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April 7, 2026

Honourable Mickey Amery
Minister of Justice
424 Legislature Building
10800 97 Avenue
Edmonton, AB T5K 2B6
Ministryofjustice@gov.ab.ca

Dear Minister Amery,

On behalf of the ALS Society of Alberta, I am writing to share our concerns regarding the proposed changes to Medical Assistance in Dying (MAID) legislation (Bill 18), and the potential unintended impact on individuals and families living with Amyotrophic Lateral Sclerosis.

ALS is a progressive, terminal neurological disease with no cure. Individuals may live for years while experiencing significant and irreversible loss of mobility, speech, and independence. The trajectory is often unpredictable, but the decline is profound. This creates unique challenges in health decision-making, particularly when considering future care and end-of-life options.

The ALS Society of Alberta supports the right of individuals to make their own informed decisions about care, including at end of life. We recognize that medical assistance in dying is a deeply personal and complex choice. Our role is to ensure that individuals and their families have access to accurate information, compassionate support, and the opportunity to consider all available options.

Supporting autonomy requires more than the ability to choose. It requires the conditions that make that choice truly free. Individuals living with serious and progressive illnesses must have access to quality care, appropriate supports, and timely information. They should also have the opportunity to engage in advance care planning while they have the capacity to clearly express their wishes, including decisions about how they want to be cared for and, where legally permitted, how they wish to approach end-of-life options.

We are aligned with our colleagues across the neurological community in Alberta in emphasizing that progressive suffering matters, not just terminal status. Policies that rely heavily on the predictability of death risk overlooking the lived reality of those experiencing significant and irreversible decline over time.

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We are particularly concerned that elements of the proposed legislation may unintentionally disadvantage individuals living with ALS and other progressive neurological diseases by:

- Limiting eligibility based on predictability of death rather than severity of suffering
- Restricting advance care planning, despite the likelihood that individuals will lose decision-making capacity
- Limiting access to information necessary for fully informed decisions
- Requiring the presence of a family member at the time of provision, which may create barriers or emotional distress for those who do not have that support or who prefer privacy

These are not easy decisions. As policies and legislation continue to evolve, we encourage the Government of Alberta to consider the lived experience of those facing progressive neurological diseases like ALS. Legislative changes should reflect the realities of these conditions and the importance of preserving dignity, autonomy, and choice.

We support appropriate safeguards to protect vulnerable individuals. At the same time, it is essential that policy frameworks do not unintentionally exclude people from making deeply personal decisions about their care.

We respectfully encourage the Government of Alberta to engage with patients, neurological disease organizations and clinical experts to ensure the full impact of these changes is understood before implementation. We would welcome the opportunity to contribute to this dialogue.

Thank you for your attention to this important matter.

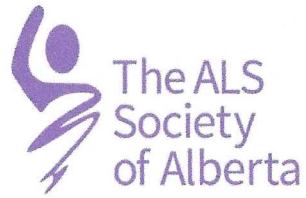
Sincerely,

Leslie Ring Adams
Executive Director
ALS Society of Alberta

Lynn Headley
Chair, Advocacy Committee
ALS Society of Alberta Board of Directors

Honourable Danielle Smith, Premier
Honourable Adriana LaGrange, Minister of Primary and Preventative Health Services
Honourable Jason Nixon, Minister of Assisted Living and Social Services
Honourable Matt Jones, Minister of Hospital and Surgical Health Services

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Dr. Louanne Metz, Chair of Future of Health Care
Irfan Sabir, Shadow Minister for Justice
Janet Eremenko, Shadow Minister for Health and Addictions
Marie Renaud, Shadow Minister for Community and Social Services
Sarah Hoffman, Shadow Minister of Hospital and Surgical Facilities