 2014.

She has published in top research ethics and qualitative methods journals and has delivered paper presentations at national and international conferences.

Jameson is currently undertaking her PhD studies in clinical ethics at the University of British Columbia's W. Maurice Young Centre for Applied Ethics under the direction of Drs. Anita Ho and Sally Thorne. In 2014, Jameson was awarded the Frederick Banting and Charles Best Canada Graduate Scholarship – Doctoral Research Award from the Canadian Institutes of Health Research through the Parkinson Society Canada. Her dissertation research project will focus on Parkinson's disease patients', family caregivers' and clinicians' perspectives of advance care planning for end-of-life care.

ASK THE EXPERT WITH SHERRI K. ZELAZNY

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of drooling and the oral phase of swallowing.  For more information, go to www.lsvtglobal.com.

 **Are there any classes I can take to help strengthen my voice besides attending PSBC's Workshops? What do you recommend?**

First and foremost, if you have Parkinson's disease, you should have a speech-language pathologist on your health care team. Participating in evaluations for both communication and swallowing will yield important information for you, your management of Parkinson's and help maintain and improve quality of life. Specifically, with swallowing problems, there may be concerns for safety and lung health. A RSLP can help minimize the risk related to swallowing problems.

In addition to that, anything that allows you to continue using the muscles that move for voice and swallowing is great. We are learning more every day about the importance of exercise for people with Parkinson's—so go out and exercise your voice. Your vocal folds are muscles—they need exercise like the rest of your body. Keep talking, count your physical exercises



out loud, read headlines out loud, read to your grandchildren, sing in the shower, sing in the choir, join your local theatre group, etc. Stay involved in whatever you love and keep talking!

References:

Speech-Language & Audiology Canada. (2016). *What do Speech-Language Pathologists do?* Retrieved from <http://sac-oac.ca/public/what-do-speech-language-pathologists-do>

Join us for Parkinson SuperWalk!

*Everyday Heroes.
Extraordinary Hope.*



Gather your family, friends and colleagues to form a fundraising team. Together we can support critical research and provide essential programs to help 13,300 individuals living with Parkinson's in BC.

Register now for a Parkinson SuperWalk near you!
<http://bit.ly/SuperWalkBC>.



June

REGIONAL CONFERENCE

25 Kelowna

Date: Saturday, June 25

Time: 9:30am Registration Opens
10am–4pm

Place: Kelowna Ramada Hotel
& Conference Centre
2170 Harvey Avenue

Cost: \$30 Member
\$50 Member (Couple/Pair)
\$40 Non-member
\$70 Non-member (Couple/Pair)

July

COMMUNICATION AND SWALLOW WORKSHOPS

22 Parksville

Date: Friday, July 22

Place: Parksville Community and Conference Centre
Garry Oaks/Arbutus Room
132 Jensen Ave E

Time: 8:30am Registration Opens
9am–4pm

Cost: \$40 Member
\$70 Member (Couple/Pair)
\$50 Non-member
\$90 Non-member
(Couple/Pair)

SuperWalk Dates & Locations in BC

Saturday, September 10

- **ELK VALLEY**
Senior Drop In Centre
(101 4th Avenue, Sparwood)
- **INVERMERE**
Pothole Park
(5th Street & 7th Avenue)
- **KAMLOOPS**
Riverside Park / Rotary Bandshell
(100 Lorne Street)
- **KELOWNA**
Waterfront Park / Concession Plaza
(1200 Water Street)
- **PARKSVILLE**
Parksville Community Park
(141 East Island Highway and Beachside Drive)
- **PITT MEADOWS/MAPLE RIDGE**
Spirit Square, Pitt Meadows
(12027 Harris Road, behind community centre)

- **PRINCE GEORGE**
Lheidli T'enneh Memorial Park, by picnic shelter
(17th Avenue & Taylor Drive)
- **RICHMOND**
Minoru Park / Running Track
(7191 Granville Avenue)
- **VERNON**
Polson Park
- **VICTORIA**
Esquimalt Gorge Park
(1070 Tillicum Road)

Sunday, September 11

- **CAMPBELL RIVER**
Willow Point Hall
(2165 Island Highway)
- **FRASER VALLEY/LANGLEY**
Douglas Park Recreation Centre
(20550 Douglas Crescent, Langley)
- **NELSON**
Virtual Walk
- **OLIVER**
Oliver Community Centre

(6359 Park Drive)

- **SURREY**
Bear Creek Park / Bear Creek Pavilion
- **VANCOUVER**
Stanley Park at Ceperley Playground
- **WHITE ROCK**
Kintec Store
(15185 Russell Avenue)

Monday, September 12

- **BURNABY**
Confederation Park / Track
(4585 Albert Street)

Saturday, September 17

- **CHILLIWACK**
Evergreen Hall
(9291 Corbould Street)
- **FORT ST. JAMES**
Nak'azdli Health Centre
(284 Kwah Road West)
- **SALMON ARM**
McGuire Lake Park
(599 10th Street North East)

August

25 Cranbrook

- Date:** Thursday, August 25
Place: College of the Rockies
2700 College Way
Time: 9am–4pm
Cost: \$40 Member
\$70 Member (Couple/Pair)
\$50 Non-member
\$90 Non-member (Couple/Pair)

September

DANCE FOR PD®: INTRODUCTORY TRAINING & ENRICHMENT WORKSHOP

17 & 18 Vancouver

Mark Morris Dance Group and Parkinson Society British Columbia, in association with Simon Fraser University's School for the Contemporary Arts, present this special workshop, designed for dancers, dance teachers, students, therapists and allied health professionals.

- Date:** Saturday, September 17
Sunday, September 18
Time: 9am–6pm
Place: Simon Fraser University
Vancouver Downtown Campus
School for the Contemporary Arts,
Goldcorp Centre for the Arts
149 West Hastings Street
Cost: \$200 USD Dance for PD® Member
\$250 USD Non-member

There is a \$100 USD pre-requisite online course and assessment that trainees need to complete in advance of the workshop.

4TH WORLD PARKINSON CONGRESS (WPC 2016)

20–23 Portland

- Date:** Tuesday to Friday
September 20–23
Time: 8am–6:30pm
Place: Oregon Convention
Center (Lloyd District)
777 NE Martin Luther
King Jr Blvd
Portland, OR 97232
United States
Cost: \$300 USD

For registration, please visit:
 www.wpc2016.org

Champions FOR PARKINSON'S

We need your help. As the number of people diagnosed with Parkinson's grows every year, so does the need to invest in more programs, services and research. In 2016, Parkinson Society British Columbia (PSBC) doubled the number of educational sessions offered to ensure we were reaching more people affected by the disease. You can help us continue our growth by becoming a Champion for Parkinson's.

Champions help raise the critical funding needed for programming and research—but helping to raise funds doesn't have to be a huge chore. There may already be things you are doing this summer that you can turn into a fundraiser for PSBC, such as:

- **Garage sales.** Missed your spring cleaning? Why not hold a garage sale with proceeds benefiting PSBC.
- **Birthday parties.** Ask your friends and family to make a donation to the Society in-lieu of bringing a gift.
- **Beach volleyball tournament.** Enjoy a little friendly competition? Gather together your friends and family for an outdoor volleyball tournament and donate the registration fees.

Whether your idea is big or small, the staff at Parkinson Society British Columbia is well-equipped to help you make the most of your event.

For more information, contact Lucy Isham-Turner at lishamturner@parkinson.bc.ca or 1 800 668 3330.

 Parkinson Society
British Columbia
600—890 West Pender Street
Vancouver, BC V6C 1J9

