

SHARED PURPOSE

2018 - 2023
Strategic Plan



COLLECTIVE IMPACT



Degenerative and paralyzing, ALS is a complex and challenging disease.

Over 3,000 Canadians are living with ALS right now, and about 10,000 more will be diagnosed in the coming decade. Eight out of 10 people die within five years of their diagnosis. Today, there is no cure.

Reasons for Hope

These are hard truths. But the reasons for hope continue to grow.

The Ice Bucket Challenge of 2014 raised unprecedented awareness and funds for ALS. More research progress has been made in the last 5 years than in the previous 100. And the number of potential therapies in the pipeline is the greatest it's ever been.



A future without ALS is possible.

As a collective, the ALS community within Canada and internationally will play a critical role in shaping that reality. This strategic plan is the roadmap ALS Canada will be following.

WORKING WITH AND FOR THE ALS COMMUNITY

A strategic plan is important because it tells us how to get from where we are today to the future we want to create. It keeps us focused on the areas that will have the greatest impact in achieving our vision.



The Vision 2024 session held in April 2017 was an opportunity to have the ALS community inform the development of this strategic plan.

ALS Canada's strategic plan was informed by a thoughtful process that included input from the widest possible range of stakeholders and experts. There were four key stages:

A review of board and employee perspectives and an analysis of similar organizations in Canada and internationally to help us clarify our role as part of the broader ALS community.



Engaging the ALS community. This included input from people living with ALS, their families, health professionals, the ALS research community, ALS Societies across Canada, donors, and policy makers.



A synthesis and planning stage, which summarized the information from the previous two steps to establish clear direction for the "future state" we will be working toward and a plan of action to get there.



Validation of the draft strategic plan through consultation with many of the same stakeholders who participated in earlier phases, making further refinements to ensure the final directions resonated.

The final strategic framework was approved by the ALS Canada Board of Directors in April 2018.

TURNING HOPE INTO REALITY

Our strategic plan is grounded in three strategic impacts that speak to how the lives of people affected by ALS will be different in the future.

Aligning our work to advance these strategic impacts marks a future focus for ALS Canada and the people we serve while continuing to address the reality of the disease today. But we can't create the future we envision on our own.



As we begin this journey to turn an era of hope into a future without ALS, we look forward to working in partnership with all of the remarkable and talented people in our community: patients, families, caregivers, researchers, clinicians, partners, policy makers, and donors.

Strategic Impact 1:

People affected by ALS receive the best possible standard of care.



WHAT WILL BE DIFFERENT FROM TODAY?

By 2021: People accessing service and support from ALS Canada are having a better experience.

Ontarians living with ALS have access to quality multi-disciplinary care in the community, hospital and other settings.

By 2023: A Patient Bill of Rights is helping to address gaps in service within Ontario and federally.

By 2028: People are diagnosed with ALS earlier than they are today.



ALS CANADA'S FOCUS AREAS:

Services and support

We'll continue to improve on the **health system navigation, practical advice, and emotional support** we offer to people throughout Ontario. We'll introduce **technology-assisted delivery** and improve support to caregivers after their loved one has passed away. We'll continue to **provide loaned equipment** while advocating for the healthcare system to better meet this critical need.

System coordination

Living with an ALS diagnosis is challenging enough without having to arrange for services and support from multiple organizations, which is often the case given the patchwork nature of our healthcare system. ALS Canada will work with Ontario health agencies, regional/local organizations and ALS clinics to **streamline how care and support are coordinated**, to help make a difficult journey a little easier.

Tools to measure and improve care

We'll spearhead a **Canadian Patient Bill of Rights**, which will set standard expectations of care for people living with ALS. Building on the investments ALS Canada has already made to support the development of **Best Practice Recommendations** for clinical care, we will explore ALS Canada's role in supporting their dissemination, adoption and measurement, and continue to strengthen our engagement with **ALS clinics**.

Strategic Impact 2:

More treatments are available to improve quality of life and extend lifespan.



WHAT WILL BE DIFFERENT FROM TODAY?

By 2021: The impact of high-quality ALS research investments is accelerated.

Canada is seen as an attractive country for ALS clinical trials and drug commercialization.

By 2023: Affordable ALS treatments are available in Canada through a streamlined process.

By 2028: ALS is seen as a chronic illness and is no longer a “bankruptcy disease.”



ALS CANADA'S FOCUS AREAS:

Research investment

As the only organization in the country that provides dedicated funding for ALS research, ALS Canada will have an ongoing role as a **research funder**, while developing **partnerships and collaborations** that will leverage our research funding to have even greater impact and help stimulate other opportunities for ALS research investment.

Capacity-building

We'll continue to host the annual **ALS Canada Research Forum** where Canada's ALS research community shares progress and creates partnerships. We'll also continue to provide grants for Canadian ALS researchers to attend **international conferences**, and for **early-career researchers** to specialize in ALS and drive future discovery. We will look for ways to connect the network of ALS researchers across Canada.

Access to therapies

The best ALS research is of little use if therapies aren't accessible to the people who would benefit. We'll continue to support Canada's ALS clinics in **building capacity to host clinical trials**, so that people living with ALS across Canada have access. We will engage with industry, Health Canada and other organizations that play a role in drug access to advocate for **timely, affordable and equitable access** to ALS therapies.

Strategic Impact 3:

People are empowered to make informed decisions about ALS.



WHAT WILL BE DIFFERENT FROM TODAY?

- By 2021:** Healthcare providers, government representatives and other decision-makers are better informed about ALS.
- By 2023:** People affected by ALS have better access to high-quality, comprehensive and up-to-date information.
- By 2028:** People and families living with ALS are better supported through programs, policies and other initiatives that respond to their unique needs.



ALS CANADA'S FOCUS AREAS:

Awareness and education

Compared to many other diseases, ALS affects a smaller number of people, but in a very significant way. By **increasing awareness of the impact of ALS** – especially among decision-makers within government and potential partner organizations – we can influence funding, policy and program decisions to create positive change.

Access to information

Through our online presence and other communication channels and methods, we'll **improve the quality, amount and frequency of information** that is made available to people and families living with ALS and others who have a need for information and updates.

Community engagement

Our work will continue to be **informed by people who have lived experience with ALS**, in order to ensure that information is relevant and responds to the information needs of those we exist to support. We will engage our community in our work to identify issues and bring forward their collective experiences and perspectives to drive change.

STRATEGIC FRAMEWORK

Vision

The future state we
are driving toward

A future without ALS

This future may
come through earlier
diagnosis and effective
treatments that prevent
symptoms altogether or
through muscle function
being restored after
symptom onset.

Mission

What we do

We work with the **ALS community**
to improve the lives of people
affected by ALS through support,
advocacy and investment in
research for a future without ALS.

Values

How we go about
our work

- Accountability
- Collaboration
- Compassion
- Integrity
- Resiliency
- Respect

Guiding Principles

The lenses we use
as we consider
and evaluate
decisions

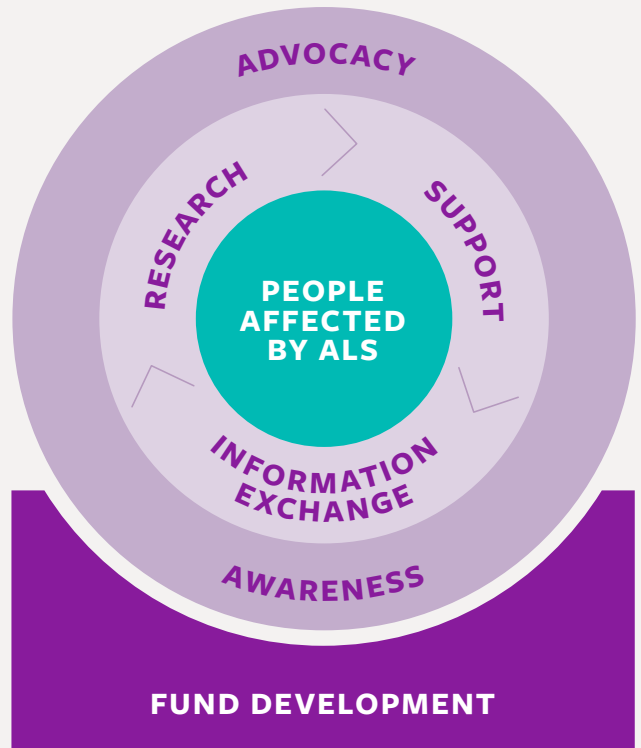
- Client and caregiver-centred
- Collaboration, partnerships
- Equitable
- Informed
- Maximize potential,
minimize duplication
- Timely

The ALS Community

ALS Canada is part of a passionate and compassionate community united by a shared cause. Our community includes people affected by ALS, the donors who make our work possible, provincial ALS societies we work with as federated partners, healthcare professionals and researchers, volunteers and employees, community members and prospective supporters, government, healthcare organizations, and the international ALS/MND community. We believe we all have a role to play in creating a future without ALS.

Strategic Impacts

- 1** People affected by ALS receive the best possible standard of care
- 2** More treatments are available to improve quality of life and extend lifespan
- 3** People are empowered to make informed decisions about ALS



The ALS Canada Model

The mandates on which our organization is focused. They are highly interdependent.



Founded in 1977, the ALS Society of Canada (ALS Canada) works with the ALS community to improve the lives of people affected by ALS through support, advocacy and investment in research for a future without ALS.

ALS Canada has national responsibilities within a federation of provincial ALS Societies across Canada. Through the ALS Canada Research Program, we fund peer-reviewed research grants, foster collaboration and build capacity within Canada's ALS research community, and participate in new areas of research where we are well-positioned to have an impact. Through federal advocacy, we give voice to the collective experience of people living with ALS to help drive program and system changes for the ALS community.

Within Ontario, ALS Canada has a role similar to that of the provincial ALS societies providing services and support to help meet the needs of people living with ALS and advocating for the needs of the ALS population within the provincial healthcare system.

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