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. Today, there is no cure. 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.

STRATEGIC FRAMEWORK

Video

You can view this strategic plan online.

Mission

Our vision is for the ALS community to work together to improve the lives of people affected by ALS through support, advocacy and investment in research for a future without ALS.

Values

- Accessibility
- Collaboration
- Understanding
- Respect

Building Principles

- Client and caregiver-centred
- Collaborative partnerships
- Evidence-informed
- Humane, patient-centred, medical duplicate
- Theory

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 markets are not our target audience. They are highly leveraged.

Shared Purpose

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.

The ALS Canada Model

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

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

Strategic Impacts

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

Video

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.

The ALS Community

ALS Canada is a community of people affected by ALS, their families and caregivers, healthcare professionals and researchers, volunteers and employees, community members and prospective supporters, government, healthcare organizations, and the international ALS/MND community.
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 ten people die within five years of their diagnosis. Today, there is no cure.

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.

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STRAIGHTFORWARD

A future without ALS

The ALS Community

The ALS Community is comprised of community partners across Canada. Our community includes people living with ALS, their caregivers and families, as well as those who support the cause through research, funding and public advocacy.

Reasons for Hope

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.

The ALS Canada Model

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

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2. More treatments are available to improve quality of life and extend lifespan
3. People are empowered to make informed decisions about ALS

Strategic Impacts

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

STRATEGIC FRAMEWORK

Mission

To 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

• Accountability
• Collaboration
• Integrity
• Respect

Building Principles

• Client and caregiver-centred
• Evidence-based
• Informed
• Values-oriented
• Mission-driven

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 follow.

The ALS Canada Model

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

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
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Strategic Impacts

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

FUND DEVELOPMENT

PEOPLE AFFECTED BY ALS

ADVOCACY

RESEARCH SUPPORT

AW AREN ESS

INFO RM ATION EXCH A NGE

FINANCEMENT ACCRU

PERSONNES TOUCHÉES PAR LA SLA

PROMOTION

RECHERCHE SOUTIEN

SENSIBILISATIO N

ÉCH A N GE'D'IN FO RM ATION
The final strategic framework was approved by the ALS Canada Board of Directors in April 2018. This strategic planning framework was informed by a thoughtful process that included input from the widest possible range of stakeholders and experts. There were four key stages:

1. Gathering insights through a community engagement process. This included input from many of the remarkable and talented professionals, the ALS community, hospital and other settings. The process involved working in partnership with all of the remarkable and talented people in our community: patients, families, researchers, clinicians, partners, policy makers, and donors.

2. A synthesis and refinements to ensure the perspectives of all participants resonated.

3. A planning stage, which involved the participation of many of the remarkable and talented people who had participated in earlier phases, making further refinements to ensure the perspectives of all participants resonated.

4. A strategic planning framework for the future we want to create. It keeps us focused on the areas that will have the greatest impact in achieving our vision.

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

Aligning our work to advance these strategic impacts marks a future 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.

ALS CANADA’S FOCUS AREAS: Scientific and research investment

Strategic impact 1: People affected by ALS receive the best possible standard of care.

Goal: By 2018, people affected by ALS will have better access to quality, comprehensive and up-to-date information. By 2021, people affected by ALS will have access to the best available research findings.

A synthesis and refinements to ensure the perspectives of all participants resonated. A planning stage, which involved the participation of many of the remarkable and talented people who had participated in earlier phases, making further refinements to ensure the perspectives of all participants resonated. A strategic planning framework for the future we envision on our own.

1. By 2018, people affected by ALS will have better access to quality, comprehensive and up-to-date information.

2. By 2021, people affected by ALS will have access to the best available research findings.

ALS CANADA’S FOCUS AREAS: System coordination

Strategic impact 2: More treatments are available to improve quality of life and extend lifespan.

Goal: By 2023, we will have made the best possible standard of care.

A synthesis and refinements to ensure the perspectives of all participants resonated. A planning stage, which involved the participation of many of the remarkable and talented people who had participated in earlier phases, making further refinements to ensure the perspectives of all participants resonated. A strategic planning framework for the future we envision on our own.

1. By 2023, we will have made the best possible standard of care.

ALS CANADA’S FOCUS AREAS: Policy engagement

Strategic impact 3: People are empowered to make informed decisions about ALS.

Goal: By 2028, we will have made the best possible standard of care.

A synthesis and refinements to ensure the perspectives of all participants resonated. A planning stage, which involved the participation of many of the remarkable and talented people who had participated in earlier phases, making further refinements to ensure the perspectives of all participants resonated. A strategic planning framework for the future we envision on our own.

1. By 2028, we will have made the best possible standard of care.
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.

Our strategic plan is grounded in three key assumptions: people affected by ALS are at the heart of everything we do; our vision is to turn an era of hope into a future of the disease; and a plan of action will be working toward the final directions of the organization. This approach enables us to establish clear priorities and a plan of action that will be working toward the final directions of the organization.

A synthesis and analysis of similar perspectives and an internationally focused analysis of similar research community, professionals, the ALS research funding, and people living with ALS, their families, health care professionals, and a plan of action will be working toward the final directions of the organization.

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, caregivers, researchers, clinicians, partners, policy makers, and donors.

The best ALS research is of little use if therapies aren’t accessible to the people who would benefit. We’ll continue to improve on the availability of timely, affordable and equitable access to advocate for the people we serve while living with an ALS diagnosis.

As the only organization in the country that provides dedicated funding for ALS research, ALS Canada will have a strategic focus on the future of ALS research investment. Compared to many other diseases, ALS affects a smaller number of people, but in a very significant way. We’ll continue to host the annual conference, where Canada’s ALS research community shares their innovations and progress and creates partnerships. We’ll also continue to provide grants for Canadian ALS researchers to attend national and international conferences, and participatory research to support them.

Informed by people who have lived experience with ALS, our work will continue to be positively influenced by our community. As our work continues to evolve, we’ll look for ways to connect the network of ALS researchers across Canada. We’ll continue to improve on the availability of timely, affordable and equitable access to advocate for the people we serve while living with an ALS diagnosis.

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, caregivers, researchers, clinicians, partners, policy makers, and donors. This approach enables us to establish clear priorities and a plan of action that.

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A strategic plan 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.

As we begin this journey to learn more of hope for a future without ALS, we look forward to working in partnership with all of the remarkable and dedicated 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.

Strategic impact 2:
More treatments are available to improve quality of life and extend lifespan.

Strategic impact 3:
People are empowered to make informed decisions about ALS.

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. As such, the impact of high-quality ALS research investments is accelerated.

Alignment of our work to advance the strategic impacts marks a future state that is focused on putting people first. As we begin this journey to understand what’s possible, we will look for ways to connect the network of ALS researchers across Canada. Continuing to address the reality of the disease today.

ALS Canada’s strategic plan is informed by a thoughtful process that included input from the ALS community, ALS societies across Canada and with many of the people living with ALS, professionals, the ALS research community, hospital and other settings.

Engaging the ALS community. The best ALS research is of little use if therapies aren’t accessible to the people who would benefit. We’ll continue to host the annual ALS Canada Research Forum and to support Canada’s ALS clinics in their commercialization.

By 2023:
- People affected by ALS have access to the latest information from the ALS research community.
- ALS clinics in Canada have access. We will engage with industry, Health Canada and other organizations that play a role in drug development.
- The best ALS research is of little use if therapies aren’t accessible to the people who would benefit. We’ll continue to host the annual ALS Canada Research Forum.

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. As such, the impact of high-quality ALS research investments is accelerated.

By 2028:
- By 2028, to help make a difficult journey a little easier.
- By 2028, a Patient Bill of Rights is helping to inform the development of policies and other initiatives that respond to the unique needs of those living with ALS.
- By 2028, the disease is seen as an attractive destination for international conferences, which will set standard expectations of care for people living with ALS.
- By 2028, the impact of high-quality ALS research investments is accelerated.

The ALS Canadian Bill of Rights is helping to inform the development of policies and other initiatives that respond to the unique needs of those living with ALS.

By 2021:
- By 2021, people are empowered to make more informed decisions about ALS.
- By 2021, compared to many other diseases, ALS affects a smaller number of people, but in a very significant way.
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As we begin this journey to learn more of hope for a future without ALS, we look forward to working in partnership with all of the remarkable and dedicated 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.

Strategic impact 2:
More treatments are available to improve quality of life and extend lifespan.

Strategic impact 3:
People are empowered to make informed decisions about ALS.
The final strategic framework was approved by the ALS Canada Board of Directors in April 2018. The Vision 2024 session held in April 2017 was an opportunity to have the ALS community inform the development of this strategic plan. A review of board analysis of similar organizations and input from policy makers, Canada, donors, and research community, their families, health people living with ALS, community. This working in partnership with all of the remarkable and talented people in our community: researchers, clinicians, partners, patients, families, caregivers, others who have a need for information and updates. By 2021: Awareness and education — especially among decision-makers within government — is raised, in order to ensure access to high-quality, comprehensive and up-to-date information. Compared to many other diseases, ALS affects a smaller number of people, but in a very significant way. The impact of high-quality ALS research investments is accelerated.

**ALS CANADA'S FOCUS AREAS:**

**Research and investment:**

- **Strategic Impact:** People affected by ALS receive the best possible standard of care

- **By 2021:** People affected with ALS receive timely, affordable and equitable access to an array of presentations of ALS.

- **By 2023:** People affected with ALS benefit from high-quality multi-disciplinary care in the community, hospital and other settings.

- **By 2028:** As the only organization in the country that provides dedicated funding for ALS research, ALS Canada will have extended lifespan.

- **Strategic Impact:** More treatments are available to improve quality of life and extend lifespan.

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

- **By 2023:** By Canada is seen as an attractive country for ALS clinical trials and drug commercialization.

- **By 2028:** As many early-career researchers and a diverse set of stakeholders, including representatives and other decision-makers, engage in our community in our work to identify issues and bring forward their collective experiences and perspectives to our national conversations. People are empowered to make informed decisions about ALS. Committed to help those who have lived with, or are living with, ALS and to continue building our capacity to build community and our own knowledge base.

**Community engagements:**

- **Strategic Impact:** People are empowered to make informed decisions about ALS.

- **By 2021:** We'll introduce the ALS CARE application. We'll look for ways to connect the network of ALS researchers across Canada.

- **By 2023:** We'll continue to improve on the quality, availability, and accessibility of services and support for people living with ALS.

- **By 2028:** As many people who have lived with, or are living with, ALS and to continue building our capacity to build community and our own knowledge base.

**Information:**

- **Strategic Impact:** Aligning our work to advocate for the future focus for ALS Canada. It keeps us focused on the areas that will have the greatest impact in achieving our vision.

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**For the ALS Community:**

- **Strategic Impact:** People affected by ALS receive the best possible standard of care.

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**Working with and for the ALS Community:**

- **Strategic Impact:** More treatments are available to improve quality of life and extend lifespan.

- **By 2021:** We'll introduce the ALS CARE application. We'll look for ways to connect the network of ALS researchers across Canada.

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- **By 2028:** As many people who have lived with, or are living with, ALS and to continue building our capacity to build community and our own knowledge base.

**Tools to measure and improve care support are coordinated through consultation and collaboration with all partners and stakeholders to ensure the best possible outcomes for people living with ALS.**

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

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

As we begin this journey to learn what hope looks like in 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, healthcare practitioners, researchers, clinicians, partners, policy makers, and donors.

Aligning our work to advance these strategic impacts marks a future focused on the ALS community 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.

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: consultation with many of the remarkable and talented people in our community, hospital and other settings.

Policy makers, and donors.

The best ALS research is of little use if therapies aren’t accessible to the people who would benefit. We’ll continue to work with Health Canada, 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.

As the only organization in the country that provides dedicated funding for ALS research, ALS Canada will have an ongoing role as a catalyst to accelerate future discovery.

We’ll work to ensure that information is relevant and responds to the information needs of those we exist to support. We will increase awareness of the impact of ALS – especially among decision-makers within government.

We’ll continue to improve on the health system navigation, practical advice, and emotional support that people throughout Ontario. We’ll introduce tools to measure and improve care and support are coordinated to streamline how care and support are delivered.

ALS CANADA’S FOCUS AREAS:

**Strategic Impact 1:**

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

**Strategic Impact 2:**

Access to therapies will be improved.

**Strategic Impact 3:**

People are empowered to make informed decisions about ALS.

### Strategic Impact 1: People affected by ALS receive the best possible standard of care.

**By 2021:** By 2028:

**Strategic Impact 2: Access to therapies will be improved.**

**By 2021:**

**Strategic Impact 3: People are empowered to make informed decisions about ALS.**

**By 2021:**

### ALS CANADA’S FOCUS AREAS:

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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.

### STRATEGIC FRAMEWORK

#### Mission

To 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

- Client and caregiver-centred
- Collaborative
- Equitable
- Informed
- Maximize potential, minimize duplication
- Timely
- Accountable
- Collaborative
- Compassion
- Integrity
- Resilient
- Respect

### Videos

- Outcomes
- Function
- Quality of Life
- Support

### 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

### Building Principles

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

### The ALS Community

The ALS 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.

### The ALS Canada Model

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

1. People affected by ALS receive the best possible standard of care
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### Strategic Impacts

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

### FUND DEVELOPMENT

PEOPLE

AFFECTED

BY ALS

ADVOCACY

RESEARCH

SUPPORT

INFORMATION

EXCHANGE

FÉDÉRATION CANADIENNE DE LA SLA

MÉDICAUX

SOUTIEN

SÉNÉSIBILISATION

ÉCHANGE D'INFORMATION

### 2018 - 2023 Strategic Plan

### COLLECTIVE IMPACT

### SHARED PURPOSE

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.

### The ALS Canada Society

393 University Avenue, Suite 1701
Toronto, ON M5G 1E6
T 416-497-2267   F 416-497-8545
Toll-free 1-800-267-4257
www.als.ca

Amyotrophic Lateral Sclerosis Society of Canada
Charitable Registration Number 10670-8977-RR0002
@ALSCanada
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.

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### Mission

Our mission is to improve the lives of people affected by ALS through support, advocacy and investment in research for a future without ALS.

### Vision

A future without ALS

### Values

- **Client and caregiver-centred**
- **Collaboration, partnerships**
- **Equitable**
- **Informed**
- **Maximize potential, minimize duplication**
- **Timely**
- **Accountable**
- **Compassion**
- **Integrity**
- **Resiliency**
- **Respect**

### Strategic Framework

#### Values

- **Support**
- **Advocacy**
- **Research**
- **Information**
- **Exchanges**

#### Strategic Impacts

1. People affected by ALS receive the best possible standard of care
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#### The ALS Canada Model

The market's constitutional organization championed. They are highly involved.
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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

1. FUND DEVELOPMENT
2. PEOPLE AFFECTED BY ALS
3. ADVOCACY
4. RESEARCH
5. SUPPORT
6. INFORMATION EXCHANGE

1. FUND DEVELOPMENT
2. PEOPLE AFFECTED BY ALS
3. PROMOTION
4. RESEARCH
5. SUPPORT
6. SENSIBILISATION
7. ÉCHANGE D’INFORMATION

1. The ALS Canada Model is a community of people 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.

2. We believe we all have a role to play in creating a future without ALS.

COLLECTIVE IMPACT

The ALS Society of Canada

ALS Canada works with the ALS community to improve the lives of people affected by ALS through advocacy and investment in research for a future without ALS.

ALS Canada has national responsibilities whereas a federation of provincial ALS Societies within Canada. The role of the ALS Canada National Office is to support and align provincial ALS Societies in Canada, to ensure consistency and parity across provinces, and to provide national leadership in areas where ALS Canada has a unique mandate, such as federal advocacy, research, data collection and dissemination, and educational initiatives.

Within Ontario, ALS Canada has a role similar to that of the provincial ALS societies providing local support and support in close proximity to the patient and the provision of innovative new therapeutic medications system.