

# SEVERE ASTHMA

## THE CANADIAN PATIENT JOURNEY

A study of the personal, social, medical and economic burden of Severe Asthma in Canada

## EXECUTIVE SUMMARY



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Asthma Society of Canada

# Severe Asthma: The Canadian Patient Journey

## The Unmet Needs of Patients with Severe Asthma

Asthma is a chronic inflammatory disease. A person experiences an asthma attack when his or her airways become inflamed. This inflammation can produce symptoms including wheezing, shortness of breath, coughing and tightness in the chest. In less severe events, asthma might look like a dry, wheezing cough. In more severe cases, the person's airways can become obstructed to the point of making it impossible for the person to breathe. In the most severe event, the person may die.

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*"My first specialist didn't really involve me but I didn't question it because I felt I wasn't that knowledgeable and he was the expert."*

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Asthma, the third-most common chronic disease in Canada, affects nearly 3 million Canadians. Severe Asthma (SA), a more severe form of asthma and a greater threat to health, impacts the health and wealth of between 150,000 and 250,000 Canadians.

Beyond the costs to human health, asthma has an enormous impact on Canada's finances. Asthma is the leading cause of hospital admission in Canada. Between 2010 and 2011, direct and indirect costs associated with treating asthma topped more than \$1-billion.

## A Study of Severe Asthma in Canada

*Severe Asthma: The Canadian Patient Journey*, a study overseen by a panel of academics and conducted and published by the Asthma Society of Canada, examined SA patients in three provinces to determine their experiences with SA, the healthcare system, medication adherence and course of treatment. The study made several important discoveries about SA's impact on Canadians.

### **SA is not well-managed for most patients**

- SA is a regular—and often a sudden—health crisis for most of the respondents to the ASC study.
- Only 17% of the study's respondents believe their asthma is well controlled. Half believe their asthma is adequately controlled, 27% believe their asthma is not well controlled and 7% don't believe their asthma is controlled at all.

### **Inconsistent diagnoses and treatments impair quality of care**

- The study found that not all healthcare practitioners can appropriately identify SA.
- Most patients rely on family physicians for care, but would prefer a specialist if they could access one. Access to specialists is limited.
- Healthcare professionals use inconsistent criteria and differing diagnostic techniques when diagnosing and grading asthma.
- Asthma symptoms, control, treatment and management are not always discussed with healthcare providers. A surprising number of patients are not receiving information about the newest kinds of therapies for their asthma.

### **Patients are not equipped to manage their SA**

- Most patients have no written plan to manage their asthma and many patients are unsure about their therapy.
- Useful medical devices like spacers and peak flow meters are not used by many SA patients.

### **Financial challenges create significant barriers to better health outcomes**

- Despite the fact that most respondents use their asthma medication every day, many do not, and for different reasons.
- Many patients cannot afford the cost of their medication. Many respondents (33.7%) have at some point skipped filling a prescribed medication because they could not afford it. Many respondents (21.1%) indicated they missed a dosage because they couldn't afford it.
- Many insurance carriers do not provide complete coverage to asthma patients. Most respondents (74.4%) have been denied coverage for recommended treatment options by insurance programs.

### **SA impairs a patient's quality of life**

- SA limits physical activity and leads to lost productivity. More than half of respondents (55.1%) indicated that asthma has affected their work or school performance in the past year, and 40% of these people indicated it has affected their work or school "a great deal."
- Asthma creates social barriers for some patients and affects family members, too. SA attacks tend to be lengthy and costly.
- SA is an emergency condition for many patients.

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*"I was diagnosed with asthma many years ago at 19. I was diagnosed with Severe Asthma five years ago [at 48]. I don't love my asthma, but it was familiar, and something that was familiar turned into something dangerous. Falling into the water without control is dangerous. Not breathing is dangerous."*

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## **About the Study**

- Severe Asthma remains one of the least understood and least studied manifestations of asthma.
- To examine the complex health, social and economic issues related to SA, the Asthma Society of Canada conducted a study of Canadians about their experience with SA. The study, which included in-depth interviews as well as an on-line survey, was conducted in the summer and fall of 2013. It sheds light on how SA, controlled and uncontrolled, affects a patient's quality of life, expectations for the future, medication preferences and experience with the healthcare system.
- All participants in the study were Canadian adults 18 years and older who live with severe, controlled or uncontrolled, asthma. All potential participants were evaluated through a strict screening process and only qualified applicants were interviewed.

## The Severe Asthma Patient Journey

Every person interviewed in this study has SA. Many participants were diagnosed with childhood asthma and most had breathing problems. As one interview participant explains, childhood revolved around the hospital: “Until I was six years old I spent a lot of time in the hospital with an IV stuck in my arm because of my asthma. I always had asthma. I think I’ve always known it was severe. It was just a part of growing up, going to doctors all over the place.”

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*“As a young adult, I felt like the sky’s the limit. Now, I’m still breathing and I see a whole lot, but I’m not sure if I’m actually going to make it out there.”*

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### Diagnosis and a million feelings

For many who suffer with ineffective asthma treatments, the correct diagnosis of SA is often upsetting and usually doesn’t come until adulthood. One man explains his frustration at living for so long with an improper diagnosis: “I didn’t get diagnosed until later in life. Part of me is angry that no one figured it out before and why I couldn’t be physical, like go running.”

The interviews also uncovered a troubling fact about SA—it often isn’t called by name. Doctors use a variety of terms—like “strong asthma” and “complicated asthma”—rather than calling it SA. In one case, a participant was misdiagnosed twice. The first diagnosis attributed his breathing troubles to his premature birth. The second diagnosis categorized his breathing problems as “severe COPD.” After ten years, he received the correct diagnosis—SA—and started receiving an effective treatment.

In several cases, patients were never officially told that they had SA. They only found out after a referral to an asthma clinic or after discussing treatment options. For many, the frustration of learning about their SA diagnosis doubles when they discover that they’ve been left out of the decision-making. One interviewee explains his experience: “My first pulmonologist simply said, ‘Yeah, you have asthma,’ and put me on steroids. I felt like I needed more support and wanted more accurate testing but I lacked confidence to talk to him. I felt that I was not involved in the decision-making.”

### Quality of Life

A chronic condition, SA limits social activities and leads to a decline in health. People with SA remark about how the condition isolates them—it is hard to stay social when you have unpredictable flare-ups, and it becomes hard to stay physical when physical exertion exacerbates SA.

The physical toll often has a social toll, and it is not uncommon to hear SA patients lament how diminished they feel about themselves and how SA strains their family life. One man says that SA keeps him from doing the things he loves, like taking his son biking. “I’m just so tired that I can’t do anything anymore. Severe Asthma has changed everything,” he says.

But where family is supportive and understanding, patients with SA often find their colleagues and coworkers unsupportive and frustrating. One respondent says she keeps her SA a secret because she doesn’t want her boss to think it inhibits her job performance. Another person describes some of the ridicule she faces because of her SA: “People at work will make jokes about it. ‘Oh, Phyllis is here, we can hear her puffing.’”

Many people lack sympathy with SA patients because they don’t understand the threat SA poses—they don’t know that it is a matter of life and death. The stress and anxiety that the threat SA poses shouldn’t be discounted by anybody. It is real.

“I remember a family doctor telling me that if I didn’t have my medications with me I could die,” says one respondent. “Now I worry about being in an emergency situation, such as stuck in a subway in the heat, I could die.”

## Managing Severe Asthma

Many patients report going through several years of trying different medications before finding the medication, or combination of medications, that will keep their asthma manageable. Some participants report having spent up to seven years experimenting with treatments before finding the right treatment.

The expense of medications causes additional stress for many patients. A significant number of participants did not have complete coverage (if any) and reported skipping or delaying their prescription until they could afford it. One participant indicated that he simply cannot afford the treatment recommended by his doctor.

“Asthma is very expensive,” explains one participant. “People don’t realize how much the asthma drugs cost. When you are on a disability pension, even when insurance covers three-quarters, the other 25% kills you.”

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*“The frustration comes when I end up in the hospital or emergency and they can’t contact my doctor to find my routine. It’s up to me to remember all of the drugs and often to update my doctor after about what happened.”*

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## Surviving the System

Many participants spoke about the difficulty of maintaining consistency in their treatment. One participant who moves regularly says he has trouble finding a family doctor each time he moves and finds it difficult to update doctors about his long and complicated medical history. And some doctors treat asthma as a low-priority condition—it is the concern to get to last, even though for many patients it is the most significant threat to their health.

Another SA patient interviewed for the study said that few support services and educational tools exist to help SA patients navigate the complex medical system: “If you are not connected to the right system, right facility or right doctor, you will be naïve and lost.”

A key ally to the SA patient is the Certified Asthma Educator, say respondents to the study. Those who see a Certified Asthma Educator learn how to manage their asthma and treatment regime, and stay motivated.

## The Burden of SA

SA is a progressive disease, often becoming more difficult to treat as the patient ages. “Back in my 20s medications and treatments worked, and through my 30s, but it got worse when I got in my 40s,” explains one respondent. Not only does SA become more challenging to treat, respondents say it becomes a bigger issue in life, demanding more attention and causing more stress. In younger years, says one respondent, SA didn’t seem like a big issue—it was, at most, a looming question. “But it has turned into a big thing as I get older. I am getting scared,” says the respondent.

# A Call to Action: Recommendations to Improve the Quality of Life for People with Severe Asthma

## For professional associations

- Establish a definition of SA based on new international guidelines that patients can understand and that physicians will use to make diagnoses
- Promote physician adherence to the most recent asthma consensus guidelines, including objective diagnostic testing in addition to clinical assessment of patient symptoms
- Promote specialization in pulmonology, respirology, immunology and allergies among medical school graduates to increase the number of specialists in Canada
- Encourage healthcare professionals to gain certification as Certified Asthma/Respiratory Educators
- Educate patients about diagnostics, treatments, triggers and management through support groups and educational programming
- Develop innovative tools such as effective electronic Asthma Action Plans

## For doctors, healthcare professionals and medical researchers

- Proactively enquire about patients' symptoms, their ability to engage in day-to-day activities and physical exercise, their understanding of asthma control, and recent exacerbations, absences from work and other quality of life concerns that may indicate SA
- Ensure patients with Severe Asthma receive objective measures of lung function testing including Spirometry, Peak Expiratory Flow (PEF), Challenge Testing (methacholine and/or exercise challenges) and Sputum Cell Counts as appropriate to assist with treatment recommendations and are referred to a specialist when indicated
- Develop, in partnership with the patient, a written, easy-to-understand personalized Asthma Action Plan that provides guidance on self-managing medications, dealing with asthma triggers and surviving asthma attacks and ensure proper inhaler technique is being employed
- Inform patients about alternative medications, including new biologics and medical procedures such as bronchial thermoplasty that may be suitable for some patients to help better control SA
- Continue research into medication adherence including options for better medication delivery devices that are easier to use and more effective

## For patients

- Know patient rights and responsibilities
- Learn what it means to “control” asthma and how to recognize when asthma is “not controlled”
- Learn to manage asthma triggers wherever possible and to insist upon asthma and allergy friendly environments at work, at home and in public places
- Follow an Asthma Action Plan and ensure compliance with prescribed medication, and if this fails to establish asthma control, consult with physicians about other treatment options
- Ensure appropriate inhaler technique knowing it can make a significant difference in medication delivery and asthma control
- Join a patient support group such as the National Asthma Patient Alliance to engage with other Canadians with asthma



## For governments

- Encourage healthcare professionals (family physicians, respirologists, allergists, immunologists, pharmacists, nurses and certified asthma/respiratory educators) to engage in cross-disciplinary discussion about the diagnosis, treatment and care of people with SA
- Increase secure, cross-sector access and transfer of medical records to ensure consistency of care for patients throughout their healthcare system experience
- Recognize the financial burden of SA on the patient for both medical and non-medical expenses through reimbursement and equalization programs in the income tax system
- Increase funding for research into SA, its causes, types, treatments and cure

## For employers

- Recognize the personal, social and financial burden of employees with SA through enhanced employee benefit programs
- Accommodate employees with SA regarding workplace environment, flexible working hours and medical leave when required
- Proactively promote an understanding of asthma in workplace to lessen stigma and improve overall health of employees

## What Patients with Severe Asthma Want

Patients with SA showed a general willingness to take medications when associated with the strong desire to live normal lives, participate in routine household activities and daily exercise and attend the hospital for asthma-related issues less frequently. Nighttime symptoms and the consequent loss of sleep were ranked more critical than daytime symptoms, but an overwhelming number of respondents simply wanted to be able to go to work and be involved in the economic life of Canada.

Activities that other Canadians take for granted continue to be the dream of people with SA. They ranked the following as their main goals with respect to their disease:

- To function normally while completing household activities, walking and enjoying life (98% very important, 1% somewhat important)
- To not have to visit the emergency department or be admitted to hospital (89% very important, 9% somewhat important)
- To sleep without nighttime symptoms (87% very important, 11% somewhat important)
- To exercise without asthma symptoms (80% very important, 17% somewhat important)
- To go to work (84% very important, 5% somewhat important)
- To improve breathing test results (74% very important, 17% somewhat important)
- To live without daytime symptoms (68% very important, 26% somewhat important)
- To lower the overall amount of asthma medication taken (69% very important, 17% somewhat important)
- To escape from dependence on reliever medications (55% very important, 24% somewhat important)

*“When I found out I had asthma  
I felt like I was drowning: I was  
having difficulty breathing which  
made me feel like I was struggling  
under water. Everything was so  
overwhelming that I didn’t know  
where to turn or what to do.”*

**A Canadian Patient with Severe Asthma**

The Asthma Society of Canada is a national health charity committed to improving the quality of life for people living with asthma and associated allergies. The Asthma Society’s vision is to empower every child and adult with asthma in Canada to live an active and symptom free life.

The National Asthma Patient Alliance (NAPA) is a group of asthma patients, parents and caregivers who support and advocate for people with asthma.



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