

Stories from the Asthma Community

Asthma and the Impact on Quality of Life:

“My daughter was diagnosed with asthma as a baby and now, at 16 years old, we are hard-pressed to find any part of her life that is not negatively impacted by her asthma. She has multiple significant episodes per year, and usually at least one hospitalization. As a result, she has missed at least a month of school every year - requiring her to have an Individual Education Plan signed by the school district to help accommodate her absences. Her time away from school impacts her social life as well”.

“I hear my friends talk about their kids dreams – backpacking across Europe, moving to another country or to a remote location – and I know these aren’t options for [my daughter]. I can’t even let her vacation with friends, and our family holidays are usually limited to staying within the country and within vicinity of a hospital.”

“One of the hardest things for us is the complete lack of understanding from the general community. I wish I had a dollar for every time someone has told me ‘well – it’s just asthma’ or ‘why are you worried – they’re going to outgrow it’. I have two friends with kids who have gone through 18 month treatment plans for cancer who admit that Charlotte, my daughter, has spent more time in hospital and has taken more medication than their kids – but gets none of the sympathy and understanding. Not that I would wish cancer on anyone – but honestly, I would prefer to put her through that kind of treatment if we had a high percentage chance of full remission that these kids have been fortunate enough to have”.

Claire McCutcheon, BC
Caregiver for Daughter who has Asthma

“Our Son is now 5 years old, the past five years have been very difficult with hospital stays, multiple operations, multiple doctors’ appointments and running back to the pharmacy for his prescriptions. He tries to lead to a normal life and we let him try. He has tried sports and is doing well in school but we fear each day when he will have another severe attack. Asthma affects the whole family not just the person with asthma”.

Susan Suess, ON
Caregiver for Son who has Asthma

The Importance of Clean Air:

“I am a parent of a now 9 year old severe asthmatic. A short time after I returned to work from my maternity leave is when our lives changed forever.

My son had been in the hospital a few times with what they classified as asthma over the course of his life from beginning. He was approximately 18 months old when I went to pick him up at day care after work. I arrived at the daycare to find my son lying in his crib unresponsive and blue. The daycare staff just thought that he was extra tired and sick. I met with an asthma specialist who told me that our lives

were going to involve hospital visits every few weeks because of asthma issues in his environment or I could leave work and control his environment until he was strong enough to do it himself.

I took a leave of absence from work in order to figure out a route. The decision was made that I was going to leave my career that I spent 14 years building, ironically, in clinical research to ensure that our son was as safe as possible. I have still not returned back to work approximately 8 years later.

When my son started school the issues became obvious that his environment triggered a great deal of his asthma issues meaning he missed a lot of school. Year one he missed 67 days of school because of asthma.

Being the care giver of an asthmatic child is not an easy task. It almost seems like a balancing act most times.”

Tracey Beaudry, ON
Caregiver for Son who lives with Asthma

“I moved to Grimsby, Ontario in 2003. I was unaware of the pollution that was directly caused by the steel mills located in the Hamilton area. This black particulate was and is a by-product of steel production. When I asked about the source of this dirty substance, I was told it was simply dust. Well, the dust gave me asthma at the ripe old age of 58 in 2005”.

Leigh Morton, ON
Lives with Asthma

“Cigarette smoke – [in all forms] - is a large trigger for me and can induce an asthma attack. Walking some streets in cities or taking transit means having to hold my breath and wait for a smoke-free moment to take a breath. I have had to move seats on the train when seated near someone who smokes, or stand far from the bus stop. I've lived in a few cities in Canada and this is a consistent issue”.

Tristan Joseph, ON
Lives with Asthma

“It is my understanding that Toronto has had, for a number of years, a measure of air quality and warnings out for people like myself who suffer lung trouble. It would be terrific if more Canadian communities across the nation would put air quality warnings on the news websites, weather websites, newspapers, and many other places where ever possible so that persons suffering from any sort of breathing problem [are] aware of weather conditions, and what can happen, where to get help, etc. When the weather is really cold out here in Calgary, or there is a strong wind outside, or it looks like I may have troubles breathing if I am not careful, I do use the inhaler, if I have to absolutely go out, but stay in if going out is unnecessary”.

Flo Smith , AB
Lives with Asthma

“My asthma was severe enough that I slept in a mist tent every night, I came very close to needing home oxygen. I was rushed to the ER innumerable times. Spent countless days and weeks in the hospital. My condition was so severe that my parents considered moving to Arizona for its better climate”.

Bill Swan, NS
Lives with Asthma

The Importance of Access to Medication:

“In the past, I have been employed full-time or on contract with no health insurance plan. I need an expensive medication - Advair - on a daily basis to be "normal" and largely symptom-free. This has meant having to half my dosage because I could not afford to purchase it on monthly basis. As a result, my symptoms worsened, and I had to supplement with Ventolin - what is normally an emergency medication for me. We have to make sacrifices in order to afford just enough to be productive in the workplace. Medication is not a luxury or a choice. It allows me to be work, volunteer, pay taxes and live”.

Tristan Joseph, ON
Lives with Asthma

“I am using three puffers. I am working part time with no benefits. I have had to pay for private healthcare insurance which has a \$1,000 dollar [annual] medication limit. I usually reach this limit in 5 months and then pay out of pocket. I find it difficult to keep up with these expenses”.

Michele Mijatovic
Lives with Asthma

I am 59 years old. I was diagnosed early with asthma at the age of one. My worry is that although the pharmaceutical company is currently covering the cost for one of my drugs with an approximate price tag of \$2,400 per 4 week injection, what will happen when they stop covering it? My monthly income doesn't even come to this, so there's no way I could afford it.

Louise de Lugt, BC
Lives with Asthma

“Standing on the sidewalk outside of the Blue Cross-Blue Shield, [where I was first denied medical drug coverage], I pondered my lack of options. I could no longer keep my university coverage. I couldn't get back on my father's plan due to my age. I could not even BUY coverage. I now HAD to pay FULL price for any and all of my medication. But I was recently graduated, unemployed, uninsured and - soon without medication - unstable. The meds started running out and by summer I was visiting the ER every few weeks throughout July and August. In the end, I re-enrolled in university that fall with a thesis topic drawn from my experience, and learned the shameful truth: Our health care system is woefully inadequate. I am fed up, because, this was THIRTY years ago! And nothing - except the shocking increases in drug costs - has changed”.

Bill Swan, NS
Lives with Asthma

[My daughter's] current maintenance medication list includes 4 prescription meds for asthma and allergies: Xolair, Breo Ellipta, Singulair and Nasonex, another 2 for side-effects, Ciprolex and Losec, as well as 2 OTC medications for allergies and weight control. All of them are for daily use except for the Xolair. This doesn't even include her Ventolin, Atrovent and Prednisone for treating exacerbations. The cost of these medications is close to \$20,000 a year. We are extremely fortunate that my husband's work includes excellent coverage for prescription medications, but we are aware that there is a time limit on this coverage. Her life choices are limited to staying in school to continue this coverage, and we know she will need to move immediately into a job with a good extended health plan when she's done."

Claire McCutcheon, BC
Caregiver for Daughter who has Asthma

"I was eventually diagnosed with Severe Asthma. After it became clear I had tried every modestly priced asthma pharmaceutical available, my specialists prescribed Xolair and an expensive antifungal. Total cost - \$20,000 annually. With these drugs I am able to live a normal life. Thankfully my health insurance covers 90% of the cost. However, there is a lifetime limit. I am in a good financial position, but I worry about what will happen when my insurance runs out."

"I worry even more about friends I've met through the Asthma Society who do not have access to the drugs they need. Why? Because they can't get insurance and their provincial coverage does not include such necessary but expensive drugs as Xolair."

Penny Grant, BC
Lives with Asthma

"I'm a twenty-something, self-employed Manitoban with a chronic disease. I take common medications for asthma and ADHD, which does not mean inexpensive. I have been uninsured since graduating university in 2014 and [have lost] coverage through my dad's group plan he had through his employer. Near the end of each year, I sit down with a spreadsheet and calculate whether or not it is cheaper for me to pay out-of-pocket for my pharmacare deductible, extra medical expenses, dental care, and travel insurance, or if it is time to opt into an insurance plan that might actually accept someone like me, with multiple "pre-existing condition". I am young, and though I may have chronic diseases, affordable Pharmacare coverage will keep me healthy. However, as I cycle into different phases of my life, Pharmacare deductibles may move out of my financial reach – a reality I stare down regularly".

Kerri MacKay, MB
Lives with Asthma

"After about five years of rewarding retirement, my wife became very sick. She coughed all day and at night her breathing sounded as if she was drowning. Our plans for travel, volunteering and lifetime-learning ground to halt. Everything revolved around her numerous medical appointments. Eventually

she was referred to specialists in Vancouver – a 2 hour ferry trip away. She was diagnosed with Severe Asthma, allergic fungal sinusitis and eustachian tube dysfunction and was prescribed what amounted to \$20,000 worth of asthma drugs per year. She now seems much more like her old self. We are lucky that we have excellent pensions and good health insurance. However, I am concerned about the future. Our son and two grandsons also have asthma. One day their mild to moderate asthma may become severe and they may need similar costly drugs. If the government of Canada does not deal with the lack of universal pharmacare soon, I hate to think what the future will bring for them”.

Mike Grant, BC
Caregiver for Wife who has Asthma