

THE BURDEN OF ALS IN CANADA

The financial and psychosocial cost of amyotrophic lateral sclerosis (ALS) on Canadians living with the disease, their caregivers, and the health system in 2025.

ALS SOCIETY OF CANADA | 2026



TABLE OF CONTENTS

Executive Summary	3
Introduction	7
About ALS	9
Financial Burden of ALS	11
Psychosocial Burden of ALS	23
What The Findings Mean	30
Conclusion	33
Acknowledgements	34
Appendices	35



Raj, diagnosed with ALS in 2024, and his children.

EXECUTIVE SUMMARY

AN ALS DIAGNOSIS CHANGES EVERY ASPECT OF PEOPLE'S LIVES, INCLUDING THEIR FINANCIAL STABILITY.

At a time when Canadians are already facing rising living costs and economic uncertainty, people living with amyotrophic lateral sclerosis (ALS) and their caregivers are often confronted with sudden income loss, escalating expenses, and significant caregiving responsibilities. In 2026, the ALS Society of Canada (ALS Canada) undertook a national study to quantify the total economic burden of ALS in Canada. Drawing on a survey of people living with ALS and their caregivers on disease-related expenses in 2025, qualitative focus-group research, and published literature, the study models the disease's annual burden from three perspectives: the individual, the unpaid caregiver, and the health and social system.

The study estimates the total annual burden of ALS in Canada at approximately \$628.2 million, or about \$157,000 for each of the roughly 4,000 people living with the disease across the country. It is important to note that these estimates represent the economic burden incurred in a single year. ALS is a progressive disease, and survey respondents were, on average, 2.8 years post-diagnosis. While the report estimates an annual cost of approximately \$157,000 per person living with ALS, this translates to nearly half a million dollars (\$440,000) over the average disease trajectory. The true financial burden experienced by families is therefore substantially greater than the annual figures presented in this report.

The more consequential finding concerns how that cost is distributed. The health system bears an estimated 22% of the total; the remaining 78% falls on individuals living with ALS and their families. The financial weight of this terminal disease, with no cure, is therefore carried largely by households, rather than the system.

LOST HOUSEHOLD INCOME IS THE SINGLE LARGEST DRIVER OF COSTS.

As individuals' disease progresses, people living with ALS leave the workforce, and caregivers reduce their hours or stop working entirely. Among survey respondents, the share of people living with ALS who were working fell from 52% at the time of diagnosis to 13% at the time of the survey. More than 50% stopped working within six months of diagnosis. The resulting loss of household income is estimated at \$449.3 million a year – roughly 72% of the national total, or about \$112,000 per affected household.

Direct out-of-pocket costs, though a much smaller overall share, arise suddenly and early – often forcing families to forgo certain equipment and home modifications they cannot afford. Half of the households that modified their homes spent \$5,000 or less, while the average was close to \$25,000 and the largest single expenditure reported was \$250,000. Nearly one in six households bought a different home or moved into a rental because of ALS. Seventy-nine per cent of survey respondents bought at least one device themselves, and among those who did, only a small minority had the full cost covered.

\$628.2M

**TOTAL ANNUAL
COST OF ALS
IN 2025**

\$157,000

**ANNUAL COST PER
PERSON LIVING
WITH ALS**

78%

**SHARE BORNE
BY FAMILIES**

EXECUTIVE SUMMARY [CONT.]

THESE FIGURES DESCRIBE WHAT FAMILIES PAID. THEY DO NOT DESCRIBE WHAT FAMILIES NEEDED.

Ability to pay therefore shapes every direct cost figure in this report, and the households under the greatest financial pressure are often those that appear least expensive. The direct costs reported here should be understood as a floor rather than a ceiling – the minimum cost of living with ALS, set by what families could afford rather than by what the disease requires.

WHEN NEED DOES NOT BECOME SPENDING – CASE STUDY

Margaret* is 54 years old and was diagnosed with ALS 14 months ago. She lives alone in a two-storey home she has owned for 20 years, approximately three and a half hours from the nearest multidisciplinary ALS clinic. Her adult son provides unpaid care on a part-time basis.

Employment and income Margaret left the workforce within four months of diagnosis. Her household income has declined by approximately half. She does not qualify for provincial income assistance, as the eligibility threshold falls below her current income and substantially below her current expenses.

Home modification needs Stair access became unsafe approximately four months ago. Her bedroom and the home's only full bathroom are on the second floor, and neither is now reachable. Quotes for a lift and for a main-floor bathroom were obtained; both were beyond what she could pay. Her living room has been converted into a bedroom. She has not been upstairs in four months.

Transportation Margaret has no accessible vehicle and cannot meet the cost of one. The entrance to her home has three steps and no ramp. Travel outside the home is limited to clinic appointments and requires assistance.

What Margaret spends Margaret's direct costs are close to zero. She purchased no equipment out-of-pocket, was not able to make any home modifications or purchase a new vehicle that fits her needs. Not because she did not need them, but because she could not afford them. A need that cannot be paid for never becomes a purchase.

Her spending is low precisely because her circumstances are difficult. The less a household can afford, the less it spends, and the smaller its costs appear.

This is why direct costs must be read as a floor rather than a ceiling. What a household spends is confined by what it can pay, not by what the disease requires.

92%

**OF PEOPLE LIVING WITH
ALS DEPEND ON AN
UNPAID CAREGIVER**

94%

**OF WORKING CAREGIVERS
MISSED WORK BECAUSE
OF CAREGIVING**

**Margaret does not represent an individual participant in this study. Each circumstance described was reported by one or more participants, and these have been brought together for illustrative purposes*

EXECUTIVE SUMMARY [CONT.]

These financial findings exist alongside a profound psychosocial cost that economic terms cannot fully capture. Families describe losing independence and identity, expanding caregiving responsibilities, social isolation, and long-term effects on careers, savings, and future plans. For families affected by genetic forms of ALS, those consequences can extend across generations.

TOGETHER, THE FINDINGS SUGGEST THAT ALS IS BEST UNDERSTOOD AS A HOUSEHOLD-LEVEL FINANCIAL CRISIS, NOT A PURELY CLINICAL ONE, AND THAT SUPPORT MUST EXTEND BEYOND MEDICAL CARE.

Jason, diagnosed with ALS in 2024, with his two daughters, Olivia and Aleksandra, and his wife, Christina.

EXECUTIVE SUMMARY [CONT.]



ABOUT ALS

ALS is an unrelenting and currently terminal disease. It progressively paralyzes people because the brain can no longer communicate with the muscles of the body that we are typically able to move at will. Over time, as the muscles of the body break down, someone living with ALS will lose the ability to walk, talk, eat, swallow, and eventually breathe.

Nearly 4,000 Canadians live with ALS, and approximately 1,000 Canadians are diagnosed each year. Four out of five people living with ALS will die within two to five years of their diagnosis. ALS carries a lifetime risk of 1 in 300 for each of us.

ALS is most commonly diagnosed between the ages of 40 and 60, striking people while they are raising families, advancing careers, and contributing to the economy. Veterans face an elevated risk relative to the general population.

For the 90 to 95% of people living with ALS without an obvious family history, traditionally referred to as “sporadic”, it is estimated that between 11 to 16% of cases are caused by known ALS variants. To date, many genes have been identified that, when altered, can contribute to ALS. The four most common genetic causes of ALS involve variants in four genes: C9orf72, SOD1, FUS, and TARDBP. Approximately 5 to 10% of people living with ALS will have a family history of the disease. A family history means multiple family members were affected by the disease due to a hereditary variant in a gene related to ALS.

Jason, diagnosed with ALS in 2024

INTRODUCTION

BACKGROUND

In 2014, ALS Canada funded the first foundational study by Gladman et al. that quantified the direct and indirect costs of ALS in Canada, providing some of the first Canadian evidence on the financial impact of the disease. That work remains a reference point. In the decade since, however, the ALS treatment landscape, the models used to deliver care, and the broader economic pressures on Canadian households have all changed substantially.

There is a clear need for current, Canada-wide evidence that reflects the realities faced by people living with ALS and their families today. This study was undertaken to provide an updated, comprehensive assessment of the economic and psychosocial burden of ALS in Canada in 2025 and to generate evidence to inform policy and raise awareness.

Study objectives

- 1) Quantify the total economic burden of ALS in Canada, including direct and indirect costs experienced by people living with ALS, unpaid caregivers, and the healthcare system.
- 2) Generate credible evidence grounded in the experiences of people affected by ALS, raise public awareness, strengthen advocacy efforts, and inform policy decisions.

Methodology

The study used a mixed-methods approach. The primary data came from a national online survey developed by ALS Canada in collaboration with Leger, which collected complete responses from 223 participants across eight provinces: 127 answering from the perspective of a person living with ALS and 96 from the perspective of a caregiver.

Survey respondents completed the survey at different lengths of time after diagnosis and at different stages of disease progression. On average, respondents were an estimated 2.8 years post-diagnosis. As a result, measures reported “at the time of the survey” provide a snapshot of experiences across the ALS journey rather than at one common point in disease progression.

REPORTED STAGE OF PROGRESSION	SHARE
Progression mainly affects one area (arm, leg, or speech); still independent in daily activities	23%
Progression affects more than one area; some help, mobility aids, or a communication device needed	43%
Reliant on a wheelchair; regular assistance with daily activities, occasional breathing support	29%
Very limited movement; reliant on breathing or feeding support	5%

Reported stage of progression in the survey among people living with ALS.

This was complemented by qualitative focus-group research conducted by ALS Canada, including several sessions with members of families affected by genetically inherited ALS, and by secondary research drawn from epidemiological data, peer-reviewed literature, government and health-system sources, and ALS and healthcare association publications.

INTRODUCTION [CONT.]

Quotes used throughout this report are drawn from open-ended survey responses and focus groups. They are reproduced as written, with minor edits for clarity, and are attributed by respondent type. A full account of the survey design, the construction of the economic model, and the study’s limitations are provided in the appendices.

HOW COSTS ARE DEFINED

TERM	DEFINITION USED IN THE REPORT
Direct Costs	Out-of-pocket expenses incurred as a result of living with ALS or providing care to someone with ALS. These include prescription and non-prescription medications, transportation to medical appointments, and the equipment and home modifications required as the disease progresses.
Indirect Costs	Income loss as a result of ALS. For people living with ALS, this is measured by comparing annual household income before and after diagnosis. For caregivers, it reflects reduced hours or withdrawal from paid work to provide care.
System Costs	Costs incurred by the health system, governments, and employers. Care not paid for directly by individuals, including medications, hospital and physician services, allied health, and lost productivity.

Raj, diagnosed with ALS in 2024, and his wife, Mohini.



ABOUT ALS

SYMPTOMS AND PROGRESSION

Symptoms often begin subtly and can vary from person to person. Early signs may include muscle weakness, tripping, hand weakness, muscle cramps or twitching, fatigue, slurred speech, or difficulty swallowing. Some people first experience symptoms in their limbs, while others notice changes in their speech, swallowing, or breathing. Because the early symptoms can resemble other conditions, diagnosis is often delayed.

As ALS progresses, muscle weakness spreads to other parts of the body, leading to increasing loss of mobility and independence. Everyday activities such as walking, speaking, eating, dressing, and eventually breathing become more difficult as more motor neurons are lost.

The rate of progression varies considerably and is difficult to predict at diagnosis. Some people decline over months, others over many years. This unpredictability itself creates financial strain, because families must decide whether to commit to large expenditures such as home modifications without knowing how long the adaptation will be needed.

TREATMENTS

Disease-modifying treatments in ALS are limited with modest effects. Riluzole has been available in Canada for many years and has evidence of a modest effect on survival that varies by individual. Edaravone has demonstrated the ability to slow functional decline in some individuals in a single clinical trial. Qalsody, approved in Canada in 2025, targets the targets SOD1, the known genetic cause in approximately 2-3% of people living with ALS. This is largely viewed by scientists and clinicians as the first transformative treatment for the disease, with some individuals stabilizing or regaining modest levels of function over time. Beyond these, treatment consists of symptom management including medication for cramps, spasticity, excess saliva and pain, alongside respiratory and nutritional support.

THERAPY	SHARE OF RESPONDENTS TAKING IT	STATUS IN CANADA
Riluzole	64%	Approved and publicly funded
Edaravone	33%	Approved and funding varies by province
Qalsody (SOD1-ALS only)	4%	Approved with conditions; public funding pending
None of the above	31%	—

Use of disease treatments among people living with ALS as reported in the survey.
Respondents could select more than one treatment.

Almost one in three respondents reported taking none of the approved ALS treatments. Reasons include ineligibility under funding criteria, clinical judgement, tolerability, and cost.

ABOUT ALS [CONT.]

MULTIDISCIPLINARY CARE

Canadian best practice recommendations for the management of ALS identify multidisciplinary clinics as the standard of care. These clinics bring together an ALS neurologist with occupational and physical therapists, speech-language pathologists, respiratory therapists, dietitians, social workers, and nurses, with clinic visits every three months. The model is associated with better symptom management, improved quality of life, and longer survival.

Multidisciplinary clinics are concentrated in urban academic centres, and access is not uniform across the country. Analyses of the Canadian Neuromuscular Disease Registry have documented significant differences between provinces in time to diagnosis. Survey respondents described travelling several hours for appointments, and in some cases relocating to be within reach of a clinic.

“After diagnosis, I moved to another province for two reasons: to be closer to family for support, and to be near an ALS clinic, as the closest one was three and a half hours away.” ~ Person living with ALS

Seventy-eight per cent of respondents reported requiring assistance to travel for care, at least some of the time. Travel burden therefore falls on caregivers as well as on the person living with ALS.

ACCESS TO TREATMENTS AND REIMBURSEMENT

In Canada, Health Canada approval of a treatment is only the first step toward access. A health technology assessment follows, then price negotiation through the pan-Canadian Pharmaceutical Alliance, and only then do individual provinces and territories decide whether to list the therapy on their public drug plans and under what conditions. Each stage can take months or years.

For people living with ALS, timely public reimbursement is essential. An ALS diagnosis often leads to a rapid loss of employment income while healthcare, caregiving, and other disease-related costs continue

to rise. Survey results show that many families rely on employer-sponsored insurance, yet these benefits can be reduced or lost when a person is no longer able to work. Among survey respondents, 65% reported public or provincial drug coverage, 38% private insurance paid for by an employer, and 20% private insurance they paid for themselves. Nearly 1 in 12 reported no drug coverage of any kind.

Without public reimbursement, the cost of treatment can place effective therapies out of reach for families already facing significant financial strain. Public drug coverage helps ensure access to treatment is based on clinical need, not ability to pay.

65%

**HAVE PUBLIC OR
PROVINCIAL DRUG
COVERAGE**

38%

**HAVE PRIVATE COVERAGE
THROUGH AN EMPLOYER**

8%

**HAVE NO DRUG
COVERAGE OF ANY KIND**

FINANCIAL BURDEN OF ALS

KEY FINDINGS

An ALS diagnosis comes with significant financial costs that extend well beyond healthcare costs alone. Across all expense categories, **the study estimates the total cost of ALS in Canada at \$628.2 million**, or \$157,000 per person living with ALS. Of this, individuals and their families bear an estimated \$491.6 million, and the health and social system bears \$136.6 million.

How these costs are distributed matters as much as the total. Out-of-pocket expenses such as equipment, home modifications, transportation, and care-related purchases are the most visible costs families face. Yet, they represent the smallest component of the overall burden. The largest cost driver by far is lost household income, as people living with ALS leave the workforce and caregivers reduce employment to provide care.

Taken together, these findings demonstrate that ALS is not only a devastating diagnosis to receive but also a significant financial shock for families. As a result, the true cost of ALS is shared across individuals, families, caregivers, the healthcare system, and charitable organizations, highlighting the need for comprehensive support that addresses both financial and care-related needs.

PERSPECTIVE	ANNUAL COST	PER PERSON WITH ALS	SHARE OF TOTAL
Individuals and families — direct costs	\$42.3M	\$11,000	6.7%
Out-of-pocket medical costs	\$31.5M	\$8,000	—
Equipment and home modifications	\$10.8M	\$3,000	—
Individuals and families — indirect costs	\$449.3M	\$112,000	71.5%
Lost household income	\$449.3M	\$112,000	—
Total borne by individuals and families	\$491.6M	\$123,000	78.2%
Health and social system	\$136.6M	\$34,000	21.7%
Total annual cost of ALS in Canada	\$628.2M	\$157,000	100%

Estimated annual cost of ALS in Canada, 2025, by cost category and by who bears it.

COST TO INDIVIDUALS AND FAMILIES AFFECTED BY ALS

An ALS diagnosis reshapes a family’s financial reality almost immediately. As the disease progresses, the majority of people living with ALS are forced to reduce or leave paid employment, often within months of diagnosis. At the same time, families face growing expenses for medications, transportation, equipment, and home modifications. These pressures often arrive at once, rather than gradually – creating a profound financial shock in which household income declines while costs rise.

FINANCIAL BURDEN OF ALS [CONT.]

The study estimates that **individuals and families bear \$491.6 million in ALS-related costs each year, representing approximately \$123,000 per person living with ALS and nearly 78% of the total annual cost of ALS in Canada.** The largest share of this burden is not direct spending, but income that families lose when ALS affects their ability to work.

LOSS OF INCOME

Loss of income is the most significant financial consequence of an ALS diagnosis. Survey findings show employment drops sharply after diagnosis, with the majority of respondents leaving the workforce within the first six months. No respondent reported working for more than five years after diagnosis.

Average annual household income among these respondents fell from approximately \$146,000 at diagnosis to approximately \$98,000 at the time of the survey, a decline of roughly \$43,000. The median decline was smaller, at \$20,000, which indicates that a subset of households experienced very large losses that pull the average upward.

Extrapolated nationally, the study estimates that lost household income associated with ALS totals \$449.3 million annually, equivalent to \$112,000 for each person living with ALS. Families meet this gap by drawing on retirement savings or funds previously set aside for a child's post-secondary education, selling assets, borrowing from relatives, or abandoning long-term financial goals to cover immediate needs.

“Not being able to work any longer and collecting my old age pension and my post-retirement pension, I’m not making enough money to cover my mortgage, food, vitamins, gas, and parking costs at many visits.”

~ Person living with ALS

Faced with this, many people living with ALS remain in their jobs as long as they are physically able, out of financial necessity rather than choice. Employer health benefits often cover the very medications and services that would otherwise be paid out of pocket, and a salary is worth substantially more than the disability benefits that replace it. Several respondents described income thresholds that excluded them from public assistance while leaving them unable to meet their actual costs.

“Without my private long-term disability insurance, I would be in a financial crisis, and I am frustrated that although my cost of living has increased and my earnings have diminished, I do not qualify for any municipal, provincial, or federal subsidies because the income threshold is so low.”

~ Person living with ALS

FINANCIAL BURDEN OF ALS [CONT.]

DIRECT COSTS

Direct costs such as medications, supplements, and transportation are estimated at **\$42.3 million annually, or roughly \$11,000 per person living with ALS annually.** While publicly funded programs, private insurance, and charitable organizations such as the provincial ALS Societies help offset some expenses, coverage can be incomplete or uneven. As a result, many households continue to absorb significant costs themselves.

Spending on prescription medication illustrates how uneven the picture is. Half of respondents who reported such spending paid \$300 or less over the year, while the average across all respondents was far higher, reflecting a small number of people carrying very large costs. Non-prescription medications and supplements, which are rarely covered by any plan, added a median of \$425 a year. Respondents also identified recurring costs that no program covers, including adaptive clothing and incontinence supplies.

Chris and his mother. Chris lost his father to ALS in 2021.

FINANCIAL BURDEN OF ALS [CONT.]

EQUIPMENT

As ALS progresses, wheelchairs, hospital beds, feeding and breathing equipment, lifts, ramps, and bathroom modifications become necessary. Provincial ALS Societies operate equipment loan programs that are widely used and highly valued by families affected by ALS. Sixty-five per cent of respondents who acquired equipment obtained at least one item through their provincial ALS Society, and 54% obtained at least one item through a provincial or regional health program, such as an assistive devices program.

Even so, the results show that families purchase more equipment than they borrow. Seventy-nine per cent of survey respondents who acquired equipment reported buying at least one item themselves. Among those who paid for new equipment in the past year, the median cost was \$2,000 and the average was close to \$7,000.

“The cost of equipment and modifications to the home is extensive. We need more help in this area. Thank heavens for my provincial ALS Society, otherwise it would cost a fortune, which we don’t have.” ~ Caregiver

Respondents also described delays between identifying a need and being able to meet it. Assessments, approvals, and deliveries take time that the disease does not allow for, and some families purchased equipment privately rather than wait.

“It is a long process, with waiting and appointments with occupational therapists even to get a ramp or a raised toilet seat, so many purchases have been made with our own money.” ~ Person living with ALS

HOME MODIFICATIONS

Home modifications are among the largest single expenses, and they are unevenly distributed. Fifty-nine per cent of respondents reported modifying their home because of ALS. The average amount spent was approximately \$25,000, and the largest single amount reported was \$250,000. Respondents described costs of roughly \$25,000 for a stair lift and ramp, \$38,000 for a main-floor bathroom, \$40,000 for an accessible bathroom renovation, \$75,000 for a bathroom financed through family borrowing, and \$100,000 for a full condominium renovation. Although these examples are not representative averages, they illustrate how large one-time expenses can place significant pressure on households already coping with reduced income.

Even when financial support is available, families often must pay for home modifications upfront and wait to claim a tax credit later. For many households, this creates a significant barrier to accessing needed adaptations.

FINANCIAL BURDEN OF ALS [CONT.]

“Home renovations to accommodate ALS can be very expensive, however they are only funded in the form of a tax credit, so you have to have the available funds to make the renovations before receiving the credit.”

~ Person living with ALS

For some families, modification is not possible and the only remaining option is to move. Nearly one in six respondents reported buying a different home or moving into a rental because of ALS. Moving carries its own costs, and respondents described carrying two properties at once, taking on debt, and struggling to find housing that was both accessible and affordable. Therefore, moving is not always a realistic option.

For families who cannot afford major home modifications or to move to a new home, the consequences can be significant. As ALS progresses and mobility changes, people may find themselves living in homes that no longer meet their needs, unable to safely access important parts of their home or enter and leave it independently. In these circumstances, accessibility is not a matter of preference or personal choice. Financial limitations can leave people living with ALS with few alternatives, effectively forcing them to remain in spaces that become increasingly difficult to navigate.

“We listed our condo and immediately moved into an accessible apartment. The condo is still not sold. We have paid for two places for almost a year now. The debt, and the financial stress on top of watching ALS take the love of my life, has been overwhelming.” ~ Bereaved caregiver

Vehicle modifications can create a similar financial burden. Fourteen per cent of respondents purchased an accessible vehicle, with one respondent reporting a cost of \$113,000 for a vehicle suited to the region they live in. Some respondents also reported needing an accessible vehicle and not having one, including several who stated plainly that they could not afford it. The difficult reality is that without an accessible vehicle, many people living with ALS are effectively confined to their homes.

Timing also plays a central role in the burden. Functional changes often create an immediate need for equipment or home adaptations. Some families reported purchasing ramps, mobility devices, and bathroom equipment to meet urgent needs, while others delayed large purchases because they could not afford them, or were uncertain how quickly their condition would change. As a result, these types of expenses were frequently the ones families could not undertake.

FINANCIAL BURDEN OF ALS [CONT.]

“We live in a townhouse and getting up and down the stairs is becoming more difficult. We had a couple of companies come in to provide quotes for a stair lift, and that cost would be entirely out of pocket. At roughly \$20,000, it’s simply not something we’ve been able to take on, even though we know it will become necessary.” ~ Person living with ALS

IMPACTS ON CAREGIVERS

The majority of the day-to-day care that makes it possible for a person living with ALS to remain at home and in their communities is provided by family members and friends without pay. The study found that 89% of people living with ALS require support from a non-professional caregiver, with an average of 1.7 unpaid caregivers involved. These caregivers are most often spouses or partners, but also include children, parents, siblings, and friends. Their work can include personal care, mobility assistance, communication support, transportation, medication management, equipment coordination, appointment scheduling, emotional support, and advocacy within the healthcare system.

In any other setting, many of these responsibilities would be recognized as paid care work. Within Canada, however, they are frequently seen and treated as an extension of the relationship rather than as labour with measurable economic value. Nationally, unpaid care for people living with long-term conditions or disabilities was valued at \$97.1 billion in 2018¹. Unpaid caregiving therefore represents a substantial form of economic activity that supports the broader health and social care system, despite being largely invisible in the conventional measures of health spending.

The findings in this section highlight that unpaid caregivers are not separate from the ALS care system but a central part of how that system functions. Their unpaid and underrecognized labour helps people living with ALS maintain their quality of life, fills gaps in formal services, and generates significant economic and social value. In doing so, caregivers absorb a substantial share of the disease burden, demonstrating that the true financial burden of ALS extends beyond direct expenses to include lost income, forgone opportunities, and the physical, emotional, and practical demands of caregiving.

¹Fast, J., Duncan, K. A., Keating, N. C., & Kim, C. (2024). Valuing the contributions of family caregivers to the care economy. *Journal of Family and Economic Issues*, 45, 236–249. <https://doi.org/10.1007/s10834-023-09899-8>

FINANCIAL BURDEN OF ALS [CONT.]

THE COST OF TIME

One of the most significant costs associated with caregiving is the value of time itself. The time commitment associated with caregiving can be comparable to a full-time role, with nearly half of caregiver respondents reporting 30 hours or more of ALS-related care and support in a typical week. This was dedicated specifically to caregiving and did not necessarily include the other household responsibilities caregivers often absorb. The significant time commitment associated not only limit caregivers' ability to attend to their own health and well-being but also their ability to engage in paid employment.

“There is a lot of time needed to figure things out with this disease. Appointments, meetings, researching. How do you quantify that?” ~ Caregiver

EMPLOYMENT

Among employed caregivers, 94% reported missing work because of caregiving, and 25% reported missing at least four weeks of work. Many caregivers also reported reducing their hours, modifying their work schedules, taking leaves of absence, declining career opportunities, or leaving employment entirely to meet the growing care needs of the person living with ALS. Caregivers also spend significant time navigating healthcare systems, attending medical appointments, organizing equipment and home modifications, coordinating services, and responding to unexpected health needs. As the individual's disease progresses, these responsibilities can become difficult to manage alongside full-time employment.



Andrea, diagnosed with ALS in 2021.

FINANCIAL BURDEN OF ALS [CONT.]

“I would show up to work and put on a face like everything was fine, and then I would run to my car during my lunch break so I could coordinate her [person living with ALS] appointments and make sure support workers showed up on time. I feel like I live a double life. I am just so tired, but I can’t afford to quit my job.”

~ Caregiver

Formal income support through government programs rarely fills the gap. Only 3% of caregivers reported receiving Employment Insurance and other caregiver benefits in the last 12 months. Others described being ineligible, or exhausting the available weeks well before caregiving ended.

“I had to stop working when we realized that my spouse [living with ALS] would need me next to him 24/7. We were fortunate to have some savings, but what about people who don’t have any? Since I am a part-time worker not registered with Employment Insurance, I don’t receive any financial support to face daily expenses or pay bills.” ~ Caregiver

Sandra, diagnosed with ALS in 2021



FINANCIAL BURDEN OF ALS [CONT.]

Where employers can offer flexibility, the difference is significant. Several respondents attributed their ability to keep working to remote arrangements or supportive employers, and that without them their circumstances would have been very different.

“I am fortunate that I am able to work remotely most days, and that my work accommodates this. Otherwise our situation, and my answers to this survey, would look very different.” ~ Caregiver

HOUSEHOLD INCOME LOSS

Despite these difficulties, for many caregivers, staying in the workforce is not a choice but a necessity as caregiving can be a major contributor to household income loss. Caregivers reported an average household income of approximately \$137,500 before they became caregivers, compared with approximately \$115,700 at the time of the survey or most recently – a decrease of roughly \$22,000 a year.

This loss can have consequences far beyond a family’s immediate budget. Reduced earnings may limit a family’s ability to contribute to retirement savings, maintain mortgage payments, or build emergency savings. Caregivers who reduce their hours or leave the workforce may also lose employer benefits, pension contributions, opportunities for career advancement, and future earning potential.

The result is a difficult financial paradox, where caregivers may need to remain employed to protect their short- and long-term financial security, while the demands of caregiving can make maintaining that employment increasingly difficult.

“My income dropped significantly, and the stress has hindered my speech and cognition. I don’t feel capable of working anymore. My husband [living with ALS] still controls all of our finances, and I fear once he is gone, I will not have the means to support myself.”

~ Caregiver

FINANCIAL BURDEN OF ALS [CONT.]

COSTS TO CANADA’S HEALTHCARE SYSTEM

The health and social system’s share of the cost is estimated at \$136.6 million annually or about \$34,000 per person living with ALS. This includes healthcare services as well as some costs to the governments (provincial and federal) and employers.

Hospital and emergency care

Hospital care is a major part of this cost. Based on the survey, an estimated 37% of people living with ALS had an ALS-related hospitalization in the previous year. When extrapolated nationally and combined with hospitalization cost estimates, this represents approximately \$45.9 million in annual costs.

The scale of hospitalization costs is particularly important because hospital admissions are often caused by gaps elsewhere in the care continuum – such as a fall, a respiratory issue, caregiver burnout or inadequate access to community-based services, which can quickly lead to emergency visit or hospital stays. This means that some of this spending may be avoidable through more sustainable investments in home and community-based care across Canada. In this way, costs related to hospital care reflect not only disease progression, but also the challenges families face in sustaining increasingly complex care at home.

TYPE OF CARE	COST EACH	SHARE WHO USE IT	TOTAL PER YEAR
Hospitalization	\$31,000	37%	\$45.9M
Transportation to care	\$285/mo	24%	\$3.2M
Doctor visits	\$115	100%	\$1.8M
Ambulance rides	\$550	35%	\$1.5M
Emergency Department visits	\$385	35%	\$1.1M

Annual health-system costs of ALS-related care, by type.

“Private care is very costly, and without good care the person will be in emergency more, and then have to be in long-term care, as opposed to staying in the home with proper care.”

~ Caregiver

Respondents also described the system struggling to accommodate ALS specific needs, which can extend admissions or prevent transfer to more appropriate settings.

“Many healthcare staff are not familiar with the nuances of ALS care. My mother has almost lost her voice and relies on an eye-gaze device, and many nurses don’t take the time to set the device up at eye level or to listen to her.”

~ Caregiver

FINANCIAL BURDEN OF ALS [CONT.]

Allied health professionals

ALS care is rarely delivered by an ALS neurologist alone. As the disease progresses, timely access to multi-disciplinary care becomes increasingly important to help manage symptoms. Allied healthcare professionals such as occupational therapists, physiotherapists, speech language pathologists, respirologists, dietitians, and social workers are typically involved in the care of a person living with ALS.

Eighty-seven per cent of the respondents accessed at least one of these professionals in the previous year, most commonly an occupational therapist, followed by physiotherapists, in-home nurses, and personal support workers. Their services account for an estimated \$18.5 million annually, or about \$5,000 per person.

Access to mental health professionals was markedly lower than access to physical care, with 30% of respondents reporting a visit.

It is important to note that while these services represent a significant healthcare system investment, they are also an essential component of comprehensive ALS care. Appropriate access to allied health professionals can help people living with ALS manage symptoms earlier, maintain independence, and potentially avoid more intensive and costly healthcare utilization. As a result, these costs should be understood not simply as system expenditures but as resources that support better outcomes and may help reduce pressure elsewhere in the healthcare system.

Lost productivity

ALS also results in significant productivity losses across the economy as people living with ALS leave the workforce earlier than planned, while family members often reduce their working hours or leave employment altogether to provide care.

The estimated annual productivity loss related to ALS is \$15.4 million, including Employment Insurance costs for people living with ALS and caregivers who can no longer work, as well as productivity losses associated with missed working days.

At the same time, the productivity impact of ALS is not experienced equally by every individual. Factors such as the nature of a person's role, workplace flexibility, remote work options, and the availability of paid time off influence how long someone remains employed and the extent of how disruptive ALS is to their work.

Beyond the financial costs to households, these losses reduce workforce capacity, skills, and experience, creating impacts that extend beyond affected families and into the broader Canadian economy.



Andrew, diagnosed with ALS in 2022.

FINANCIAL BURDEN OF ALS [CONT.]

COSTS BEYOND THE HEALTHCARE SYSTEM

The financial cost of ALS extends beyond publicly funded healthcare. Many supports that allow people living with ALS to remain safe and independent at home are provided by organizations such as provincial ALS Societies across Canada. While they play an essential role, their full value is not always reflected in healthcare spending estimates.

Across Canada, ALS Societies in each province provide a wide range of programs and services, including equipment loan programs, education, support groups, community services, and system navigation. These supports help fill critical gaps in care and ensure people living with ALS can access the resources they need as their disease progresses.

Many of these programs are funded through charitable donations rather than government investment, meaning that a significant portion of the ALS support system depends on philanthropy. Equipment loan programs illustrate this particularly well. Sixty-one per cent of the respondents reported accessing assistive equipment through their ALS Society in the previous year. Items such as wheelchairs, hospital beds, and lifts can be costly and may only be needed for a relatively short period as a person's needs change.

These community-based supports generate value that extends beyond individual families. Access to equipment, education, and community services can help people living with ALS remain at home longer, promote safety and quality of life, and reduce pressure on family caregivers. Without it, many of these needs would likely shift to families themselves or to already strained health and social service systems.

The Government of Ontario has recognized the importance in 2024 of this model through a more than \$13 million investment over three years in the Ontario Provincial ALS Program, which supports multidisciplinary ALS clinics across the province as well as ALS Canada's Equipment and Community Services Programs. Similar investments in other jurisdictions could help sustain these essential services, improve equitable access to support, and reduce reliance on charitable funding.

When considering the total financial cost of ALS, the contribution of **ALS SOCIETIES SHOULD NOT BE OVERLOOKED.** Their programs represent real resources with tangible economic value, even when those costs do not appear in government healthcare budgets. More importantly, **THEY HIGHLIGHT A FUNDAMENTAL REALITY OF ALS CARE IN CANADA:** many essential supports remain dependent on charitable funding to meet needs not fully addressed by the public system. This reliance on philanthropy can also constrain investment in research aimed at developing more effective treatments.

PSYCHOSOCIAL BURDEN OF ALS

The psychosocial cost of ALS refers to these broader social, emotional, and personal impacts experienced by people living with ALS and their caregivers. While these impacts are often discussed separately from financial costs, the experiences shared through focus groups and open-ended survey responses reveal that they are deeply interconnected.

Participants described how financial pressures, changes in family roles, social isolation, uncertainty about the future, and the emotional realities of living with a progressive disease often reinforce one another, shaping daily life and overall well-being. As a result, a comprehensive understanding of the cost of ALS must consider both its financial and psychosocial dimensions. The study was designed to capture not only the financial cost of the disease, but also the lived experiences that help explain its broader impact on individuals and families.

“Although the dollar costs for medications, adaptive devices, supports, and moving can be measured, and can be quite substantial, I believe the social costs are even greater, due to the difficulty of engaging with society and the loss of community, especially when required to move from your home.”

~ Person living with ALS

The findings presented in this section explore each of these themes and illustrate their influence on quality of life for people living with ALS and their caregivers.

LOSS OF INDEPENDENCE AND IDENTITY

For people living with ALS, the loss of independence is one of the earliest and most significant effects of the disease. As physical abilities change, activities that were once routine such as working, driving, managing a household, or participating in social life can become increasingly difficult or no longer possible. Individuals often describe a gradual shift from independence and self-reliance to needing increasing support from family members, caregivers, and healthcare professionals. This transition can affect not only daily functioning, but also a person’s sense of autonomy and control over their life.

Beyond the practical challenges, ALS can also affect how individuals see themselves. As roles and responsibilities change, many experience a loss of purpose, identity, and confidence, particularly when they can no longer participate in activities that once defined them.

“I built my whole life around being the person others could lean on. If something needed fixing or moving, or if someone needed advice, they called me. ALS took that away. Losing my independence has been hard, but I’m also losing my sense of who I once was.”

~ Person living with ALS

PSYCHOSOCIAL BURDEN OF ALS [CONT.]

“For myself, as a very athletic person my entire life, this new journey in mental health is the most difficult. I feel I have lost my identity. The number one issue for me mentally is seeing what it is doing to my wife and family, as they watch their husband and father struggle with day-to-day tasks.” ~ Person living with ALS

Dependence also carries its own emotional weight. Several respondents described guilt about the support they required, framing their needs as a burden imposed on the people closest to them.

“I hate having to be dependent on my husband to help me dress and undress. I don’t like that he has to do all the household chores. Mentally I feel guilty.”

~ Person living with ALS

Jason, diagnosed with ALS in 2024, with his two daughters, Olivia and Aleksandra.



PSYCHOSOCIAL BURDEN OF ALS [CONT.]

CHANGING FAMILY ROLES AND CAREGIVER BURDEN

An ALS diagnosis affects entire households. As symptoms progress, family members often take on new responsibilities and roles that fundamentally change established routines and relationships. Responsibilities that were once shared may increasingly fall to a partner, child, parent, or other caregiver, creating new pressures for families already adapting to a life-changing diagnosis.

“My wife and I split everything totally 50/50 since the kids were born. Suddenly you’re dealing with just one half of that being gone. My wife has to do all of those things. On top of that, she also has to take care of me as well. Just the burden on her has been huge.” ~ Person living with ALS

Respite care exists to relieve some of the pressures, but it reaches very few families. Only 11% of the respondents had used a respite program. Among those who had not, more than a third reported not knowing such programs existed. Others cited concerns about the quality of care in their absence, difficulty arranging cover, a lack of suitable programs in their area, and cost.

Nearly half of caregivers reported seeking mental health support as a result of their caregiving role, while some families described how that support itself was an out-of-pocket expense that they could not fully meet.

“The caregiving stress and responsibility placed on untrained family members, with very little training and minimal mental, social, and emotional support, is cruel.” ~ Caregiver

Beyond direct caregiving related duties, caregivers are often called on to make a continuous stream of decisions, from major care and treatment choices to everyday household responsibilities. Over time, this can contribute to what is commonly referred to as “decision fatigue,” the reduced ability to make decisions after repeated and sustained periods of decision-making.

As the disease progresses, caregivers may also take on the role of surrogate decision-maker and advocate, helping communicate the wishes, needs, and preferences of the person living with ALS. This responsibility can become particularly important when changes in speech or communication make it harder for individuals to express themselves independently. In many cases, caregivers become the person’s voice in interactions with healthcare providers, service providers, and others involved in their care.

“The toughest part is that his [person living with ALS] mind is still sharp, but his voice is just gone. I have to speak for a man who knows exactly what he wants but can’t tell anyone. I do that for him too now.”

~ Caregiver

PSYCHOSOCIAL BURDEN OF ALS [CONT.]

SOCIAL ISOLATION

ALS affects individuals' ability to remain connected to their communities and support networks. As the disease progresses, physical limitations, communication challenges, and accessibility barriers make it increasingly difficult for families to participate in social activities. People affected by ALS describe a gradual narrowing of their social world, with reduced opportunities to maintain friendships or take part in activities that were once an important part of daily life.

For many, isolation was not only a result of the disease itself but also of societal barriers and social stigma with people feeling misunderstood, treated differently, or overlooked because of visible disability or the use of mobility equipment.

“Suddenly there are people you thought were friends who have just cast aside years of friendship over a wheelchair. Like the person in it is an inconvenience and not a person that they know. The world becomes small for someone with ALS, the world is not built to accommodate them. It is in fact built to ignore them and anyone with such physical limitations.” ~ Caregiver

Respondents described the challenge of arriving at venues advertised as accessible only to find they were not, making outings feel too risky to attempt.

“Restaurants and theatres are not clear on their accessibility status, and often say they have wheelchair-accessible washrooms when in fact they are too small, grab bars are not properly positioned, and toilets are too low. This also adds to a sense of isolation.” ~ Person living with ALS

Isolation extends to caregivers, whose own social lives become increasingly limited alongside those of the person they care for. Several described withdrawing from friendships and activities simply because of the lack of time, energy, or the ability to leave the house.

PSYCHOSOCIAL BURDEN OF ALS [CONT.]

“Socially, my husband and I do not see friends as often as we did. We do not go out to restaurants or any other events now. Our lives have completely changed, from very active to staying at home.” ~ Caregiver

Language and geography compound isolation for some families. Respondents in minority-language situations described the added difficulty of managing a complex diagnosis without services in their first language.

“I am fortunate to be bilingual [in English and French], but with this type of serious diagnosis, being helped in my mother tongue would be much appreciated, as the stress of it all makes me a bit muddled.”

~ Person living with ALS

Marda, diagnosed with ALS in 2014, and her son.

PSYCHOSOCIAL BURDEN OF ALS [CONT.]

LIVING WITH A GENETIC FORM OF ALS

In the 5 – 10% of people living with a family history of ALS, the impact of ALS begins long before a diagnosis is received. ALS Canada explored this through focus groups with people who are from families carrying known ALS-linked genetic variants, including SOD1, C9orf72, and KIF5A. Participants included people living with ALS, unaffected gene carriers, and individuals at genetic risk. While these experiences may not be representative of all people affected by genetic ALS, they provide insight into this community's distinct set of psychosocial challenges that are not always captured in discussing the broader cost of ALS.

A common theme across discussions was uncertainty. Participants spoke about growing up with ALS in their family and living with the knowledge that they themselves could be at risk. Some chose to pursue genetic testing, while others preferred not to know their status. Regardless of the decision, participants described the emotional weight of not knowing if, when, or how ALS might affect them or other members of their family. How individuals cope with this uncertainty looks different even within a single family – one participant with a known genetic risk described the pragmatic course as to assume that they have it until proven otherwise, while another participant's instinct is to “ignore until it is here” – but uncertainty remains constant.

Inherited risk of ALS also influences decisions related to genetic testing, disclosure of genetic risk, and long-term life planning. Families face difficult questions about whether and when to pursue genetic testing, how to communicate the risk to relatives and how to navigate the realities that may come with the results of the test. These decisions often carry significant emotional weight and can affect entire family networks.

“I know I have a 50% chance of having the gene, and I believe I’ll need to find out my status soon because my children are older now. They’ve grown up with this disease in our family, and I need to understand what it means for them and the decisions they may want to make.” ~ Person living at genetic risk of ALS

Both potential diagnosis and caregiving responsibilities influenced career choices. Some individuals chose jobs that would be more manageable if physical symptoms developed later in life, favouring work that is less physically demanding, more flexible or offered stable benefits. Others remained in the same role and title for years rather than pursuing promotions or career changes because they felt unable to take on additional responsibility. Time that might otherwise have gone toward pursuing advancement instead went to caring for parents, coordinating care, or supporting family members affected by the disease.

“I couldn’t manage anything, so I was like, I stay doing what I’m doing [at work] because it’s familiar. You don’t make any changes in your work because then... the added stress of that... any other change would just be too overwhelming.”

~ Person living at genetic risk of ALS

PSYCHOSOCIAL BURDEN OF ALS [CONT.]

Depending on the time of their lives when caregiving responsibilities became a reality, participants shared that their educational opportunities were also affected. For some, taking reduced course loads, interrupting their studies, or abandoning educational paths felt like the only way to balance caregiving duties. For some families, the financial consequences of caregiving also limited educational opportunities, particularly when household resources were redirected toward care needs instead of tuition or living expenses. Although raised by participants from families affected by genetic ALS, disruptions to education and career pathways are challenges that may affect young caregivers across the broader ALS community.

“Staying close to home to help care for my dad [living with ALS] influenced where I studied and what opportunities I could realistically take on. Balancing caregiving and school meant reducing my course load, losing access to student loans, and ultimately not being able to finish the program. By the time I was in a position to return and complete it, I was dealing with my own diagnosis.” ~ Person living at genetic risk of ALS

In this way, the impact of ALS for people who are genetically at risk can become cyclical. When caregiving responsibilities affect educational attainment, career progression, or earning potential, the consequences may be felt long after the immediate caregiving period has ended. Families may find it more difficult to accumulate wealth, invest in education, purchase accessible housing, or build long-term financial security. The effects of ALS can therefore extend across generations, shaping life opportunities and socioeconomic outcomes in ways that traditional measures of disease burden do not capture.

Understanding these longer-term and intergenerational consequences is important because it highlights that the burden of ALS is not limited to a single diagnosis or a single point in time. For some families, ALS becomes a recurring influence on life planning, caregiving capacity, financial stability, and future opportunities across multiple generations. ALS affects every part of life for families affected by it, and inherited forms of the disease can amplify that impact over time.

Shaleen, diagnosed with ALS in 2022, and her mother



WHAT THE FINDINGS MEAN

THE BURDEN OF ALS IS SUBSTANTIAL, BUT ITS IMPACT EXTENDS FAR BEYOND FINANCIAL COSTS

The total annual financial cost of ALS in Canada is **estimated at \$628.2 million, or approximately \$157,000 for each person living with ALS**. This measure reflects the financial consequences of the disease, but the findings throughout this report demonstrate that ALS also imposes substantial psychosocial burdens that cannot be readily quantified.

Even within the measurable economic burden, the impact extends far beyond medical care. Individuals and families bear an estimated 78% of the total cost, while the health and social system bears approximately 22%. This distribution demonstrates that healthcare spending captures only a portion of the disease's impact. Much of the burden arises through lost household income, unpaid caregiving, equipment, home modifications, transportation, and other supports that fall outside the traditional healthcare system.

At the same time, the financial estimates presented in this report are likely conservative. Many respondents chose not to answer household income questions, some important costs could not be quantified with confidence, and the survey focused on expenses incurred during the previous 12 months. As a result, major one-time expenses, such as home renovations completed earlier in the disease journey, may not be fully reflected. The study also cannot capture costs that families were unable to afford. In many cases, unmet needs do not appear as expenses but instead as reduced independence, limited mobility, or lower quality of life.

Taken together, these findings suggest that the true burden of ALS is greater than any single dollar figure can represent. The \$628.2 million estimate should therefore be viewed as a conservative measure of the annual economic burden of ALS, while the broader psychosocial impacts described throughout this report highlight the substantial consequences experienced by people living with ALS, caregivers, and families.

LOST HOUSEHOLD INCOME IS THE LARGEST COST DRIVER

Lost household income is the most significant component of the economic burden of ALS, accounting for an estimated \$449.3 million annually, or approximately 72% of the total cost.

Employment can change quickly following diagnosis: among survey respondents, the proportion of people living with ALS who were working fell from 52% at diagnosis to 13% at the time of the survey, and more than half of those who stopped working did so within six months.

Caregivers may also reduce their hours, take a leave of absence, or leave the workforce entirely as care needs increase. The resulting loss extends beyond immediate earnings to employer benefits, pension contributions, career progression, retirement savings, and longer-term household financial security.

WHAT THE FINDINGS MEAN [CONT.]

DIRECT COSTS CREATE SUBSTANTIAL UPFRONT STRAIN

Although direct costs represent a smaller share of the total burden, they can create significant and immediate financial strain. Families may face substantial expenses for medications, equipment, transportation, accessible vehicles, and home modifications awhile their household income declines.

These costs do not affect all families equally. Public programs, private insurance, and provincial ALS Societies help offset some expenses, but coverage remains incomplete and uneven. A family's ability to obtain necessary support may depend on where they live, their eligibility for public programs, whether they have employer benefits or private insurance, their household income, and whether they have savings available to cover upfront costs.

Respondents with stronger private insurance generally reported more manageable expenses, while others faced significant financial strain or struggled to qualify for assistance despite substantial costs.

Delays in assessments, approvals, and equipment delivery can further deepen these inequities, leading some families to pay privately, postpone necessary changes, or go without support they cannot afford. For a rapidly progressing disease, the timing and accessibility of assistance can be as important as whether support exists.

Therefore, this is not a marginal inequity. It determines whether a person can bathe safely, leave their home, communicate, or remain out of hospital.

“You need to be rich and have great insurance to get ALS.” ~ Person living with ALS

CAREGIVERS PLAY A CRITICAL ROLE

Unpaid caregivers are central to how ALS care is delivered in Canada. Ninety-two per cent of people living with ALS depend on unpaid caregivers who provide close to full-time hours of care while simultaneously trying to remain employed. This level of labour is what allows people living with ALS to stay at home rather than in hospital or long-term care, and it is what makes the health system's 22% share possible.

The system relies heavily on unpaid caregivers, yet the social and financial support available to them often falls short of their needs. The findings suggest that strengthening caregiver support is an important part of improving care for people living with ALS.

WHAT THE FINDINGS MEAN [CONT.]

PSYCHOSOCIAL IMPACTS REPRESENT AN IMPORTANT COMPONENT OF THE BURDEN OF ALS

Throughout this study, participants consistently described ALS as affecting far more than health or finances. The disease reshapes how individuals and families experience daily life, make decisions, think about their future and engage with their communities.

The findings highlight that the burden of ALS extends well beyond the person living with the disease. Family members, caregivers, children, and support networks are often affected in ways that evolve over time and may persist long after financial costs have been incurred. The experiences described throughout this report suggest that the full impact of ALS is best understood not as a collection of individual economic or health consequences, but as a profound disruption to the lives of everyone affected.

Recognizing these psychosocial impacts is essential to understanding the true burden of ALS. While they cannot be readily assigned a dollar value, they are a fundamental part of the disease experience and should be considered alongside economic evidence when evaluating support needs, services, and policies intended to improve outcomes for people living with ALS and their families.

Laurel, who passed away from ALS in 2025.



CONCLUSION

ALS Canada undertook this study to establish a current, Canada-wide understanding of the financial and psychosocial impact of ALS and to strengthen the evidence available to inform policy discussions and advocacy efforts.

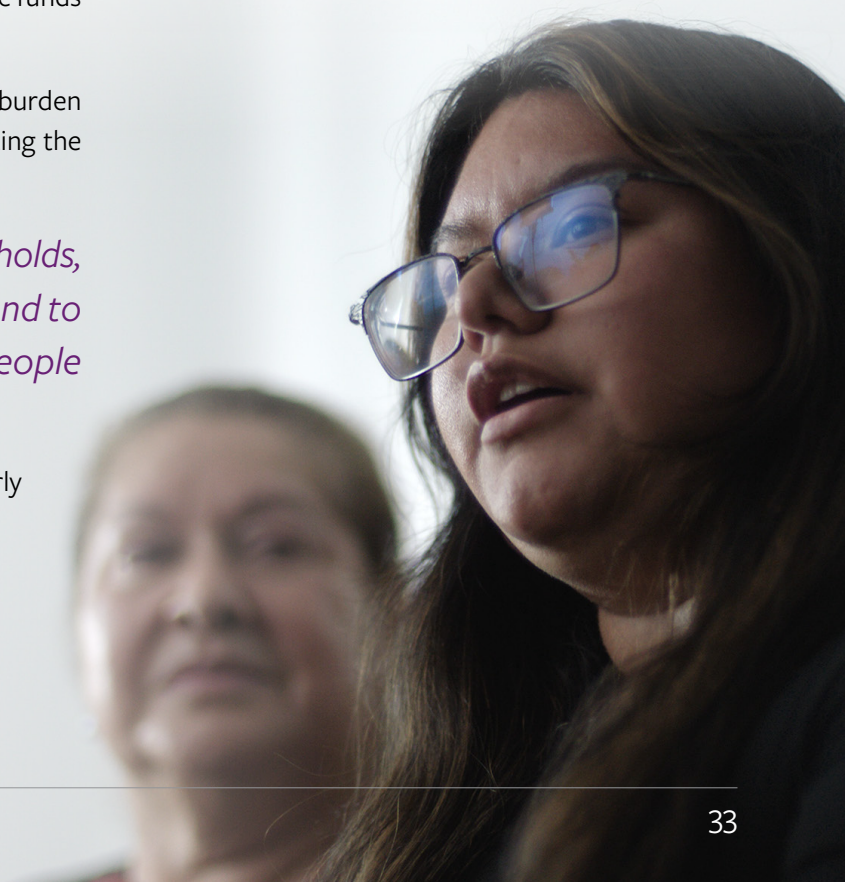
The findings demonstrate that the burden of ALS extends far beyond healthcare costs alone, affecting employment, household finances, caregiving responsibilities, quality of life, and long-term financial security for families across the country.

The study estimates the annual cost of ALS in Canada at **\$628.2 MILLION**, with individuals and families bearing approximately **\$491.6 MILLION**, or 78% of the total burden. Lost household income emerged as the single largest cost driver, while out-of-pocket expenses for equipment, home modifications, transportation and other necessities create significant financial strain at a time when many families are already experiencing declining income. These costs represent the money spent, not the needs that were not met because funds were simply not available.

Given that survey respondents were, on average, 2.8 years post-diagnosis, the cumulative economic burden over the course of the disease may exceed **\$440,000 PER PERSON** living with ALS, highlighting the profound financial impact ALS has on families over time.

Governments and public systems must recognize that ALS affects entire households, not only the person diagnosed, and ensure that programs and services respond to the financial, practical, and psychosocial challenges experienced by both people living with ALS and their caregivers.

ALS Canada will use this evidence to continue to advocate for policies and investment that more fairly reflect the realities of living with ALS.



ACKNOWLEDGEMENTS

A report of this scope would not have been possible without the contributions of many people across the ALS community.

ALS Canada extends its sincere thanks to every person living with ALS, caregiver, and bereaved caregiver who participated in the survey and shared their experiences.

Their contributions helped make visible the financial, practical, and psychosocial realities of ALS and provided the foundation for this report.

We are grateful to the ALS Canada Community Ambassadors who reviewed and helped inform the survey questions, ensuring the research reflected the experiences and priorities of the ALS community. We also thank the ALS Canada Advocacy Committee and Community Services Advisory Committee for reviewing the findings and contributing their perspectives.

Special thanks to the people living with ALS and caregivers across Canada who participated in the focus groups. Their openness and thoughtful contributions brought important context to the research.

Special thanks to **Sana Siddiqui, Sophie Duffy, Stephanie Fletcher**, and their colleagues at Leger for preparing the survey, ensuring participants across the country could take part seamlessly in both English and French, and conducting the research analysis.

This report was developed with the leadership and contributions of the ALS Canada team, including **Ilayda Ulgenalp** and **Kim Barry**.

ALS Canada also acknowledges the generous support of the **JBS Foundation**, which helped make this work possible.

APPENDICES

REFERENCES

Andrews, J. A., Jackson, C. E., Heiman-Patterson, T. D., Bettica, P., Brooks, B. R., & Pioro, E. P. (2020). Real-world evidence of riluzole effectiveness in treating amyotrophic lateral sclerosis. *Amyotrophic Lateral Sclerosis & Frontotemporal Degeneration*, 21(7-8), 509-518. <https://doi.org/10.1080/21678421.2020.1771734>

Brooks, B. R., Pioro, E. P., Sakata, T., Takahashi, F., Hagan, M., & Apple, S. (2023). The effects of intervention with intravenous edaravone in Study 19 on hospitalization, tracheostomy, ventilation, and death in patients with amyotrophic lateral sclerosis. *Muscle & Nerve*, 68(4), 397-403. <https://doi.org/10.1002/mus.27946>

Canada's Drug Agency. (forthcoming). ALS in focus: Canada's systems for ALS care and support. <https://www.cda-amc.ca/als-focus-canadas-systems-als-care-and-support>

Fast, J., Duncan, K. A., Keating, N. C., & Kim, C. (2024). Valuing the contributions of family caregivers to the care economy. *Journal of Family and Economic Issues*, 45, 236-249. <https://doi.org/10.1007/s10834-023-09899-8>

Gladman, M., Dharamshi, C., & Zinman, L. (2014). Economic burden of amyotrophic lateral sclerosis: A Canadian study of out-of-pocket expenses. *Amyotrophic Lateral Sclerosis & Frontotemporal Degeneration*, 15(5-6), 426-432. <https://doi.org/10.3109/21678421.2014.932382>

Hodgkinson, V. L., Lounsberry, J., Mirian, A., Genge, A., Benstead, T., Briemberg, H., Grant, I., Hader, W., Johnston, W. S., Kalra, S., Linassi, G., Massie, R., Melanson, M., O'Connell, C., Schellenberg, K., Shoesmith, C., Taylor, S., Worley, S., Zinman, L., & Korngut, L. (2018). Provincial differences in the diagnosis and care of amyotrophic lateral sclerosis. *The Canadian Journal of Neurological Sciences*, 45(6), 652-659. <https://doi.org/10.1017/cjn.2018.311>

Miller, T. M., Cudkowicz, M. E., Shaw, P. J., et al. (2026). Long-term tofersen in SOD1 amyotrophic lateral sclerosis. *JAMA Neurology*, 83(2), 115-125. <https://doi.org/10.1001/jamaneurol.2025.4946>

Pignatiello, G. A., Martin, R. J., & Hickman, R. L., Jr. (2020). Decision fatigue: A conceptual analysis. *Journal of Health Psychology*, 25(1), 123-135. <https://doi.org/10.1177/1359105318763510>

Shoesmith, C., Abrahao, A., Benstead, T., Chum, M., Dupre, N., Izenberg, A., Johnston, W., Kalra, S., Leddin, D., O'Connell, C., Schellenberg, K., Tandon, A., & Zinman, L. (2020). Canadian best practice recommendations for the management of amyotrophic lateral sclerosis. *CMAJ: Canadian Medical Association Journal*, 192(46), E1453-E1468. <https://doi.org/10.1503/cmaj.191721>

APPENDICES [CONT.]

METHODOLOGY

Study design

The study used a mixed-methods approach, combining primary survey research, qualitative insights, and secondary data within an economic model of the disease's total annual burden. Fieldwork was conducted in 2026 and captured disease-related expenses incurred during 2025.

Survey

The central source of primary data was a national online survey developed by ALS Canada in collaboration with Leger, which was responsible for survey programming and administration. The questionnaire was available in English and French and could be completed on a computer, smartphone, or tablet. It was designed to be compatible with assistive technologies commonly used by people living with ALS, including eye-gaze devices. Prior to launch, the questionnaire was pre-tested with a small group of people living with ALS and caregivers to assess question clarity and to identify issues with survey flow and logic.

The survey gathered complete responses from 223 participants and took approximately 20 minutes to complete. The target population included Canadian residents aged 18 or older who were living with ALS, currently providing care to someone living with ALS, or recently bereaved caregivers whose family member had died within the previous six months.

Caregivers could choose to answer only about their own caregiving experience, or to complete the survey on behalf of the person they cared for, provided they had that person's consent and the person had not already responded. This produces two analytical bases used throughout the report. The ALS perspective comprises 189 responses, combining people living with ALS answering for themselves and caregivers answering on their behalf. The caregiver perspective comprises 96 responses. Where a percentage in this report refers to people living with ALS, the base is 189 unless otherwise stated; where it refers to caregivers, the base is 96.

Recruitment was led by ALS Canada through email outreach, webinar, press release, and social media channels. Although ALS Canada conducted targeted outreach to provincial partners to support recruitment, participation in dissemination efforts varied across the country, and survey uptake differed accordingly by region.

Qualitative research

Survey evidence was complemented by qualitative focus groups conducted by ALS Canada with people living with ALS and with caregivers. Several sessions were held specifically with members of families affected by genetic ALS, including families carrying SOD1, C9orf72, and KIF5A variants, and included people living with ALS, unaffected gene carriers, and individuals at genetic risk. Focus group material was used to interpret and contextualize the survey findings and provides a number of the participant accounts quoted throughout this report.

Secondary research

Secondary research drew on epidemiological data, peer-reviewed literature, government and health-system sources, and ALS and healthcare association publications. Gladman et al. (2014) served as a comparator where scope allowed.

APPENDICES [CONT.]

Building the economic model

The economic model was developed iteratively. The 2014 study was reviewed alongside relevant literature to define the model's structure and the principal drivers of ALS-related cost, spanning epidemiology, work and income, treatments, equipment, allied health, and healthcare utilization.

Available inputs were populated through secondary research, and remaining gaps, where information was unavailable, outdated, or insufficiently detailed, were addressed through the primary survey. Primary and secondary evidence were then integrated and validated against the qualitative findings and prior research to produce estimates reflecting the healthcare, patient and caregiver, and societal perspectives.

National totals were derived by extrapolating per-person estimates across an estimated prevalent population of approximately 4,000 Canadians living with ALS.

Study limitations

The following limitations should be considered when interpreting the findings:

- The survey achieved 223 complete responses, a substantial share of a population of roughly 4,000 people living with the disease but a modest absolute sample.
- Ontario accounts for 77% of respondents, reflecting uneven participation in recruitment across provinces. Findings should be read as weighted toward the Ontario experience, and provincial comparisons were not attempted.
- Additional ALS-related expenses were captured but excluded from the model due to very low sample sizes or highly variable survey data resulting in low-confidence analysis.

ABOUT ALS AND THE ALS SOCIETY OF CANADA

Amyotrophic lateral sclerosis (ALS) is an unrelenting and currently terminal disease. It progressively paralyzes people because the brain is no longer able to communicate with the muscles of the body that we are typically able to move at will. Over time, as the muscles of the body break down, someone living with ALS will lose the ability to walk, talk, eat, swallow, and eventually breathe. Nearly 4,000 Canadians live with ALS and approximately 1,000 Canadians are diagnosed each year. Four out of five people living with ALS will die within two to five years of their diagnosis.

The ALS Society of Canada is working to change what it means to live with ALS. Grounded in and informed by the Canadian ALS community, we respond to the urgent unmet need for life-changing treatments by investing in high-quality research that will fuel scientific discovery and by engaging industry, supporting increased clinical capacity, and advocating for equitable, affordable, and timely access to proven therapies.

Responding to the tremendous need for current and credible ALS knowledge, awareness, and education, we empower Canadians affected by ALS to navigate the current realities of ALS, be informed consumers of ALS information, and advocate effectively for change. In Ontario, we provide direct community services to help people navigate ALS.

Founded in 1977, ALS Canada is a registered charity whose work is powered by generous donors who share our vision of a world free of ALS.

ALS SOCIETY OF CANADA

180 Bloor Street West, Suite 500
Toronto, ON M5S 2V6

als.ca



Cover Image:

Ana, diagnosed with ALS in 2021.