Parkinson Canada

Canadian Drug Agency Consultation 2025 on a Proposed List of Essential Prescription Drugs and Related Products

Parkinson Canada

Introduction:

Parkinson Canada, as a community-driven organization, works to ensure that no one is limited by Parkinson's. As we work towards this goal, we know that establishing a list of essential prescription drugs and related products is critical in ensuring that everyone living with Parkinson's in Canada has access to a set of basic medications to help them manage their Parkinson's symptoms.

In response to an ongoing, national consultation by Canada's Drug Agency (CDA), Parkinson Canada is pleased to contribute the following responses to the advisory panel as it prepares a list of essential prescription drugs and related products to inform the potential development of a national formulary using the Carefully Selected and Easily Accessible at No charge Medications (CLEAN Meds) list as a starting point. Informed by WHO Model Lists of Essential Medicines, and including a range of safe, effective, evidence-based drugs and related products that are commonly prescribed and reflective of the health care needs of Canada's diverse population, the advisory panel established and followed a transparent standard set of criteria and processes to determine which products are eligible for inclusion on the proposed list.

We are pleased to respond to the **four questions** as part of this consultation and provide any additional information panellists may require.

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Question 1: Do you have suggestions that could enhance the process for including and excluding products?

Our Answer: Parkinson Canada has two main suggestions to enhance the process for including and excluding products:

1. Bring advocacy organizations to the table so the needs of people with lived experience are continuously reflected and;
2. Respect the needs of traditionally underrepresented populations.

First, no one understands people living with chronic conditions like the organizations that advocate and work for them. Patient advocacy organizations, like Parkinson Canada, must play an integral consultation role in creating and updating processes for evaluating essential medications. We have direct access to the people with lived experience and connections to the clinicians who help people living with Parkinson's every day. Therefore, we best understand the difficulties that people living with Parkinson's face when they cannot access the medications that are needed to help them live life on their own terms. Ensuring the lived experiences of chronic disease communities, like Parkinson's, are included in this process will ensure their realities are understood and appropriate mechanisms are in place to take a preventative approach to drug inclusion that supports the health system. There must be a system in place to have patient organizations at the table to ensure that the voice of the people impacted by this list is heard.

Secondly, as Parkinson Canada works for the entire Parkinson's community in Canada, we suggest that robust mechanisms be implemented throughout the inclusion and exclusion process to ensure that underrepresented populations such as Indigenous Peoples, women, seniors, and rural communities are consulted and included. When these minority groups experience a chronic condition such as Parkinson's, this intersectionality has synergistic effects that can lead to increasing disparities. Giving voices to these groups throughout the process will impact which medicines are deemed essential.

There are many intersections to highlight that should be considered when deciding on medications that should be included or excluded from a national formulary. First, 90% of the Parkinson's community is seniors aged 65 or older with many living on fixed incomes with limited discretionary funds. With medications often only partially covered under public provincial drug programs, out of pocket medication costs reach an average of $1,479 a year for a person with Parkinson's. For seniors, even small out-of-pocket costs can lead to skipped doses, delayed refills, and ultimately worse health outcomes including unnecessary hospitalization, earlier entrance to long term care and reduced independence. Parkinson's dementia and mild cognitive impairment is also common amongst seniors, and this can

make medication management difficult. To combat this challenge, any process for inclusion or exclusion should consider the importance of supportive delivery systems and formulations that are accessible to our growing senior population in Canada.

Women are another group that must be considered when creating exclusion and inclusion criteria for a national formulary. This group is underrepresented in Parkinson's research and the minimal sex-specific findings that do exist have shown that women report different symptom patterns and increased non-motor symptoms. This means that women may respond differently to medication dosing. The CDA must consider how medication coverage for Parkinson's reflects sex-specific experiences, including formulations, dosing schedules and adjunct therapies.

Indigenous and rural communities must also be considered particularly for culturally appropriate considerations for medication access. Many Canadians including Indigenous groups also live in remote regions and have limited access to medical professionals including 26% less access to neurologists in Ontario, 18% less to family doctors and experience 35% more emergency department visits. This means that rural Ontarians, and rural Canadians more broadly, rely heavily on medication than their urban counterparts and the CDA must consider this in their process for including and excluding drugs for the present and in the future.

With Parkinson's requiring several medications to manage symptoms particularly in the advanced stages medications should be considered for inclusion or exclusion with the stability of supply chains in mind. If ingredients or the manufacturing of a given medication can be more easily supplied domestically this should take precedence to prevent over-reliance on unstable international supply chains.

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Question 2: Do you have specific suggestions to support the process of updating the proposed list over time?

Our Answer: Parkinson Canada recommends that the CDA **prioritize medications for diseases with rising prevalence and incidence rates**, such as Parkinson's, as the formulary list is updated over time. In Parkinson Canada's 2024 report titled, *"The Economic Burden of Parkinson's in Canada,"* we found that both the prevalence and incidence of Parkinson's is increasing across Canada. It is estimated there will be more than 150,000 people living with Parkinson's in Canada by 2034. Additionally, our report highlights that when people with Parkinson's can't access medications to manage their symptoms, they require more trips to the hospital, increasing the strain on Canada's health system and public costs associated with hospitalization. In fact, in 2022, the average length of stay for inpatients in acute care for Parkinson's related issues was 12 days. The use of health system resources for those living with Parkinson's will only continue to grow as Canada's population ages and Parkinson's rates increase.

It is important to remember that Parkinson's affects everyone differently and treatment options must reflect this reality. There is no "one-size-fits-all" approach to managing Parkinson's and patients often need to adjust their treatment plans to address new challenges. This reality highlights the importance of the CDA to considering medications at the drug level, not just first-line therapies in each class, when making decisions about coverage. Even when taking medications within the same class, Parkinson's patients respond differently. One first-line dopamine agonist might cause side effects for a patient while another second-or third-line medication is well tolerated. Similarly, a transdermal patch or gel infusion may help someone manage their symptoms more consistently than pills ever could. By taking a drug-by-drug approach rather than relying on broad class-level decisions, we can ensure that people living with Parkinson's get the right medication at the right time, supporting them to live with dignity and maintain their quality of life as their needs change.

New Parkinson's medications have been discovered over the last two years that have made significant contributions to improving the health of our community, particularly in the advanced stages. This is why we feel that the proposed biennial update schedule for the national formulary list is not sufficient. Changes in patients' response to treatment or new emerging therapies can occur at any time and if our community was not able to access one of the new therapies that has emerged in the last two years that would have been a significant blow to improving their quality of life and preventing a serious decline in their health. The solution is to provide a more flexible approach to reviewing the list that reflects equity and the realities people with Parkinson face daily.

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Question 3: Can you identify any commonly prescribed drugs in Canada not already assessed by the advisory panel (e.g., recommended by a recognized health technology assessment (HTA) body, high usage in Canada, and listed on most public drug plans) as set out in the List OR in Appendix 2 in the discussion paper?

Our Answer: There are three Parkinson's medications that we have identified that have not already been assessed by the advisory panel. They are:

1. VYALEV (foslevodopa + foscarbidopa)

VYALEV is a 24-hour subcutaneous levodopa-based infusion that supports the management of severe motor fluctuations and hyper-/dyskinesia. This device-aided therapy does not require surgery and is particularly effective for people who lack control of their motor symptoms and are unable to take oral medication in the advanced stages of Parkinson's. VYALEV has already received positive reimbursement recommendations from the CDA and is accessible through limited use, exceptional, or conditional access programs in almost every province in Canada. We believe that including VYALEV on the national formulary will ensure that regardless of the stage of Parkinson's, people can access the medication they need.

2. NEUPRO (rotigotine)

NEUPRO (rotigotine) is a transdermal dopamine agonist patch that provides continuous 24-hour dopaminergic stimulation by directly activating dopamine receptors, unlike levodopa, which requires conversion in the brain. This mechanism allows for steady symptom control and is particularly beneficial for individuals with progressed Parkinson's who can no longer reliably take oral medication due to swallowing difficulties or gastrointestinal complications. Currently, NEUPRO is available across Canada through special access, exceptional, or limited use programs in all provinces except Manitoba and its widespread provincial use under special access pathways underscores its clinical importance. Adding Rotigotine to the federal formulary would align federal coverage with provincial practice, reduce administrative burdens on physicians and patients, and ensure equitable access to an essential therapy for Canadians living with advanced Parkinson's.

3. Selegiline

Parkinson Canada recommends that the CDA consider adding selegiline to the federal formulary to ensure equitable access to this essential treatment for Canadians living with Parkinson's. Adding selegiline to the federal formulary would align federal drug coverage with every provincial public drug program in Canada, prevent geographic and age-related

inequities, and support Canadians living with Parkinson's in maintaining their independence and quality of life.

Selegiline is a monoamine oxidase B (MAO-B) inhibitor, which works by preventing the breakdown of dopamine in the brain rather than replacing it, offering a different mechanism of action from levodopa and allowing for earlier intervention while preserving future treatment options. The CDA has not yet approved any MAO-B inhibitors for the formulary list making this a critical drug to consider. It is especially meaningful that selegiline be considered for inclusion by the CDA because it is a first-line option for younger-onset Parkinson's people (under the age of 65), many of whom would not receive provincial seniors' drug benefits. Selegiline offers a levodopa sparing strategy in early disease, helping to delay motor complications while providing meaningful symptom control.

Selegiline is publicly funded by all thirteen provincial and territorial drug programs and covered under the federal Non-insured Health Benefits Plan. This meets the CDA criteria to be publicly funded by 7 or more plans. Although selegiline did not undergo CDA review due to its approval and widespread use before the implementation of federal systematic HTA reviews, its grandfathered status on provincial formularies reflects its clinical value and trusted role in Parkinson's care across Canada.

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Question 4: Do you have any other comments that you would like to share with us about the information presented in the discussion paper?

Our Answer: Parkinson Canada believes that people with Parkinson's deserve timely access to the latest, most effective treatments. In this pursuit the CDA must continue to take steps towards broadening its clinical criteria to reflect the real-world experiences of people living with Parkinson's; by doing so the CDA can ensure its assessments are more inclusive and people centered. Given this, we understand why Entacapone, Rasagiline, and Levodopa+ Benserazide were excluded but given their importance to the Parkinson community we would appreciate if they could be reevaluated for inclusion on the list.

Second, by working collaboratively with manufacturers on pricing strategies, the CDA can encourage more companies to launch their medicines in Canada. Third, by providing more clarity and predictability around drug pricing policy, Canada can create a more stable and attractive environment for pharmaceutical innovation. By streamlining its review processes, ensuring clinical criteria reflect real patient experiences, and creating a more predictable and transparent path to coverage, the CDA can play a key role in bringing new therapies to Canadians faster.