

Letters to **ALS**

Our Journeys to Hope



Foreword

By Dr. Richard Bedlack

If you wrote a letter to amyotrophic lateral sclerosis (ALS), what would you say? Would you express your anger? Your grief? Memories of a loved one whose life was shortened by it?

In this book, you will find letters to ALS that were written by every corner of our community: patients, caregivers, clinicians, and scientists. Reading these letters may help validate, clarify, or even expand your own feelings. As I read them, I was struck by two powerful themes: hope and resilience. Over my career, I have become convinced that hope is more than an emotion or even a coping strategy — it is a treatment.

In my opinion, across every disease where hope has been studied, people with more of it do better medically. They have a better quality of life, a lower symptom burden, and a longer lifespan. By boosting hope in readers, I believe this book can be part of an ALS treatment regimen. It can also be a map. It is clear to me that many of the writers in this book defied ALS by not letting it change the best parts of them or their family members. Perhaps these examples will help others find a path to accomplish the same victories.

What would I write to ALS?



Dr. Bedlack is a professor and director of the Duke ALS program who is highly awarded for teaching, patient care, and advocacy. He has received ALS research grants, participated in clinical trials, and published over 160 articles. He leads the international ALSUntangled and ALS Reversals programs, dedicated to advancing ALS understanding.

Dear ALS,

Once upon a time, the deeds of great people were embroidered onto swaths of cloth called tapestries. Some of these still hang in castles around the world. Over the past 25 years, the folks I've met who are or were living with you have woven a tapestry that will always hang in my mind.

On my tapestry you will find a blue cornflower. These look fragile but are surprisingly tough and can maintain their beautiful colour through the harshest winters. Can you imagine a newly diagnosed person saying they will finish 50 marathons with you...then getting it done? I've seen it happen.

You will find a swallow, an ancient tattoo that sailors got because it was the first bird they saw when land was approaching. To them, it meant they weren't lost at sea. In our community, swallows have become a symbol of hope. I am convinced that those with more hope do better medically, and I am working hard to be a better hope booster.

You will find a microphone for the awareness I have seen raised and a gavel for the laws I have seen changed by powerful advocates living with you. You will find a microscope for the research so many partnered with me on.

You will find music notes, drawings, paintings, poetry, race cars, golf clubs, bows and arrows, playing cards, recipes, fashions, and funny jokes — beautiful parts of people's lives that I was fortunate to share. If a time ever came where we could no longer share these physically, we shared them through photographs and memories. You might challenge but you could never extinguish these creative passions.

One day, the formulas that end you will be embroidered on the bottom of my tapestry. Until then, may the letters in this book weave their way into the minds of readers, convincing them that they can beat you...through resilience and hope, and by not letting it take the best parts of them.

Sincerely,

Dr. Richard Bedlack

Neurologist, ALS Specialist and Researcher

ALS: Uncovering Its True Reach



In a disease that impacts various aspects of life, community support is essential. Learn how ALS societies across Canada provide vital support and resources for Canadians living with ALS and their families.

ALS Society of Quebec

“People living with ALS are among the strongest and most courageous individuals we know. They inspire us every day to carry out our work with purpose, care, and passion.

The team at ALS Quebec works tirelessly to ensure that people affected by ALS across the province have the necessary resources, support, and opportunities to live their lives to the fullest at every stage of the journey. We bring people together to fuel and fund research – a vital source of hope. We empower our community to take action alongside us so that, together, we create the visibility and influence needed to drive positive change.”

- *Claudine Cook, Executive Director, and the team at The ALS Society of Quebec*

ALS Society of Saskatchewan

“Living with ALS reshapes every part of a person’s life – and the lives of those who love them. At the ALS Society of Saskatchewan, our role is to walk alongside individuals and families from the moment of diagnosis onward, offering practical support, trusted information, and compassion at every stage. Whether it’s helping people remain at home, navigating equipment and care needs, or simply being there when the road feels overwhelming, our commitment is to ensure no one faces ALS alone.”

- *Denis Simard, Executive Director of the ALS Society of Saskatchewan*

ALS Society of British Columbia

“Our mission is to service the ALS community in British Columbia and the Yukon, with our primary focus being awareness and the well-being of patients. Through our Equipment Loan and transportation programs, we are proud to be able to provide vital equipment and services for increased quality of life. This allows persons living with ALS to remain at home for as long as possible and at no cost to families. We stand with our community during difficult times, knowing that no one battles this disease alone.”

- *Donald Miyazaki, Executive Director, ALS Society of BC*

Defying the Odds: Eleven Years of Dodging Shadows to Soak Up the Sunlight

Dear ALS,

It's been 11 years since you crept into my life, lurking like a thief in the shadows, waiting to steal my time.

On that cold December day in 2014, in a lifeless room, my legs still shaking from the electromyography (EMG), the neurologist delivered the verdict — you were no longer just the suspect. You, ALS, were unmasked. It took 15 minutes for her to explain the diagnosis and prognosis, but it felt like both an eternity and a flash. As a thousand thoughts flooded my mind, it felt insanely brief to summarize the rest of my life in a matter of just a few minutes.

That evening, I told my wife, then my three adult children, one by one. My youngest asked me: "Papa, will you still be you? I mean, inside?" "Yes," I replied, "with the same horrible jokes coming from the same terrible sense of humour."

"That's all that matters to me," he said reassuringly. My heart swelled. Inadvertently, I had already charted my course: I would face you openly and live every moment intentionally.

Here's what nobody had told me — the first year is the hardest. Sure, the challenges you bring tend to pile on, but the biggest hurdle is in my mind. It's dealing with the mourning of the life that could have been. It is a constant struggle, with endless adaptation, discomfort, and pain.

But life does go on. Whether it's a matter of months or years, whatever time is left, it's worth it to make the most of it.

While I've made mistakes along the way, I did three things right.

Firstly, I made a conscious choice to stay positive and learned to soak up every bit of sunlight you haven't managed to block.

Secondly, I decided to blog about my condition. If sharing my story could help even one person, I would tell it as often as I can and do so without filters.

Lastly, I kept travelling, and I'm proud to say that I've travelled on six continents since my diagnosis. I've seen my children graduate, two got married, and I have three grandchildren. I even "walked" my daughter "down the aisle" at her beach wedding in Australia in a 4x4 wheelchair.

My story started in a sterile environment with artificial lights, but there's been a heck of a lot of metaphorical and literal sunlight throughout my life since. So, I encourage others in your shadow to go towards the light. But no, not that light!

And, whatever happens, keep your sense of humour, even if, like mine, it's pretty horrible.

Living fully,

Norman MacIsaac

Author, person living with ALS



Norman is a distinguished leader in international development, having spent decades addressing poverty and injustice across four continents. Since his ALS diagnosis, he has become a powerful ambassador, channeling his unwavering optimism and advocacy into transforming ALS into a treatable condition, as chronicled in his inspiring book, "The Best of the Worst News."



Until the Last Piece Fits: My Relentless Quest to Solve ALS

Dear ALS,

You are a fantastic puzzle, one that has captivated my scientific curiosity for decades. I first stumbled upon you in the late 1960s, when I was among a handful of young researchers from around the world being trained in electromyography (EMG). Since then, you have become my life's mission to solve.

Like most puzzles, your edges were the first pieces we put together: the tests, the patterns, the obvious clues. But your centre, where the real answers live, takes longer to piece together. To find it, we cannot keep searching in the same places. We must ask different questions, maybe the most important one being, "Why do most of us not get ALS?"

I thought I was chasing signals in muscle, but you taught me to look deeper, into the brain circuits where your story truly begins. You are not only a neuromuscular disease; you are a complex disorder of neural networks, hiding key pieces under the picture and revealing them years later, often when we least expect it.

What began as a scientific curiosity evolved into something more profound. The people you latch onto, and the families who stand beside them, have changed my compass. Their courage and resilience have fueled my commitment for decades. They are the reason I keep returning to the table, putting together one piece at a time.

But I knew I could not do it alone. My quest to understand you has taken me across the globe, bringing together other puzzle masters. We go where your hidden pieces are, from clinics and labs to conference halls, and we have built places and programs to move the work forward, including one of the first centres in North America dedicated to solving you. Together, we have learned that your true nature overlaps with other neurodegenerative diseases and aging itself; you are not as rare as you would like us to believe.

And while this puzzle of yours remains incomplete, we are closer than ever. We are determined to keep going until you are solved. With more minds, more ideas, and more determination, the day will come when every missing piece is finally put together. The hope that one day we can untangle your web and release your clutch on those you have held onto continues to drive me and so many others forward.

Until you are solved,

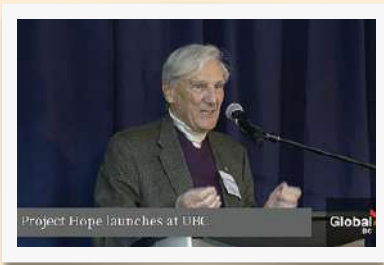
Dr. Andrew Eisen

Neurologist, ALS Specialist, Researcher and Advocate



Dr. Eisen, professor emeritus, revolutionized ALS understanding with his "dying forward hypothesis," shifting its view to a brain-based neurodegenerative disorder.

Dr. Eisen pioneered clinical care, founding one of Canada's first dedicated ALS clinics and co-founding the ALS Society of BC. His visionary research, compassionate leadership, and mentorship inspire the global community in the relentless pursuit of an ALS cure.



The Jealous Monster That Stole Our Dad

Dear ALS,

I think you are a thief. You took my dad when I was just a little girl and needed him the most. Every girl needs a dad growing up, to be taught, guided, and loved. But you robbed me of that. Ever since I was young, I dreamt of my dad walking me down the aisle on my wedding day. You've crushed that dream. I've spent most of my life wondering what it feels like to grow up with a dad, to hug him after a stressful day, to hear him say "I love you" and "I'm proud of you." I will spend the rest of my life wondering what that feels like.

You may have taken so much from me already, but I won't let you take anything else. All the love that I've missed from my dad, I pour into everyone else around me so that they don't have to feel the way I did. I am committed to transforming my loss into a source of compassion, and it is this profound empathy that inspires my pursuit of a career centred on caring for others.

Grace Stock

Daughter of Dean Stock, who lived with ALS



Grace is an 18-year-old student from Hudson, Quebec, and the daughter of the late Dean Stock. She was deeply shaped by her father's ALS journey. Her studies in Criminology Intervention reflect her commitment to supporting and advocating for people in vulnerable circumstances and making a meaningful difference.

Dear ALS,

Every girl needs her dad but for some reason you decided to take mine from me. I see you as a jealous monster who feeds on the happiness of others. You saw the huge impact my dad had on everyone, and you got jealous. Because of you, I lost my dad and my best friend, leaving me with loads of grief to replace the huge mark he made in my life.

I've been struggling with the loss of my dad since I was seven. Now, I'm 16 and struggling to handle the guilt I feel. I catch myself asking "Why? Why me? Why my siblings? And especially why my mom?" The worst part is I ask why my family and not someone else's. I feel guilty asking that because I would never want to wish this grief on anyone, not even my worst enemy.

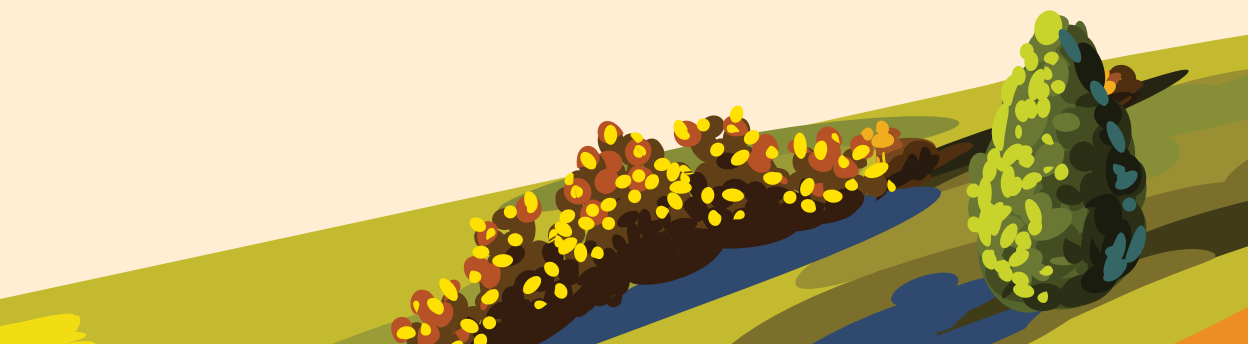
ALS, you have stolen so much from me. And while you may have tried to steal my dad, you could never steal my memories of him. I still see him as my Superman, forever strong and larger than life. He feared that I would only remember him with the identity you tried to give him, but all I can ever talk about is how incredibly cool he was. That's the dad I'll carry with me, always.

Sophie Stock

Daughter of Dean Stock, who lived with ALS



Sophie, 17, is the youngest daughter of the late Dean Stock. This profound challenge taught her never to take time with loved ones for granted. She now finds happiness helping others who have experienced loss, giving voice to their confusing thoughts and emotions, and transforming her personal journey into a positive force, offering comfort and understanding.



Finding Their Way: A Mother and Son's Journey to Healing After Loss

Dear ALS,

You are brutal and unrelenting. You not only strip the body bare, but you also destroy the dreams of all of those touched by you. You are a *TAKER*, ALS. And I refuse to let you steal anymore.

I've realized that to truly care for my children and give them the life they deserve, I needed to take care of myself first. And truthfully, I'm living this life for the first time too, navigating it day by day without a map. I'm not a pro.

What I do know is that because of you, I choose to GIVE. Give thanks, give love, and give my kids a life full of gratitude, humility, and hope. So, to honour Dean, the kids and I stay soft, humble, and will choose to love hard and live big!

In honour of Dean,

Paula Ciampini

Former spouse of Dean Stock, who lived with ALS



Paula's life has been profoundly shaped by her experience as the primary caregiver for her husband, Dean, following his 2014 ALS diagnosis. Since then, Paula and her family have remained actively involved with the ALS Society of Quebec, and she and her children found healing and connection through Myra's Kids Foundation, a local children's bereavement foundation, affirming her belief that there is indeed life after loss.



Dear ALS,

When I was 12 years old, you took my father away from me. It was an extremely dark time. Being the older brother to two beautiful girls, I knew I needed to step up and carry my weight. The months following my father's passing are seemingly blurred. I was numb and felt myself operating on autopilot daily.

Being the only "man" in the house at 12 years old left a heavy burden, and I did the best a 12-year-old could. In doing so, I continued to push my grief further away. I cried in the shower or on top of the washing machine so that nobody would hear me. I'm the older brother... so, I did my best to keep a smile on my face and assure my sisters that everything was going to be okay.

I was offered the chance to see a therapist, but I continuously refused. I was afraid and not ready. You, ALS, had this grip on me that I couldn't shake. Eight years later, I found myself lost in a crisis, overwhelmed as all the emotions I'd buried came rushing back at once. Reluctantly, I chose to seek help. And from that day forward, I began to feel lighter. What I needed most was time, as grief has no timeline. Getting help – on my own terms – was the best thing I could do for myself, and for my family. ALS, I am happy to say you are no longer the director of my life. I am.

Moving forward,

Luke Stock

Son of Dean Stock, who lived with ALS



Luke is the 20-year-old son of the late Dean Stock. He is studying Business Management and Finance, and his passions include hockey, lacrosse, and travelling. Luke and his family are active ALS advocates, participating in numerous fundraising activities, including organizing the Dean Stock Pond Hockey tournament for research. He hopes his story offers comfort to others and encourages them to seek help when needed.



The Guilt of Learning from the Pain You Cause

Dear ALS,

I remember when we first met. I hadn't yet understood the depth of your impact — how quickly you move, and how completely you alter a person's world. You are relentless. It was a brutal education. And yet, I stayed.

It's strange, isn't it? My career has led me straight into the path of your destruction. For 27 years I've been a nurse, and for the past seven, you've been my constant shadow.

Here lies my conflict: the skills I've learned, the depth of compassion I've gained — they all come at the expense of those you've touched. I feel guilty, becoming a better nurse through everything I've witnessed. Am I exploiting their suffering?

I've learned to balance empathy with steadiness, to be present without being consumed by grief. If I cried with every person that you've sunk your claws into, what good would I be? So instead, I focus on being a steady hand in guiding them through your storm. But the question often lingers: is there something wrong with me that I can separate myself? That I don't take it home, that I accept the inevitable?

You are cruel, ALS, and one of the hardest challenges a person can face. But you are also one of the greatest teachers. You've shown me the strength people carry within themselves, and the bonds that form when life is at its most fragile. You've taught me perspective — to let go of small worries, to cherish each moment, and to see the joy and courage in everyday life.



I may not be able to erase you, but I can walk alongside those you affect. And perhaps, in that presence, there is a different kind of hope. A hope that, one day, someone will discover the key to ending your story, and my career, and the suffering it's built upon, will finally be obsolete.

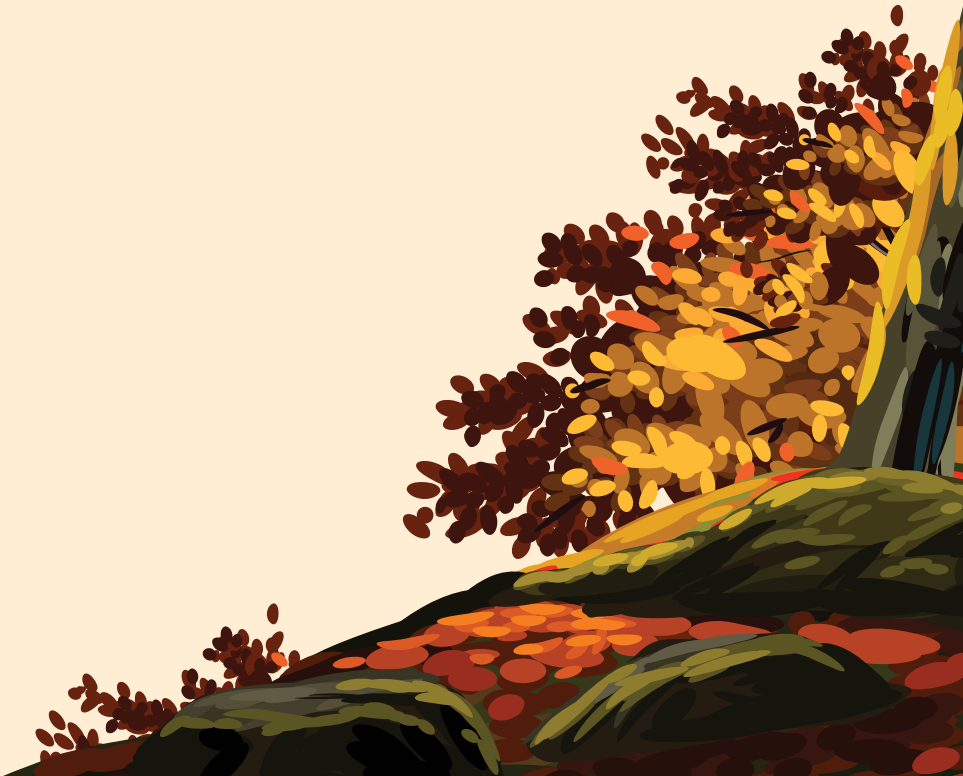
Bearing witness,

Barb Miller

ALS Nurse



Barb is an ALS nurse coordinator at McMaster University Medical Centre who provides comprehensive care to patients with motor neuron diseases. With over 27 years of experience as a registered nurse, including award-winning academic distinction (I.O.D.E. Princess Marina, Addison and Wesley Publishers Awards), her deep understanding and steady dedication offer support and hope to people navigating ALS.



Bearing Witness and Nurturing Spirit When ALS Tries to Take All

Dear ALS,

At first, I wanted nothing to do with you. I was comfortable in the woman's pavilion, unable to imagine working in neurology. When my manager suggested I cover the ALS clinic, I envisioned a desolate, challenging endeavour. I agreed to three months, but 15 years later, I am still here.

Working with you, ALS, is not for the faint of heart; it carries more than its share of grief and loss. Yet, you have profoundly shaped my understanding of life. You've taught me to cherish simple moments, be it walking in the woods, swimming, speaking, and being heard, as gifts not to be taken for granted.

While you try to take as much as you can from those you latch onto, my job is to help individuals hold onto what you cannot touch: their spirituality and humanity. My role isn't to fix, but to bear witness to profound hope and grief, shining light on dignity and meaning when so much is lost.

Beyond supporting patients and caregivers, I also extend spiritual care to healthcare professionals who navigate this journey. They walk with individuals, often from diagnosis to the end of life, experiencing their own forms of grief and compassion fatigue. I offer them a vital space to process their experiences and find strength and resilience to continue to face you, head-on.

One of my first patients was someone whose identity revolved around caring for others. As ALS stripped her abilities, my role was to help her navigate the profound shift from caregiver to receiver,



ensuring she remained a person, not a diagnosis. Despite her physical decline, her nurturing spirit persisted. Just before she passed, she shared a room with a young, scared brain tumour patient. Without speech, she comforted her roommate until their last breath, making them feel safe. This taught me that true communication and connection exist beyond words and actions, and that small gestures can overcome great hurdles.

This wisdom, and the words of Lao Tzu, profoundly inform my work: “When two great forces collide, the victory will go to the one that knows how to yield. In the end, it is the water that shapes the stone, and not the other way around.”

In the spirit of shared humanity,

Lana Kim McGeary

Spiritual Care Counsellor



Lana, a spiritual care counsellor for 15 years within the Montreal Neurological Institute and Hospital ALS program, holds a Master's in Religious Sciences. Her work centres on contemporary spirituality, guiding patients and healthcare professionals to find dignity and meaning amidst profound loss. She fosters resilience through practices like art and music, emphasizing appreciation for life and connection beyond physical limitations.



You Remind Me That Children and Youth Need Support in Families in ALS

Dear ALS,

In all my years as a social worker, knowing diseases like you, it has become completely clear that you are truly a disease of the family. Children are affected. Your presence disrupts family life. Yet, it can also be beautiful, filled with powerful and caring moments between parents and children, grandparents and grandchildren. These are the moments that inspire me, challenge me, and keep me dedicated to always bringing the voices of the youth to the fore. Through my work, I have sat with many families, often with a child present, listening, scared and silently carrying the weight of your presence in their homes.

Sitting in their Cape Town living room, Amilie asked, “Do you want to see where my daddy died?” She recounted the ways she helped care for him in the two years you were an unwelcomed guest in their home. She wanted me to remember her with a drawing, and to remember her father – memories you can never erase and I will never forget.

Aaron was one of the youngest participants in the YCare program. He seemed too serious for his age, fixated on the gait belt. When I asked why, he tearfully confessed, “I dropped my grandma last week.” We all stopped and surrounded him in a circle of embrace, as other kids spontaneously shared similar experiences. A joke came out to break the silence, and suddenly, they were laughing, being kids again, reminding me of the ups and downs of what you are, ALS.

These youth are the fuel to my practice, my research and my unwavering commitment to developing programs that offer education and support, ensuring you don't break them or their families. Even when the challenges seem insurmountable, the memory of Aaron's tears, Amilie's courage are why I keep going.

For every child and young caregiver, with persistent hope,

Melinda S. Kavanaugh

PhD, Professor of Social Work



Dr. Kavanaugh is a professor of social work at the University of Wisconsin-Milwaukee who dedicated her clinical research career for the last 25+ years to providing support for young carers/youth caregivers globally. She is the President and Founder of Global Neuro YCare, the only global non-profit dedicated to providing education, resources and support for children and families living with neurological disorders.



Her Mantra, My Mission: Living in the Paradox of Joy and Pain

Dear ALS,

It's easy for me to say that you stole from me... you took the physical life of my wise and beautiful 36-year-old daughter, Jessie. It is a pain that this vilomah – a parent who has lost a child – lives with every second of every day.

However, encouraged by Stephen Colbert's thoughts on grief, I want to learn to embrace all aspects of my life... the joy and the pain. Colbert said, "To be grateful for your life, you have to be grateful for all parts." If I had heard this in the earlier days of Jessie's journey with ALS, I would've been resentful. How could I be *grateful* for ALS?

My question, "How can I be *grateful* for ALS?" had then become, "How can I have hope?" You (ALS) make hope seem impossible, so instead, I held onto faith... faith that processing my grief will guide me to fulfilling my purpose. Through Jessie, you (ALS) have taught me that there is more to me than I have given myself credit for. I have been holding onto Jessie's daily mantra, "Today I choose joy," knowing that not every day is joyous. I have the resilience to operate daily in the paradox of joy and pain with dynamic degrees of both.

ALS, you forced a timeline upon us. You forced Jessie to think about her legacy. I recall the fascinatingly intense conversations a daughter and mom have when death is on the doorstep.



Through caring for Jessie during her 20 months of living with ALS, you gave me a wisdom otherwise unknown to me, and I can share this with other caregivers in our ALS community. The night before Jessie died, she asked me to do what I could to help those living with a life-limiting disease, and that has become my mission.

You have given me a life I didn't ask for, nor wanted. But to be honest, you have given me a strength and purpose I am proud of, and I know Jessie would be proud of as well.

With purpose,

Heather Lucier

Mother of Jessie, who lived with ALS



As a primary caregiver to her late daughter Jessie, Heather offers a deeply personal understanding of caregiving. She adapted a vital program, now delivering it specifically to ALS caregivers. Heather honours Jessie's legacy through the Jessie Ravensborg Memorial Award and shares her insights by presenting on caregiving to healthcare professionals and the public.



How We **Fight Back**



Everyone's experience with ALS is different, with its own unique challenges and learnings. ALS community leaders explain how sharing these stories can help empower, educate, and instill hope.

ALS Action Canada

“Stories of people living with ALS, and those that love them, are essential to educating people, organizations, and key decision-makers on the devastation and diverse experiences of this disease, and urgency for change. ALS Action Canada is a Canadian patient-driven ALS organization that centres and amplifies voices of those impacted by ALS to compel action for better support, treatment and research toward a cure. We are extremely grateful to all those who share their personal stories, not only for themselves, but also to drive positive change for the ALS community.”

- Leigh Naturkach, Executive Director, ALS Action Canada

ALS Society of New Brunswick and Nova Scotia

“Every individual and caregiver we are privileged to serve teaches us invaluable lessons in resilience, selfless sacrifice, and service, as well as the capacity to find joy amid adversity. Their experiences stay with us and continually guide our commitment to providing compassion and hope to those diagnosed with ALS.”

- ALS Society of New Brunswick and Nova Scotia

ALS Society of Newfoundland and Labrador

“My journey as an advocate began in 1989, when my dad Len Reid was diagnosed with ALS, and it revealed the critical need for compassionate, province-wide care. At the ALS Society of Newfoundland and Labrador, our focus is empowering individuals to maintain their quality of life for as long as possible. We deliver this vital support by sourcing essential equipment, answering questions, and collaborating with the St. John's ALS clinic to connect families to care. Our promise: dedicated, province-wide support so no one faces ALS alone.”

- Cheryl Power, Executive Director, ALS Society of Newfoundland and Labrador

Confronting ALS on Every Front: Unlocking Pathways for Those Told There Are None

Dear ALS,

I was drawn to medicine to find treatments for people who were told there were none. That conviction led me straight to you, choosing to confront you head-on, not because it was easy, but because it was needed.

When you strike, you come from every angle. So, I learned that the only way to confront you is on every front. In the clinic, the line between personal and professional blurred in ways I never expected, especially after watching a mentor receive your diagnosis. In the lab where science becomes the scaffolding for hope. And in the rooms where decisions are made, because progress depends on people willing to push it forward.

Every trial, resource, guideline, and innovation becomes a key that unlocks answers and opens pathways to care, actively working to reduce the harm you cause. In the '90s, I worked to bring clinical trials to Quebec, ensuring those you go after no longer had to cross borders to find answers. We built a Phase I clinical trial unit, strong enough that trials now come to us. I championed making genetic testing routine, family history or not, because answers shouldn't depend on assumptions; today, that approach is standard across Canada. Practical tools and frameworks were established to make care clearer, communication more consistent, and pathways more open. I keep going because these efforts change what is possible for the people you affect. And we are not done yet.

None of these keys alone are the solution. But together, they unlock pathways you once tried to keep shut.



You recognize no borders, and neither does my work. I connect teams, harmonize tools, open dialogue, and help build the global network we need, expanding collaboration to underrepresented groups. We move faster when we move together, and hope must travel as far and as urgently as you do.

You are formidable – but so am I. I have nothing left to prove, yet everything left to fight for. As long as you are here, I'll keep working because those you afflict are counting on us to stop you in your tracks.

Still fighting,

Dr. Angela Genge

Neurologist, ALS Specialist and Researcher



Dr. Genge is an internationally recognized neurologist specializing in rare neurological diseases. She is the Executive Director of The Neuro's ALS Clinic at Montreal Neurological Institute-Hospital and has established one of Canada's largest clinical research centres, including a pioneering Phase 1 Unit, and leads numerous clinical trials. Awarded for her work, she actively shapes major international ALS initiatives including ACCESS ALS, CAPTURE ALS, and TRICALS.



ALS Can't Take Everything; I Am Still Myself...

Dear ALS,

I'm angry at what you have taken from me, in a very real and deeply felt way. You have taken pieces of my life that mattered, and I carry that loss every day.

As a mother, I am angry that you stole my voice before my kids were old enough to remember its sound. They were only one and four when you began creeping into our lives. When they hear me speaking in old videos, they are always surprised. It hurts. They ask a lot of questions – questions that their dad has to field because I cannot. I am angry that I can't call their names, answer their questions without a lot of extra effort and a device, or comfort them with the ease I once took for granted.

I am still their mother in every way that counts. But you changed how I can express that love, how I nurture them. I cannot lift them. I cannot run to them. I cannot meet their needs with the simple movements and words that once flowed so naturally. Because of you, ALS, I even had to stop breastfeeding my youngest just before 18 months, as opposed to the two full (and a half) years the older one got. They deserved the full experience of me, and you denied them that, with your cruelty.

If my role as a mother wasn't enough, you also went after my professional identity; further fueling my anger. My work as a psychologist was built on communication, connection, and helping others understand their inner world. My voice was my tool, my way of being present and useful. When you took that, you forced me to relearn how to express who I am.

I can still think, still understand, and still feel empathy. But sharing those parts of myself now requires effort, patience, and time.

ALS, because of you, I've lost a part of the life I worked so hard to build. And yet, even with everything you have taken, you did not erase me, despite your best efforts.

I am still a mother. I am still a thinker. I am still someone who loves deeply and fiercely. I am still ME.

You changed my life, but you did not take away my ability to be myself.

I live in your presence every day. But I refuse to let you decide the entirety of my story. I'll keep going, despite what you keep throwing at me.

Still me in every way that counts,

Jess McCarthy

Pediatric Psychologist, Person living with ALS



Jess is a psychologist at Newfoundland and Labrador Health Services, wife to Avery, and mother of two young sons, Jack (7) and Clark (4). Despite ALS impacting her ability to speak and changing beloved pastimes like knitting and crocheting, Jess continues her valued work, supported by an excellent team.



A Shadow Looming Over Our Family

Dear ALS,

I don't think I remember life without you. You have always been there, a shadow lingering in even my earliest memories. For my family, you were not a sudden intrusion but an inherited presence – a genetic imprint passed quietly from one generation to the next. A silent dread that, over time, became our family's "normal." I grew up being told to keep quiet about our family's history with you, perhaps born of fear or a lack of understanding of your true nature – but I did the opposite.

I watched as my loved ones were taken, one by one, often within months of one another. I was just six years old when you took five of my family members within the span of three months, and questions began to burn inside of me. Why wasn't anyone helping? Why do people not understand more about you?

It isn't fair. You, ALS, aren't fair.

Knowing that you are a part of my family's genetics, it wasn't a surprise when genetic testing confirmed that you had affected me too. But while you expected me to face you in silence, I refused. I refused to let you steal my voice or the voices of those I love. I became an advocate, not just for my family, but for everyone who is impacted by you.

When it comes to my children, I refuse to be quiet. I have seen what happens when voices weren't raised, when people let themselves be silenced. I saw firsthand how trying to hide you only limits a child's questions and understanding.



You are part of their genetic story; they have a right to know! I may not be able to protect them from you completely, but I can equip them with the knowledge, strength, and tools to face you if they ever have to. They will ask questions, they will speak up, and they will be prepared.

ALS, I'm not going to let you continue to win. You may try to devastate me, you may try to silence me, but I'm strong and I won't let that happen. I'm not going down without a good fight.

Fighting for all,

Paula Trefiak

Mother, advocate, and person living with familial ALS



Diagnosed with genetic ALS at the age of 34, Paula is a powerful voice in the ALS community. She holds key roles in organizations like the ALS Society of Canada and the International Alliance of ALS/MND Associations. She was honoured with the 2025 King Charles III Coronation Medal for ALS Advocacy for her work reshaping research and support in ALS.

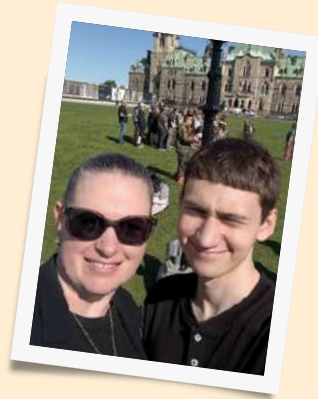


Dear ALS,

Most kids my age think of the future as an exciting time, full of possibilities. But for me, my family's history with you made the future seem scary. Because you are a part of my family's genetics, I couldn't help but wonder if you would come after me like you did my mom and others, or if I would be spared. Thankfully, my parents did what they could to prepare me for all possibilities, and because of that, I tried my best not to let you hold me back.

My mom told us stories of how she wasn't allowed to talk about you outside of the family. But I grew up having open conversations about you and your impact on my family. We talked about what it means to have you be a part of our genetics, and because of that, I may have to face you one day. While I didn't know for sure, I spent a lot of my childhood preparing for what life would be like with you.

For me, not knowing was one of the hardest parts. I just wanted to know. Because of that, I asked to be tested, and after a short referral period, it was confirmed. But even with all the preparation, nothing can really prepare you for the truth. Learning about my family history with you was one thing, but knowing for sure that I will have to face you was like going through it all over again.



But I didn't let that stop me. I wasn't going to let you stop me. If anything, knowing the truth makes me want to do something to help others like me, and my mom and my family, who are forced to live with you.

Even though this is all new to me, I have traveled across Canada to join in the fight against you. I've shared my family's story at places like Parliament Hill because I want others to know that you don't just go after people of a certain age, you go after kids and families, and we need to find a way to stop you.

No one should have to spend their childhood afraid of you, and I hope that one day, no one will have to.

Not letting you win,

Benjamin Webb

Student, advocate, and person living with familial ALS



Benjamin is the 18-year-old son of Paula Trefiak, who was also diagnosed with genetic ALS. He is a dedicated student with aspirations to study Chemistry in post-secondary. In early 2025, Benjamin discovered he carries the SOD1 ALS gene, a profound personal connection that now drives his dedication to ALS advocacy, including speaking on Parliament Hill.



Fueled by Anger: A Fight for Dignity and Better Quality of Life

Dear ALS,

You ask a lot of me. My work isn't just a 9-to-5; it's a constant, compassionate pursuit to ensure no patient (and their loved ones) loses hope, despite all you put them through. I've dedicated my life to helping to write the script for how we fight you and shaping the standards for care. While you are relentless, so am I.

I've seen the system so often fail patients at critical junctures: from the agonizing wait for a diagnosis to the devastating delivery of life-altering news. In collaboration with my peers, recognizing that delays and ineffective communication can severely impact quality of life, I helped pioneer initiatives like the Refer ALS program,* expediting early diagnosis, and the A-L S-PIKES protocol,† providing clear guidelines for compassionate communication. These aren't just programs and tools; they are about empowering both patients and providers, ensuring dignity and better outcomes during the most vulnerable moments. This was a milestone, ALS.

My anger fuels me – anger at you, at the system, at the narrow focus on statistics over genuine quality of life. I'm angry that simple interventions are often overlooked, and that our healthcare system prioritizes procedures and metrics over the very essence of living. Quality of life being measured by numbers, not by joy. It's incomprehensible.

*ReferALS is a tool that helps non-ALS physicians identify potential ALS symptoms and provides guidance on when and how to refer patients to specialized clinics to accelerate diagnosis and access to care.

† The A-L S-PIKES protocol provides healthcare professionals with a step-by-step guide to empathetically and effectively deliver difficult news, like an ALS/MND diagnosis, to patients and their families, aiming to improve communication and quality of life.

I've taken this fight beyond our borders, too, because healthcare should be a universal human right, not one defined by geopolitical lines. I've worked internationally, building capacity in low-resource areas, training healthcare workers to manage conditions associated with disability, including you, ALS. This global advocacy ensures that no one, regardless of where they live, will be forgotten.

So, back off, ALS. My commitment to these patients is absolute. My hope is that through this unwavering commitment, we can bring comfort, dignity, and ultimately, a future where your power is diminished. I'm not done fighting, not for a single patient, not for a single moment.

With resolve,

Dr. Colleen O'Connell

Physical Medicine and Rehabilitation Physician, ALS Specialist and Researcher



Dr. O'Connell is a distinguished medical director at the Stan Cassidy Centre for Rehabilitation. She is the founder of Team Canada Healing Hands, a non-profit dedicated to advancing rehabilitation in lower-resourced countries. A passionate advocate for best practices and an early adopter of innovation, she notably championed the national recognition of ALS as a compensable illness for military veterans in Canada.



Preserving Joy Through Food, Ensuring Life Still Tastes Good

Dear ALS,

I can't say it's been an honour knowing you, but I do have to thank you. You've given me the opportunity to work alongside amazing colleagues, bringing joy to the strong and resilient people you've targeted, and helping me find my purpose and passion in this work.

As a dietitian working with people living with ALS, I quickly saw how deeply patients struggled, not just nutritionally, but with the profound impact on family mealtimes. For many, cooking and eating with loved ones was their love language. This resonates with me, as it was the same for my own family. Food is far more than fuel; it's culture, memory, comfort, and celebration. It's the laughter, the family recipes, the joy of sharing. My mission became ensuring they could still savour these moments, even if differently.

When I first meet patients, I often encounter a "wall." You, ALS, try to cast dietitians as the "food police," feared for taking things away. There's an initial fear of, "Oh great, here's one more thing she's going to restrict." But as I explain my recommendations, they realize I'm not restricting; I'm encouraging, adding, and preserving. Witnessing that wall come down, seeing them open to help, is an incredibly rewarding feeling.



As you diminish their ability to swallow, I work to ensure the enjoyment of food is never lost. While it may look different, if it tasted good in its original form, it will still taste good modified. I encourage creativity, finding ways to make eating easier, less exhausting, and more joyful. I help transform the meals they enjoy, not as “hospital food” but as *their* food.

My mission is simple: as you take away, I give back. Perhaps not in the way it once was, but in a manner that still provides enjoyment and quality time with loved ones. No matter how you change the rules, ALS, I will tirelessly find ways to restore moments of pleasure, connection, and dignity. I will ensure that even in your shadow, life can still taste good.

Sincerely,

Shameem Kizar

Registered Dietitian



Shameem is a registered dietitian with over two decades of experience providing expert nutrition care for complex neurological conditions like ALS. At the Kaye Edmonton Clinic in Calgary, she specializes in dysphagia management and making nutrition fun and accessible. A passionate educator and speaker, she helps patients maintain dignity and joy through food, ensuring life still tastes good.



Keeping Life in Motion When ALS Gets in the Way

Dear ALS,

When I first started working with individuals you pursue, and their families, I was overwhelmed. Your presence meant changes in their mobility, self-care, work, and leisure, requiring constant problem solving to stand against you. Before I had met you, I worked in rehabilitation where I helped people progress, not lose function, and I was scared that I would not have the emotional strength to watch people change and eventually pass away.

Luckily, I was wrong. I can't imagine not working with the great people who face you. I provide strategies and equipment designed to help them remain safe and independent for as long as possible. I encourage them to explore new leisure activities and new ways of doing daily tasks. It is so inspiring to watch someone regain the ability to do something meaningful through adaptive aids and techniques. Together, we adjust, we troubleshoot, and we celebrate the wins, large and small.

It's a privilege to be part of teams that provide strategies and equipment to help make trips like a cruise possible, or to find ways for someone to get to their grandson's hockey game, things that often seem impossible when you, ALS, get in the way. I never expected we would joke and laugh during clinic visits, looking at pictures of trips, family, and happy moments. You, ALS, are the disease, but you don't define the person. Our focus is on LIVING with you, not being controlled by you, and finding ways to maintain quality of life.

I never expected I would learn so much about resilience, hope, and strength from the people you confront. I am excited to see them, eager to hear about their lives, and ready to problem-solve ways they can keep doing what they enjoy or try something new they never considered. This journey has motivated me to share my knowledge and how the people we support have influenced our clinic's approach. It drives me to create and share resources, so others just starting this work aren't as fearful as I once was. I still have sad days when someone passes on, but they are far outweighed by the memories of what people achieved, even when you try to take it all.

With ongoing dedication,

Krista MacMillan

Occupational Therapist



Krista is an occupational therapist with 29 years of neurological rehabilitation experience. Specializing in ALS care, she focuses on providing strategies and equipment to help individuals maintain independence and quality of life. A committed educator, she shares her expertise through lectures and resources, drawing inspiration from her patients' resilience. She also co-created "ALS: A Quick Guide to Occupational Therapy."



The Mark You Leave, The Purpose I Found

Dear ALS,

When I was first approached to work with those you inflict, I wasn't sure I wanted to take you on. The idea of it sounded heavy. I knew the weight you carried, and I wasn't certain I was ready to meet you so closely.

But within my first few clinics, something shifted. I felt an immediate connection to the people I was meeting and to the trust they placed in me. They were letting me into profound moments of fear, uncertainty, and vulnerability. It was then that I realized I could help shoulder some of the immense weight that comes with your presence. I could be a steady anchor, sitting beside them when everything else felt anything but.

Those early years were difficult, emotionally. I was the one walking into rooms to talk about breathing becoming harder, breathing muscles getting weaker, or difficult decisions that needed to be made – decisions no one ever wants to face. I still feel the weight of those conversations.

Breathing is an effortless act most rarely thought about, until it demands our attention. Something that once came so easily, can transform into an effort and ongoing chore, because of you. As a respirologist, I meet people at the point when breathing becomes frightening and uncertain. Supporting patients and their families through that stage is intense, but it is also one of the deepest privileges of my work. There is meaning in helping someone breathe more comfortably. In helping families feel prepared, supported, and not alone. In bringing calm into a room overwhelmed by your storm.

ALS, you keep me on my toes. Your movement is quick. But I am always trying to think several steps ahead. Watching you closely, anticipating what may come, and trying to prevent small changes from becoming crises is my hope. That vigilance shapes every part of my practice.

Despite what you think, you are not what you used to be. Not because you've changed, or evolved, but because we have. Over the course of my career, our approach to respiratory care against your impact has evolved. We intervene earlier. We anticipate more. We act sooner. We are better at staying ahead of you than we've ever been, and I am proud to have contributed to that shift.

Despite the heaviness you bring, I find immense purpose in this calling. I am continually inspired by the resilience of those who stand amidst your lingering shadow and grounded by the trust placed in me during some of the most vulnerable moments. This path is not easy. It is intimate. It leaves a mark. And I'm honoured to do it.

Holding steady,

Dr. Anu Tandon

Respirology Specialist



Dr. Anu Tandon is a respirologist at Sunnybrook Health Sciences Centre in Toronto, Ontario where she holds the title of Division Head of Respirology and Medical Director of the Home Ventilation Program and Pulmonary Function Laboratory. She is a member of Sunnybrook's multidisciplinary ALS clinic, where she supports people living with ALS and their families through the respiratory course of the disease, with a focus on early intervention, anticipation, and informed decision-making.



You Underestimate the Human Spirit

Dear ALS,

You underestimate us.

You think that you can strip away what makes someone themselves. That by freezing a body, you erase the person inside.

But what I've seen tells a different story. Humans are far more adaptable, far more spirited, and far stronger than you give us credit for.

As a palliative care physician, I've walked into hospital rooms and homes where you've already arrived. I've seen what you take. But more importantly, I've seen what you can't.

I've watched people who once defined strength by movement discover new forms of power – in humility, in humour, in love that expands to fill every corner you try to darken. They surprise themselves, and the rest of us, by how fiercely they keep showing up.

We've been conditioned to believe that our worth lies in what we can do physically. The legs that move, the hands that feed, the voice that answers back. But you, ALS, remind us that who we are is much larger than the body we inhabit. You challenge us to see spirit, identity, and purpose as unbreakable.



Those you target become our teachers, showing us how to live with courage and grace.

I want families, clinicians, and communities to meet you with open eyes and steady hearts. Too often I find people facing you in the dark. So, I keep speaking, teaching, and sharing, hoping that by spreading this light fewer people will face you in fear.

ALS, you may try to steal from us, but you will never take our meaning. Every day, I see people outshine you, one breath, one smile, one act of grace at a time.

With hope,

Dr. Sammy Winemaker

Palliative Care Physician



Dr. Winemaker is a dedicated palliative care physician who provides compassionate care to patients with serious illnesses like ALS. A McMaster Associate Clinical Professor, she is an award-winning leader in palliative care education. Passionate about human-centred care, Dr. Winemaker co-hosts “Waiting Room Revolution” and co-wrote “Hope for the Best, Plan for the Rest: 7 Keys for Navigating a Life-Changing Diagnosis” alongside her co-author Dr. Hsien Seow.



The Tide Is **Turning**



ALS comes with many unknowns, and constantly learning and adapting is essential. Discover how ALS societies across Canada listen, understand, and respond to the evolving needs of people impacted by ALS.

ALS Society of Canada

“People living with ALS are at the heart of everything we do. Every day, we listen to and stand beside our community, working together to help improve the lives of Canadians affected by ALS. Over the last decade, we have seen significant progress in ALS research—discoveries that help us better understand and treat the disease. Knowing how isolating this disease can be, we’ve committed to providing information and resources so that no one has to face ALS alone. By joining our voices and efforts, we keep advocating for fair and timely access to the care and treatments everyone deserves. Together, we will continue our work toward a world free of ALS.”

- Tammy Moore, CEO, ALS Society of Canada

ALS Society of Alberta

“It is an honour to walk alongside our clients and their loved ones. Their strength, honesty, and resilience shape everything we do. At the ALS Society of Alberta, we are deeply committed to providing support for today, with a commitment to change the course of this disease for the future.”

- Leslie Ring Adams, ALS Society of Alberta

ALS Society of Manitoba

“The ALS Society of Manitoba has made incredible strides in expanding our client services and support for individuals impacted by ALS across the province. We’ve also witnessed advancements in understanding this disease, bringing the community closer to unlocking real solutions. This progress fuels our unwavering hope for a future where we gain the upper hand against ALS, leading to better outcomes for individuals impacted by this disease.”

- Diana Rasmussen, Executive Director, Client Services Coordinator, ALS Society of Manitoba

ALS Society of Prince Edward Island

“The ALS Society of Prince Edward Island is dedicated to making each day the best possible for those living with and affected by ALS.”

- ALS Society of Prince Edward Island

You Took My Speech, Not My Story

Dear ALS,

I was formally introduced to you almost two years ago, just before Christmas. Though, my body was telling me something was wrong, even before we met – a lump-like feeling when I swallowed, and a slower, raspier speech, like someone recovering from a stroke. Still, nothing prepared me for hearing your name. To say I was shocked to meet you was an understatement.

No one in my family had heard of you, let alone, your second identity, Bulbar ALS. In my mind, I called you “Vulgar” because that’s exactly how you felt. It was a big education for us all.

As a retired teacher, losing my voice was one of the hardest parts of encountering you. It was difficult to accept that I could no longer tell a story, lead a discussion, describe the latest antics of my grandchildren, sing a song, or just carry on a conversation, at least not the way I was used to.

Just as hard to accept was no longer being a caregiver. I am the oldest of nine siblings, the mother of four children, and grandmother of nine grandchildren, and have always been there for them. Now I have to accept being the one cared for.

And yet, ALS, while you have made my life difficult, you have failed to make it impossible. My exceptional medical and palliative care teams have prepared me for every stage you bring.

My home and family have adapted with me. Labeling things in the fridge helps my husband decide what leftovers to eat. A whiteboard and notepad in each room helps me communicate with hubby, visitors, and home care workers. A large kitchen calendar keeps track of the many appointments. A feeding tube takes care of my nutrition.

What has truly made life bearable is the gift of retaining my voice. With the help of my wonderful speech therapist, I now use a Speech Assistant app. Through a company called ElevenLabs, a recording of my voice was transformed into a digital version. With it, I can have real conversations. I can also record messages for meetings and share my thoughts.

Because of this technology, I can still participate in the communities that matter to me, such as the Mermaid Women's Institute and the Memory Keeper's Writing Group.

ALS, you have changed my life, but not who I am. My voice may sound different now, but my story continues.

In my own words,

Donna Gallant

Retired teacher, person living with ALS



Donna is a retired teacher and lifelong storyteller from Prince Edward Island who was diagnosed with ALS in December 2023. She is a matriarch and community leader, who faced the loss of speech with grace and determination. She is the first in PEI to use advanced voice cloning technology to communicate and remain connected to her loved ones and communities.



Silencing the Disease, Saving the Voice

Dear ALS,

When I chose to become a speech-language pathologist, I imagined a career spent helping people strengthen their voices. Never did I expect to work in a field where voices were taken away. Meeting you for the first time changed everything. Initially, I wanted to resist you. I wasn't sure where I fit. Instead of restoring speech, I found myself trying to support people as they slowly lost it. How could I find purpose in helping people say goodbye to their most personal instrument – their voice?

These people you so ferociously prey on, they are what drives me. They have been my greatest teachers. Not defined by loss, yet resilient, courageous, and endlessly resourceful. This has been an amazing reminder that speech is only a small part of communication. What matters most is identity, connection and dignity. And I vow to help preserve that.

And now, I have found a way to share hope. With AI voice cloning,* I can help people preserve their natural voice and allow them to speak in tones untouched by you. Their families hear *them*, not you. Their laughter, stories, and essence shine through.



*Voice cloning uses AI to create a natural, personalized digital replica of someone's voice from recordings, enabling it to speak new text with their unique sound and characteristics.

So, ALS, while you have taken much, you have also given me a calling I never imagined. Even after 19 years working to silence you, the way you've tried to do to so many others, I haven't given up. In fact, I'm more motivated than ever. You forced me to look beyond what is lost and toward what can still be found; and use that to encourage the beautiful people who have the dreadful task of facing you. You remind me daily why this work matters: to ensure that voices endure, even in the face of silence.

I will not thank you, but I will acknowledge you. Because of you, I have witnessed courage, and because of that courage, I will continue to find hope.

Always with optimism,

Kerry Adams

Speech-Language Pathologist



Kerry Adams is a speech-language pathologist with over 30 years of experience, dedicated to supporting adult neurological populations. As an integral part of the Edmonton ALS Clinic in Calgary since 2006, her mission is to empower individuals by maintaining communication access and quality of life. Passionate about augmentative and alternative communication (AAC), she applies her expertise to help patients preserve their voices and identity.



Finding Joy and Choosing to Live Was Our Way of Defying ALS

Dear ALS,

You entered our lives in March of 2014.

After months of uncertainty and searching for answers about what was happening to my beloved wife Judy, the doctor confirmed it was you. We were shocked and shaken, but we decided that we were going to do whatever we could to have the best life possible. That was our way of ensuring that even against you we were going to WIN!

Our first visit to the ALS Society of New Brunswick and Nova Scotia showed us we were not facing you alone. Their team became our allies, offering sage guidance, knowledge, and support when we needed it most.

We stayed one step ahead of you, doing what was needed before it was needed so we could spend our energy on living, not worrying. We installed ramps, gathered equipment, had the hard conversations, and learned to accept help and support from others.

Judy was a very positive person. She decided that in spite of everything you might throw at us, she would look for joy in every day. Little novel things brought her great joy and laughter, and I tried my best to ensure she had them in abundance. Things like loads of lilies and petunias outside her window, hens eating Cheerios off a xylophone, goats bouncing around in the backyard, and even baby chicks on her lap in the house.

We learned to adapt with you in our lives, doing what we could, while we could. We traveled to Spain, Portugal, and Rome, visited family in Vancouver, and explored with the help of a trusty mobility scooter.

People became our greatest source of joy. The home care workers, her rug-hooking friends, the many people who helped raise funds for African children living with AIDS, and the young medical school students she inspired at Dalhousie University. Most of all, our three sons and their families, Judy's sister Linda, our circle of friends, and extended family all shared in this pursuit.

ALS, you are a cruel disease. But even you couldn't stop us from having a wonderful life. Over the four years that we lived with you, our family grew closer than ever, bound by an indescribable love and devotion.

Judy lived fully, loved deeply, and found joy in spite of you – and that's how she won. There is life with ALS; you just have to make it happen.

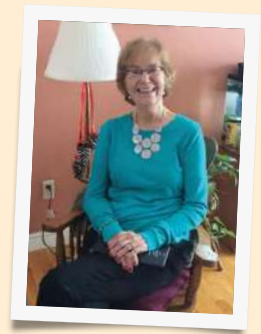
In memory of Judy's boundless spirit,

Cameron Starriff

Husband of Judy, who lived with ALS



As the devoted primary caregiver to his late wife Judy, Cameron offers a deeply personal understanding of the caregiving journey. Married in 1971, they raised three sons in their Nova Scotia farmhouse where he still resides. Through family and community support, Cameron and his family learned that "there is life with ALS; you just have to make it happen."



My Years You Spared, My Spirit You Won't Break

Dear ALS,

If there's one thing I have to be thankful for, it is that you spared me during my earlier years, as a mom to my two now adult children, during my career as a performing musician and teacher, and during my 20 years as a retired senior snowbird. I am thankful I got to experience summers spent in the wonderful home we built ourselves in the forest on Lake Winnipeg, and then six to seven months of the year in Zihuatanejo, Mexico, on the shores of the Pacific Ocean.

Thank you for allowing me to have all those amazing memories, and for not creeping sooner into my life. You ask things of me now that I am grateful I did not have to face sooner.

As I write this, I am 78 years old and was introduced to you in August of 2025 – although it is suspected that I might have already been on this journey with you for a year or more prior.

The questions I now carry centre around how long I will have enough mobility to move around our small condo with the aid of my walker; whether I will have the ability to use my mobility scooter again in the spring and enjoy riverside walks with my hubby; how long I might have the ability to use my hands to feed myself, brush my teeth, comb my hair, and type.



And then there are the decisions you have forced into my view: feeding tube or not, BiPAP or not, MAiD or not. I have already decided against resuscitation or intubation.

Through all of this, I am immensely thankful for my loving husband and children, the MND/ALS clinic, and the ALS Society of Manitoba, and for the fact that even with you here, I don't have to face this alone.

Now, like everyone else, we move forward one day at a time.

Linda Leonard

Retired musician and teacher, person living with ALS



Linda is a lifelong Winnipegger who has enjoyed a four-decade career as a prominent music teacher and versatile performer. Her adventurous retirement was split between Lake Winnipeg and Zihuatanejo, Mexico. She holds deep gratitude for a life rich in memories and cherishes the unwavering support of her husband, children, and close friends.



Fighting ALS Until My Job Is No Longer Needed

Dear ALS,

You are only three letters, and yet the weight and impact you carry is unimaginable. I have seen the moment your name is spoken aloud, the way it steals the air from a room. I have watched faces change as the truth sinks in, that there is no going back. There is life before you, and life after you – a sharp dividing line that can never be erased, a clear break of who people were and the path they now walk.

And yet. I keep coming back to “*and yet.*”

In spite of you, ALS, I have the privilege of walking beside some of the bravest and greatest people to walk this earth. You try to strip away movement, speech, breath – but you cannot touch the essence of who they are. You cannot take their love, their laughter, their tears, their connection. You cannot steal the way a hand finds another in the dark, or the way eyes can speak when the voice is gone.

I have seen you try to hollow people out, but instead, I have witnessed them *fiercely hold onto who they are*. When all the noise is stripped away, what remains is something pure, unshakable, and deeply human. I look into the eyes of those you have tried to break, and I see not defeat, but defiance. I see people still here, still fighting, still loving – and it inspires me beyond words.

I am who I am because of them. Every lesson, every moment, every goodbye has shaped me. I carry their courage with me, and I try to live in a way that honours them – those who have faced you head-on, and the loved ones who have stood beside them in the storm.

You have stolen far too much, ALS. Far too many voices, far too many embraces, far too many futures. But you will not win.

One day, you will be nothing more than a chapter in history, a page we turn with relief and triumph. And when that day comes, I cannot wait to be out of a job because you were defeated.

Until then, we fight. And we will keep fighting, together, until you are nothing but a memory.

Sincerely,

Kris Jagt

ALS Nurse



Kris is a registered nurse who completed her bachelor's degree in psychiatric nursing in 2011 and went on to also complete her bachelor in nursing degree in 2013. She has passionately worked with the ALS population for 11 years. Kris is honoured to work as a member within a multidisciplinary team that partners with those affected by motor neuron diseases.



Unveiling Hope Through Research: Peeling Back the Layers of ALS

Dear ALS,

You are a master of disguise, a tangled web of mystery. But for decades, you and I have been locked in an intricate, relentless dance. Each step forward that I have taken with my research has unveiled yet another hidden layer of your complexity.

Our first encounter felt like a mere twist of fate, happening purely by chance. As a clinical clerk at Queen's University (Ontario), my chief resident was eager to introduce me to something so rare that I might never encounter it again – one of your afflicted.

But, as fate would have it, we were always destined to tango. My studies led me to Denmark to a centre that, unknown to me, was a national ALS referral centre. What began as a once-in-a-lifetime meeting burgeoned into regular encounters, fueling a lifelong passion for unlocking your secrets.

Some ask me how I find hope in the face of the challenges that you have presented to all who cross your path. For me, the answer is simple: just a look back at how far we've come. Every research effort, whether a success or a failure, has helped us peel back your layers – that is what ignites my hope.

I remember a time when our knowledge was a skeletal framework of epidemiology, when any concept of treatment felt out of reach. As the years progressed, the scientific tide began to turn. We now possess refined diagnostic criteria and are armed with new tools and technologies that allow us to ask questions that we could not dare to ask before. And long-held theories of your past have been supplanted by new concepts fueled by a deeper understanding of you. Bit by bit, layer by layer, we are meticulously dissecting your complexities, and with that, we unveil hope.

ALS, you have been a challenging dance partner, sometimes leading, sometimes following. You've taken far too many far too early in their lives. But I can say with complete confidence that your time on the dance floor is truly limited. I watch with a bit of envy and a lot of excitement as the next generation of brilliant researchers is stepping up to take the lead, armed with knowledge, ideas and tools that are breathtaking. It is only a matter of time until your mysteries are revealed, and we will finally have the answers to put an end to your destruction. How close we are to that day, only time will tell. But the one thing I know for sure is that we won't stop until we stand triumphantly over you, your secrets laid bare.

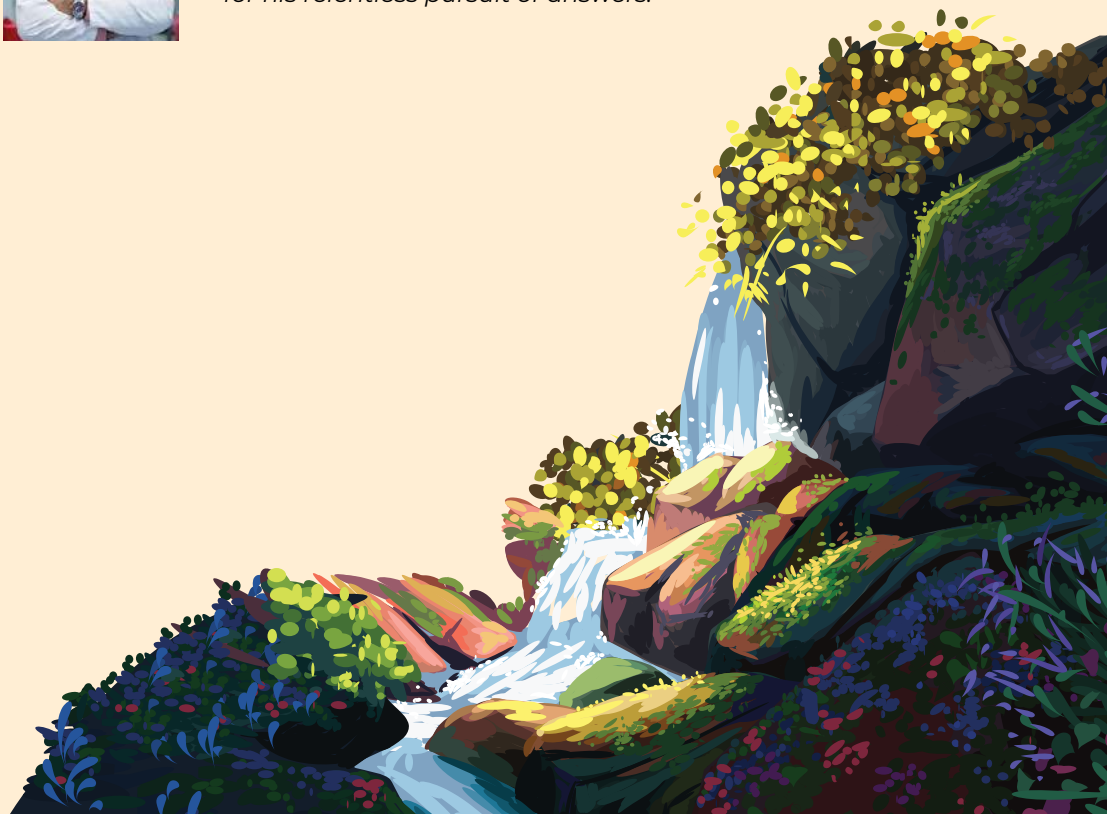
Your persistent shadow,

Dr. Michael J. Strong

Neurologist, ALS Specialist and Researcher



Dr. Strong is a distinguished professor and pioneer in ALS research. His research focuses on ALS pathogenesis, including RNA and tau metabolism, contributing significantly to advancements. As a leader in neurology, he's received prestigious awards like the Sheila Essay and Forbes Norris for his relentless pursuit of answers.



You've Had Your Moment, ALS – We're Taking the Ball Back

Dear ALS,

For the moment, you admittedly have the upper hand.

For the moment, you recklessly cause immeasurable pain and suffering, destroying countless lives.

For the moment, your indiscriminate wave of destruction has gone relatively unchallenged as you advance with impunity.

But only for the moment.

The mystery behind your invincibility is beginning to unravel, and we can feel it. As an inconsequential backup quarterback in college, I know what it feels like to be overmatched and way behind in a big game when suddenly, the momentum begins to shift. I know what a comeback feels like, and the collective realization that the beast can be slayed.

One big play can be a game-changer. In place of a big catch, it's the discovery of key biomarkers and the development of novel therapeutics that help methodically move the ball down the field. We continue to chip away at your lead and are developing strategies to neutralize your strengths.



While the enigma of your pathophysiology remains your greatest weapon, our team has drafted a growing army of scientists, researchers and clinicians to expose your weaknesses. With the support of our fearless patients and tireless advocacy from dedicated families, your once seemingly insurmountable lead is under threat, and it's just a matter of time before we are victorious.

So, for the moment, ALS, you continue to have a menacing lead, robbing patients of their speech, mobility and breath.

But the tide has turned, and our team now has the ball deep in your end.

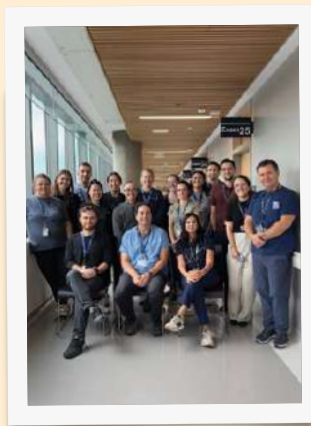
Time's up, ALS – you've had your moment.

Dr. Lorne Zinman

Neurologist, ALS Specialist and Researcher



Dr. Zinman, an associate professor, profoundly reshaped Canadian ALS research and care. He founded the Canadian ALS Research Network (CALN), unifying 16 academic clinics into a vital consortium. As director of Canada's largest ALS Clinic, he leads international trials, spearheading crucial studies and best practices. His visionary leadership has transformed the ALS landscape, offering renewed hope to patients nationwide.



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