

HELP TO CREATE A FUTURE WITH ACCESS TO PROVEN ALS THERAPIES

ALS FACT SHEET

As someone with a significant interest in the needs of Canadians affected by ALS, I want to see the federal government address the challenges in our healthcare system related to access to therapies. This fact sheet provides more information on this topic for your party to consider.

At this very moment, there are **more than 60 ALS drugs** in development, any one of which could be proven effective and become a **future treatment**.

These are some ways in which the federal government can help to create a future with access to proven ALS therapies:

1. **Accelerate patient access:** Coordinate, streamline and increase transparency of the regulatory processes and timelines associated with bringing a drug to Canada so there is faster, more equitable access in the future when more proven ALS therapies are expected.
2. **Put patient needs first:** Managing the cost of new and innovative therapies, must not be done at the expense of people whose very lives may depend on access to new, life-changing therapies that are backed by scientific evidence.
3. **Include the perspectives of people with lived experience:** Meaningful involvement from Canadians with lived experience throughout the drug access pathway can help ensure the program will meet the needs of those it is intended to serve. People affected by the realities of the disease can help with the decisions that need to be made and they deserve to be at the table.

Equitable, timely and affordable access to tomorrow's ALS therapies **shouldn't be a luxury** — it should be a given.

Here are the facts about ALS today:

- ALS is a terminal disease with no cure. It results in progressive paralysis, gradually taking away the ability to walk, talk, eat, move, and eventually breathe.
- ALS can strike young and old, men and women, & all ethnic and socio-economic groups.
- There are 3,000 Canadians living with ALS right now. The number of people affected is much greater when you take into account the impact on family and friends.
- Four out of five people diagnosed with ALS will die within five years
- Each year approximately 1,000 people die from ALS.

The ALS community measures time not by months or years, but by loss – loss of function and loss of life. There is no time to waste: for people living with ALS, the timelines associated with how drugs are evaluated and made available in Canada should not be a barrier to accessing future proven treatments.

