

# If ALS hadn't taken Sheila, she'd be knocking on Ford's door

JANICE KENNEDY

My sister Sheila was a keener. Five years younger, with a disposition far sunnier than mine, she was: a volunteer, an activist, a photographer, a belter-outer of songs, a skilled cook, a committed NDP supporter, a music lover. She believed in people, cherished her family and friends with quiet ferocity, and routinely dispersed whatever clouds she spotted on someone else's horizon. She laughed easily and smiled often.

She never lost that contagious smile either, even when she'd lost everything else.

Ten years ago, she wore it while participating in the Ice Bucket Challenge, the phenomenon that raised \$220 million globally for ALS clinical care and research. Canada's \$17.2 million was more per capita than any other country.

Sheila could still talk then, though her speech had a drunken slur to it, which she hated. But sitting there in her wheelchair, friends around her, local Vancouver TV cameras rolling, she endured the icy water poured over her head and laughed.

That was Sheila and her ALS — indomitable spirit captured in a smile. By the time she died a year later in hospice, age 63, she was trapped inside an unresponsive body, no longer able to move, eat, breathe without help, talk or communicate in any way other than by using her eyes to spell out a sentence, letter by agonizing letter. Amazingly, though, she could still smile.

ALS (Amyotrophic Lateral Sclerosis) is a neurodegenerative disease that attacks the body's voluntary muscles progressively and relentlessly. Ten per cent of cases are genetic, while the rest, like my sister's, are random. Despite ongoing research and some discoveries, there is still no cure, and most people diagnosed with it will die within five years. ALS is unspeakably cruel.

Roughly 4,000 Canadians are living with ALS at any one time (in the grim calculus, 1,000 annual deaths cancel out 1,000 new diagnoses), so, unlike cancer, it is not one of health care's headliners. ALS is much easier for governments to ignore. Which is tragic.

"It's such a horrendously expensive disease," says Tammy Moore, CEO of ALS Canada. The need for complex equipment and assistive devices evolves for patients with dismaying speed, but sufferers and their caregivers are often left to the kindness of strangers. Government help across Canada for such needs is uneven and, in Ontario, nonexistent.

ALS Canada provides nearly 40 different kinds of necessary equipment to patients, involving purchase, maintenance, shipping, setting up, education — and gets zero dollars from Ontario.

"We're actually augmenting the system," says Moore. "We're funding it through philanthropy."

And don't get her started on the disparities in clinical care. You're in good hands if you live near the five multidisciplinary ALS clinics in Toronto, London, Hamilton, Kingston and Ottawa. But good luck if you live in Kapuskasing or Kirkland Lake.

ALS Canada and the Ontario clinics are currently lobbying the government for \$6.6 million in funding, says Moore. "After all, one stay in ICU for an ALS patient at Sunnybrook costs \$30,000. We're just asking for \$5,000 per patient annually." Sounds reasonable.

If Sheila were still here, I suspect she'd be at Doug Ford's door, knocking with gusto. She was tireless that way, a committed activist to the end. Six months before she died in 2015, she received the "Exceptional Public Awareness" award from ALS BC, whose executive director spoke at her memorial service.

From the beginning, Sheila knew her nearly four-year battle with ALS would end in defeat. That didn't stop her from preparing gracefully for her death while animating each painful day with her own guiding spirit. With assistance, she voted early in the October federal election. On Thanksgiving, a week before she died, she insisted on posting a message. It exhausted her, but she knew she was leaving soon, and saying a final thank you to those she'd loved was urgent.

No science will ever prove this, but I suspect that the ALS monster chooses its victims from the ranks of exceptional people, people with great hearts and stunning courage.

The Ice Bucket Challenge is history now, with ALS associations back to less frenzied days of lobbying and fundraising. But the hope — for donations, for government support, for a cure — that hope remains.

It's stubborn that way. Like a smile that will not fade.

JANICE KENNEDY IS A RETIRED JOURNALIST LIVING IN OTTAWA. FOR MORE INFORMATION, GO TO ALS.CA.



COURTESY OF JANICE KENNEDY  
Sheila Tynan, centre, attended Vancouver's annual ALS Walk with her family in June 2015, four months before she died.



"Jennifer is gone," my father said in a weary and heartbroken voice, a voice I had never heard before and never heard again, David L. Clark writes.  
DREAMSTIME PHOTO

# Remembering the short life of Jennifer, my stillborn sister

DAVID L. CLARK

When I was but a young boy, I had a baby sister. Her name was Jennifer. She was stillborn. Stillborn. What a strange word that is.

Born, yes, but also still, meaning motionless, inert ... waiting. Or perhaps lingering forever on the threshold of coming into this terrible and beautiful world, always about-to-be-born?

Where are you and what are you now, little one? I never met you, because all that transpired around your stillbirth took place at a hospital that I was not allowed to visit. Parents were different in those days, coy about matters of the body. But I knew you. I saw you grow in my mother's belly, and I fed on the pleasure that your coming gave my mother and father as you flourished unseen. You were warmly welcomed as a sister to a home of three boys. And you had a name.

And then a blur of a sudden medical emergency, only weeks before you were due. I recall the anguish etched in our father's face, our mother's screams, all of it intensely frightening to a 13-year-old's eyes. You too must have been fearful, feeling something was horribly wrong while our mother was doubled over in pain, you and she whisked away to the hospital in the dead of night.

Hours later, I received a phone call from my father. "Jennifer is gone,"

he said in a weary and heartbroken voice, a voice I had never heard before and never heard again.

But those were the words that he spoke and that I still hear to this day. Words matter. Perhaps that is why I became an English professor. For my father didn't say "dead." He said "gone." That single word, that well-intentioned euphemism, that attempt to soften the blow of our family's loss, transformed something in me, forever altering my relationship with you, Jennifer. For "gone" confirmed that you had been here, that you had come, if only to depart.

In some way that I still struggle to understand, I have always thought of you as having once arrived, even though I was not there to greet you, and even though I know that you also left this world, never to return.

You taught me so much, Jennifer, one child to another. My first inkling of mortality was not the fear of my own death but fear of the death of another — you, dear sister. From you I first learned what grief is, felt its cold and clawing powers undo me.

From you I learned that a lifetime is beyond measure. For what can it matter that you lived one day, one hour or one second? Who could say, well, after all, because you lived so little your life didn't really count, or count as much? Only murderers believe that the dead are nothing, the great French philosopher and Talmudic scholar Emmanuel Lévinas once said.

No, Jennifer, you lived an entire life, full to the very brim, no matter how quickly it passed. To mourn your loss meant that you had possessed a life to lose. You lived, which is why I thought my heart would break in two when I saw that your name was missing from our mother's obituary.

You had a billion possible futures ahead of you, and with each breath a different path to take, but happened — by chance, and only by chance — to live the particular life in which you did not survive. But who is to say that you were then without a future?

All those other lives, uncountable and unfathomable, were also yours to live, and because you didn't live them doesn't make them any less yours.

Still, you were born. That is why I sometimes see you, out of the corner of my eye, each time with different face and of a different age. You are a silent but always smiling apparition.

I began by saying that I had a sister. But that is not true. I have a sister, Jennifer. She passed away, stillborn, more than half a century ago.

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# A letter to the prime minister

CAROL VICTOR

Dear Mr. Trudeau:

First, let me be very clear. I am a Liberal and a dedicated party member. I contribute through the "Victory Fund" and campaign in my Burlington riding. No matter what happens, I will never vote for Pierre Poilievre.

I was excited when our country embarked on "sunny days" with you at the helm. I was never prouder than when you met with Barack Obama in Washington: two neighbours, espousing similar values, in power together.

Unfortunately, in 2016, the shocking rise of Trumpism shifted the U.S. political landscape dramatically. Needless to say, this influence on Canada affected a certain segment of our population whose dislike and distrust of government is part of their DNA.

A new government is always under scrutiny, but when it comes from within the party in power, it is especially grating. You got no favours from Jody Wilson-Raybould and Jane Philpott as your first controversy emerged. Even a seemingly innocent holiday with a family friend was viewed as a conflict of interest and your guilt was upheld by the ethics commissioner.

But COVID-19 was your undoing. It upended our lives. Canadian businesses and institutions were shuttered, citizens scrambled to get masks, hundreds died and health care was taxed to the max. While there was the usual criticism re: unpreparedness, your government was relatively quick to react, providing financial assistance. But many were angered by your consistent restrictions messaging. Over time, vaccines emerged, but so too did the rise of anti-vaxxers egged on by the crazy and outlandish leadership of Donald Trump.

The pinnacle of frustration in Canada came in January of 2021 with the Ottawa "Freedom Convoy" protest. This was the result of a vaccine mandate for cross-border truckers, but soon escalated into a protest for just about everything. Poilievre capitalized on this by not only marching with the protesters, but reinforcing anti-Trudeau sentiments. Flags denigrating you personally started to make an appearance.

It is understandable that the recovery after COVID would mean global inflation. Prices went sky high as businesses tried to make up



THE CANADIAN PRESS FILE PHOTO  
"You have been prime minister for nine years, Mr. Trudeau, but the public is simply tired of your leadership," Carol Victor writes.

for losses. While inflation is moderating, your government has been deemed responsible because nothing will ever be the same again.

While you offered initiatives around the critical issue of climate change, there are still those who do not share your opinion. The oil and gas industry in Western Canada is dependent on fossil fuels and has leadership that is aligned with this industry to the exclusion of significant green energy development.

Much of the immigration situation is due to migration from nations where there are repressive regimes or severe food shortages. Many Canadians blame our housing crisis on too many refugees and immigrants. Under you, Mr. Trudeau, most think we have admitted too many and with no foresight, re: housing and jobs.

Your alliance with the NDP was viewed as a black mark on too many unaffordable social programs. The child care program is a great federal initiative, but not all provinces put the resources behind it. Now with dental and pharmacare programs driven by the NDP, can we really afford all of this with our crumbling health care?

You have been prime minister for nine years, Mr. Trudeau, but the public is simply tired of your leadership. I, for one, do not want the baby to be tossed out with the bath water. For the most part, I like the policies. You have some strong party members with great integrity. I implore you to make the right decision and put the Liberal party in different hands while you can still salvage the good things that you have done. Sunny days are over.

CAROL VICTOR LIVES IN BURLINGTON.