



Faces of Mito

Alyson Maxwell

A fierce advocate for the MitoCommunity
and dedicated community connector



Ever since she can remember, Alyson Maxwell has experienced chronic pain and near-constant headaches. Growing up in the '70s and '80s, Alyson knew she wasn't quite like the other kids. "I used to randomly fall down the stairs – my legs would just give out," she says. "I often tripped and my coordination was horrible. I'd play really hard with the other kids one day and then the next day I'd hang out on the couch with a book or play quietly by myself. I think that I knew, subconsciously, that I had to recharge my body."

As a young adult, Alyson continued to be challenged by balance and coordination issues, severe GI problems, pain, and fatigue. Doctor visits were all dead ends. "Anytime I went to a new medical professional, the first thing they'd ask was my family medical history," says Alyson. "I'd say, 'I'm adopted,' and that would end the conversation right there."

Searching for answers

One morning, in her mid-20s, Alyson woke up in particularly bad shape. The entire right side of

her body was in extreme pain and her face was numb. Scans and tests turned up nothing. Alyson kept thinking, "What if there's something in my family that I need to know about?"

Desperate for answers, she registered with an adoption registry. Days later, the phone rang — they had a match.

Alyson met her birth mother, who had her own health challenges, which included profound hearing loss.

The search for answers to Alyson's growing list of symptoms continued. Doctors suspected that Alyson had reflex sympathetic dystrophy – a mysterious disorder causing long-lasting pain – and she was eventually diagnosed with fibromyalgia, but the diagnosis never quite fit. Medications prescribed to Alyson only made her symptoms worse, and doctors had no explanation for why her illness was progressing (fibromyalgia is not a progressive disease).

"I kept plugging along, trying to function, visiting specialist after specialist," says Alyson.

Desperate for answers, Alyson registered with an adoption registry. Days later, the phone rang — they had a match.

continued...

She repeatedly ended up in the ER, where she was accused of being a hypochondriac. "It was a journey of being disbelieved everywhere I turned," she says. It was only after Alyson's birth mother had a stroke and was diagnosed with mitochondrial encephalomyopathy, lactic acidosis and stroke-like episodes (MELAS), a mitochondrial disease primarily affecting the nervous system and muscles, that Alyson began to learn about the condition that had plagued her all her life. "As I read about MELAS symptoms, I was like, 'Oh, this explains everything,'" says Alyson. "Light bulbs were going off." After genetic testing, the mystery was finally solved. Alyson would finally be diagnosed with MELAS, at age 44.

Supporting the MitoCommunity

Since being diagnosed, Alyson has immersed herself in the world of patient support and advocacy. "Helping community members navigate information and resources and providing peer support is so rewarding," says

Alyson. "Helping people was part of my career for the 22 years I worked at a credit union.

I miss that part of my identity and my work life, which I had to give up." Alyson is

an administrator on a few mitochondrial

disease-related Facebook groups and a member of several more. She checks in regularly to add to the conversations and answer questions.

"Helping community members navigate information and resources and providing peer support is so rewarding."

"Being able to help people has been a great outlet for me and has given me purpose," she says.

"Being able to help people has been a great outlet for me and has given me purpose."

Life is relatively quiet for this Red Deer, AB, resident. "Sometimes I feel like I just exist, but I don't," says Alyson. "I fight to do what I do and I get enjoyment from it. I'm

content." Alyson has made peace with the fact that leaving her job was best for her health, and she is now on disability benefits. She has learned to listen to her her body and to conserve her energy.

From waking up "feeling like the Tin Man" to evenings where her brain fog can feel insurmountable, Alyson's symptoms are never-ending and dictate the rhythm of her days. She experiences constant muscle weakness, muscle pain,

difficulty walking, headaches, and fatigue. Nonetheless, she has crafted a balanced daily routine full of activities she enjoys and that enrich her life: cooking ("I use food as medicine," says Alyson), reading, socializing with her neighbours, and either exercising lightly in the building's gym or going for a walk on the nearby nature trails.



continued...

Staying positive

"I try to find something to be grateful for every day," says Alyson. "It's not the big fantastic things I'm grateful for – it's the small things." It could be the chirping of a songbird on her lilac bush, a great song on her playlist (depending on the day, it might be Frank Sinatra, AC/DC, or U2!), snuggles with her two senior cats, or gratitude for her husband, who has supported her every step of her journey.

"I try to find something to be grateful for every day."



"My superpower is having a mindset that won't allow me to be defeated," says Alyson. "Being a willing participant in maintaining good health is huge for me. I have bad days and I throw myself a pity party once in a while, but I can't park there." Processing grief and disappointment has been an unavoidable part of Alyson's journey. She's had to let dreams go, as has her husband – like their wish to explore Eastern Canada.

But despite it all, she maintains a positive attitude of gratitude, optimism, and hope. "I have hope that there will someday be a proper treatment for mito and possibly a cure, but I can't just sit around being complacent waiting for it," says Alyson. "I need to make sure I keep trying and challenging myself, and that I don't compare my accomplishments to anyone else's."

"My superpower is having a mindset that won't allow me to be defeated."



MitoCanada focuses its energy on creating a world where all lives are powered by healthy mitochondria. We use our collective energy to reduce the devastating impact of mitochondrial disease by creating MitoCommunities that are empowered, inspired and connected.

MitoCanada.org.