

SEVERE ASTHMA

THE CANADIAN PATIENT JOURNEY

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



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Asthma Society of Canada

About the Asthma Society of Canada

The Asthma Society of Canada (ASC) is a national charitable volunteer-supported organization devoted to enhancing the quality of life and health for people living with asthma and associated allergies through education, research and advocacy. The ASC has a 40-year reputation of providing health education services to patients and healthcare professionals.

Acknowledgements

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“The worst part of living with asthma used to be that nobody believed me. It’s kind of an invisible illness. You don’t always want to say ‘I am not feeling well, I have asthma’ because there is still a stigma. Even when you go to the hospital, they ask, ‘Well, how bad is your asthma attack?’ What difference does it make? An asthma attack is an asthma attack and I need help, otherwise I wouldn’t be here.”

A patient explaining the difficulty in getting treatment

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Executive Summary

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 may present as a dry, wheezing cough. In more severe cases, the person's airways can become obstructed to the point of making it impossible to breathe.

Asthma, the third-most common chronic disease in Canada, affects nearly 3 million Canadians. Severe Asthma (SA), a more acute form of asthma and a greater threat to the health, impacts the health and well-being of between 150,000 and 250,000 Canadians.^{1,2}

Beyond the personal costs to human health, asthma has an enormous impact on Canada's finances. Asthma is the leading cause of hospital admission in Canada.³ Between 2010 and 2011, direct and indirect costs associated with treating asthma topped more than \$1-billion in Canada.^{3,4,5}

What the Study Found

Severe Asthma is not well-managed for most patients.

- For many, asthma is not controlled. 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.

- 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
- Many respondents do not carry their reliever asthma medication with them
- Many patients are unsure about their therapy including proper use of inhalers and most do not use spacers (or have ever been prescribed one by their physician) even if they regularly use medication by pressurized metered-dose inhalers (pMDI)
- While some patients could benefit from monitoring their Peak Expiratory Flow (PEF) with a meter, few are maintaining electronic or paper records of PEF

Financial challenges create significant barriers to better health outcomes.

- Many patients cannot afford their medication
- Many insurance carriers do not provide complete coverage to asthma patients



SA impairs a patient's quality of life.

- SA limits physical activity
- SA leads to decreased productivity
- Asthma creates social barriers for some patients
- SA attacks tend to be lengthy and costly
- SA is an emergency condition for many patients

Recommendations

- Establish a clear definition of SA based on new international guidelines
- Promote physician adherence to asthma consensus guidelines
- Ensure patients receive objective measures of lung function testing
- Increase secure, cross-sector access and transfer of medical records to ensure consistency of care
- Increase the number of respiratory and allergy specialists in Canada
- Encourage more healthcare professionals to gain certification as Certified Asthma/Respiratory Educators
- Educate patients about diagnostics, treatments, triggers and management strategies through support groups and educational programming
- Encourage patients to use Asthma Action Plans and ensure compliance with prescribed medications
- Ensure patients are aware of new therapeutic treatments for Severe Asthma
- Increase interest in and funding for research into Severe Asthma and its many manifestations

About the Study

Severe Asthma: The Canadian Patient Journey, a study overseen by a panel of clinicians and academics working in the field of Severe Asthma and conducted and published by the Asthma Society of Canada, examined SA patients in three provinces to determine their experiences with the disease, the healthcare system, compliance and course of treatment. The study used two methods: a qualitative survey and an online-based quantitative survey. The study was funded in part by educational grants from Novartis Pharmaceuticals Canada Inc., Roche Canada and Boston Scientific Ltd.

Introduction

If you have asthma, you know what it's like to struggle to breathe. And if you have Severe Asthma, you know what it feels like to drown.

Severe Asthma (SA) is a more severe, more lethal form of asthma. It is a chronic condition that impairs a person's ability to breathe, work and live a happy, healthy life. As many as 250,000 Canadians suffer from SA, and despite SA's prevalence⁶, its burden on the Canadian health system has neither been well-understood from the patient perspective nor well-recognized within national and regional health system priorities.

This study, ***Severe Asthma: The Canadian Patient Journey***, is the first patient study to look specifically at how this disease impacts the lives of everyday Canadians who have SA. This study uses a mixed method approach consisting of qualitative and quantitative methodologies to examine the patient experience of SA. What this study shows will startle anybody involved in Canadian healthcare:

- SA reduces the social, financial and health outcomes for people with the disease. It is severe enough to have a noticeable impact on the Canadian economy.
- SA is generally poorly understood and diagnosed, and inconsistently managed by healthcare providers.
- Treatment of SA is hindered by availability of specialists and misdiagnoses.
- New treatment options, though still relatively limited, are not well-known by patients and often not made available to them by physicians.

This study provides new baseline data about the patient experience with SA that we can use to monitor our improvement in caring for people with this life-threatening disease. It examines the prevalence and burden of SA, outlines the needs and expectations of patients with SA and offers insight into why patients comply or don't comply with asthma management plans.

This study is a call to action. It is the first step towards establishing national, provincial and territorial perspectives on the social and economic impact of SA in Canada for governments, researchers, industry, and health care providers to offer a response. The recommendations at the end of the study deliver a way forward for patients with SA.

The good news in this report is that SA is a disease Canadians have the possibility to control. We need more research into SA, more attention to the issue by doctors and government, and better resources to educate patients about how to manage their disease.

If we can rally against SA, we will save lives and improve the quality of life for hundreds of thousands of patients and their family members. All we need to do is act.

Sincerely,



Robert Oliphant, President and CEO
Asthma Society of Canada

Canada: An Asthma Nation

Few diseases touch as many Canadians as asthma does. Visit the synagogue, church or mosque, stand in line at the corner coffee shop, or step onto the city bus and somebody close will have some form of asthma or know somebody with the disease. Asthma impacts the lives of Canadians of every age, gender, ethnicity, in every town and city in every province and territory.

- **Asthma is the third-most common chronic disease in Canada.** It affects 2.4 million Canadians over the age of 12 (8.5 per cent of the population) and another 490,000 children between the ages of 4 and 11 (15.6 per cent of children in this age bracket).^{7,8}
- **Severe Asthma impacts the health and wealth of even more Canadians.** It is estimated that between 150,000 and 250,000 Canadians who have asthma suffer from SA, a more severe form of asthma and a greater threat to the health of these Canadians.⁹
- **Many asthma patients do not have control over their asthma.** Fifty-three per cent of Canadians with asthma have what doctors call “poorly controlled” asthma. This means that their treatment is ineffective. Poorly controlled asthma lowers the health outcomes and the quality of life for these men, women and children.^{10,11,12,13}
- **Asthma hits Aboriginal Canadians hardest.** Asthma is 40 per cent more prevalent among First Nations, Inuit and Métis communities than in the general Canadian population.¹⁴
- **Asthma kills.** Approximately 250 Canadians die each year from asthma.¹⁵ Around the world, approximately 250,000 people die prematurely each year because of asthma.¹⁶

The Economic Impact of Asthma

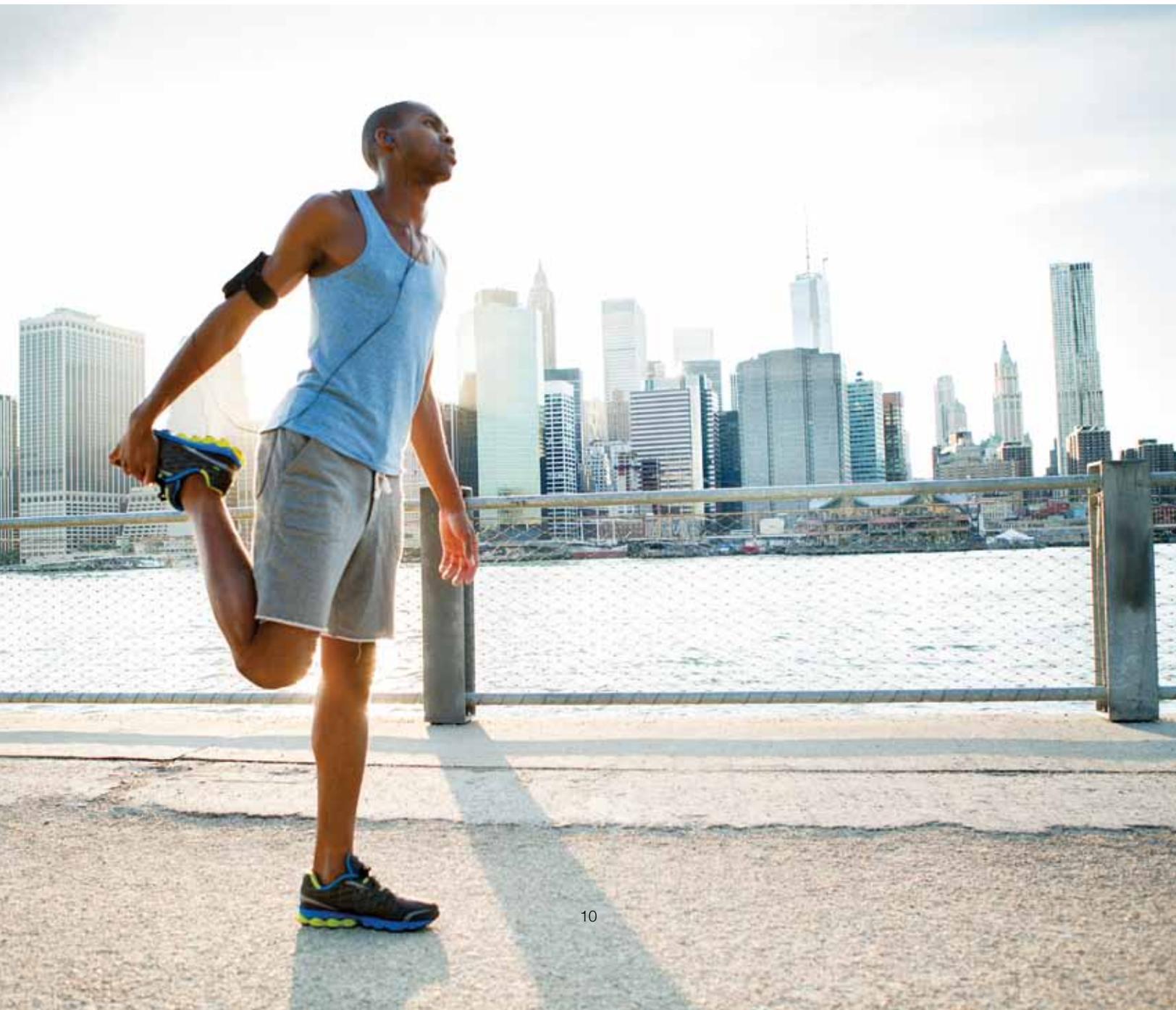
Along with lowering the quality of life for people with it, asthma levels a huge expense to the Canadian healthcare system and individual Canadians. These costs are mostly reactive – that is, they are costs incurred to deal with a patient after an asthma attack.

- **Asthma is the leading cause of hospital admission in Canada.** In 2011, Canadian emergency rooms dealt with 64,526 asthma-related events. Of these visits, nearly 27,000 patients were under the age of 19.¹⁷ A recent study shows that 30 per cent of respondents reported having one or more emergency department visits each year.¹⁸
- **Asthma is a billion dollar problem in Canada.** According to the Conference Board of Canada, the cost of hospitalization for asthma in 2010 was \$250,728,024. The physicians who cared for these patients cost \$196,321,334. The cost of asthma medication in 2010 was \$535,681,566. Indirect costs associated with asthma, including decreased productivity, are estimated at \$646 million.^{19,20,21,22,23}

Asthma and Severe Asthma

What Causes Asthma?

Asthma is normally defined by symptoms rather than its underlying cause or causes. The causes of asthma are not presently known and appear to be very complex. Genetics, allergic reactions, hormonal changes, obesity, stress, exercise and environmental conditions can contribute to asthma or trigger asthma attacks. But asthma can also erupt spontaneously in some people. The symptoms of asthma can recede without treatment, but often a person experiencing asthma will need treatment—medication or hospitalization—before they will be able to breathe comfortably on their own. Crucial research is still needed to help us understand why certain people are prone to asthma, and what types of asthma there are.



Severe Asthma

Defining Severe Asthma is not easy. From the patient perspective, this difficulty presents a barrier to better management of asthma. The difficulty in defining SA creates inconsistencies within clinical practice guidelines, clinical practice and medical literature.

Since 1996, Canadian clinical practice guidelines have used the concept of an asthma continuum—with an emphasis on “control of symptoms” rather than on “severity of the disease.”²⁴ For the most part, the concept of severity is used with respect to level of control, degree of symptoms and number and severity of exacerbations, as in “severely uncontrolled asthma.” However, SA is not clearly defined as distinct from mild or moderate asthma as it is in reports of the European Respiratory Society and American Thoracic Society.²⁵ Yet, the term “severe asthma” continues to be used by Canadian physicians without a clear and consistent definition.

When SA is defined in the literature, it is based on the minimum medication required to achieve adequate asthma control, rather than by the symptoms themselves, or on objective testing of lung functions. A large body of evidence indicates that patients have widely different understandings of asthma control and thus control can become meaningless as diagnostic evidence.²⁶

Newer research—including the research presented later in this report—shows that patients experience SA as a chronic, persistent yet intermittent disease, sometimes controlled and sometimes uncontrolled. Like many health problems, asthma exists on a severity spectrum. For some people, asthma is a challenge that is easily treated with medication. For others—those people suffering from SA—asthma is a chronic, life-threatening condition that requires more aggressive medication and often times medical care. The patient experience of life with SA is qualitatively and quantitatively different from other expressions of the disease.

For the purposes of this study, SA is defined as:

Continued asthma symptoms, frequent worsening of asthma symptoms, and asthma attacks among patients who take multiple asthma medicines with a high degree of compliance and good trigger management. Additionally, SA is the experience of patients who are not necessarily therapy resistant, but whose asthma is difficult to control and manage and requires a different level of care than milder versions.

The patient experience of SA is diverse. This diversity suggests that SA is not a single disease. There appear to be many types of asthma or “phenotypes” that may have similar symptoms but different physiological or biological characteristics.^{27,28} Much more research will be needed to move SA from a symptom-based diagnosis primarily related to the amount of medication used to reach control (or not) to an objectively defined condition with effective strategies for each of its manifestations.

Severe Asthma: The Canadian Patient Journey

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 following pages detail the insights gathered from this new study of SA in Canada.



Findings: The Severe Asthma Patient Journey

Life with SA is an arduous and confusing journey. While no single story exists to describe the journey, many of the respondents interviewed shared similar life experiences.

Early Days

Every person participating in this study has SA. Many participants were diagnosed with childhood asthma and most had early 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.”

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 to explain why I couldn’t be physical, like go running.”

The interviews also uncovered a troubling fact about SA: it is known by multiple names, like “strong asthma,” “complicated asthma,” “brittle asthma,” “difficult to control asthma” or “refractory asthma” rather than a single diagnostic name, “SA”. This can lead to misdiagnoses. One patient interviewed, said that his 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. But until that time, his SA lowered his quality of life.

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. And 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.”

What an SA Diagnosis means for Patients

- “It was a good feeling to know that I had a diagnosis and, because it was specific, it was helpful for me. But at the same time it was sad, knowing that it’s a chronic condition that I am still in denial about. There are a lot of questions I have so in a sense I feel worse since the diagnosis.”
- “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.”
- “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.”

Quality of Life

A chronic condition, SA limits social activities and can lead to a decline in general health. People with SA remark about how the condition isolates them—it is hard to stay social when one has unpredictable flare-ups—and it becomes hard to stay active 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. “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 are unaware that it is a life and death issue. 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 drugs 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 one.

Not uncommon was one participant’s journey through pharmaceutical treatment. Her doctors experimented with Beclovent, Pulmicort, Prednisone, Singulair, Advair, Ventolin, Spiriva, Qvar, Medrol and finally Xolair. Finding the right medication combination took close to eight years.

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.”

Contact the
**Allergy and Asthma
Education Support Program**



Toll-free at:

1-866-787-4050

or by email at: info@asthma.ca

To speak with a Certified Asthma/Respiratory Educator

Allergy and Asthma Education and Support Program

The Asthma Society of Canada provides education and support to people with asthma and associated allergies through information provided by Certified Asthma/Respiratory Educators. Call 1-866-787-4050 or email info@asthma.ca to get help today.

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. Some doctors treat asthma, even SA, 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.

Severe Asthma Patient experiences with the healthcare system

- “I was sitting in the emergency waiting room for over three hours and when the doctor did see me he was freaked out that I was there so long because I was coughing so badly. I just kept telling them, ‘Just give me the mask with the Ventolin. That’s what I need and as soon as you do, I’ll be better.’ But they just looked at me because they are not allowed to do it, and I waited and kept coughing.”
- “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 later about what happened.”

Severe Asthma Lowers Expectations for a Whole, Healthy Life

- “As a young adult, I felt like the sky was 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.”
- “Every time something happens I feel surprised because I don’t think about it otherwise. When I am affected by symptoms I am not happy, I feel like I am drowning and I have to start the process again, figuring out which meds they want to try and what will work this time.”
- “People tell me to call 9-1-1 if I have a bad attack, but I can’t breathe. How can I make a telephone call?”

The Burden of SA

SA is a progressive disease, often becoming more difficult to treat as the patient ages. “Back in my 20s and through my 30s medications and treatments worked, but it got worse when I got in my 40s,” explains one respondent. Not only does SA become more challenging to treat over time, but respondents say it becomes a bigger and bigger issue in life, demanding more attention and causing more stress. In younger years, says another 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.

One Patient's Story: Robert's Journey with Severe Asthma

Severe Asthma has heavy costs—to the pocketbook and to family life.

“I can't work. I can't bring money in,” says Robert, a 51-year-old man living near Edmonton.

Robert has SA, a chronic condition that sidelines him with breathlessness and the feeling of suffocation. SA prevents him from spending time outdoors with his son and maintaining a steady career.

“I can't even take my son hiking because of my health,” he says. “My limitations affect other people and it makes me angry that I can't do the things others can and that I used to be able to do.”

A Lifelong Journey

Robert, now 51, was first diagnosed with asthma as an infant. By age 7, doctors found a way to control his asthma enough for him to participate in childhood activities, although never any typical endurance sports. As a teenager and a young adult, he experienced chest infections every couple of years.

Robert's condition changed when he entered his 30s. He ended up in hospital at least once a year because of asthma attacks. Doctors gave him a variety of diagnoses for his breathing troubles. Some said he had malformed lungs and others said he had severe COPD.

It wasn't until he met a respirologist with an expertise in SA that Robert received an accurate diagnosis—he had SA and required a different kind of treatment to keep him healthy.



The Asthma Society of Canada has published a patient self-advocacy guide to help people with asthma navigate the complex Canadian healthcare system. Copies are available at asthma.ca

The SA Journey Today

Over the years, Robert has lived in different cities and different provinces and had a series of doctors to help him care for his disease. Today, he has a healthcare team that works together to review his medications and keep him on track with his Asthma Action Plan. His daily slate of medication includes Ventolin twice a day, Advair, Atrovent, Prednisone and other medications. He says he is lucky that the only side effect of this arsenal of medications is the occasional yeast infection in the mouth.

“My asthma is controlled the best it can be,” he says. “It's not getting better and it will only get worse. But we are keeping at it.”

Bureaucratic and Geographic Barriers to Health

Robert's healthcare plan doesn't make it easy for him to manage his health. The plans only let him purchase a 30-day supply of his medications, and he can only renew his prescriptions when he nears the end of his supply.

A rural Canadian, Robert often worries whether he will have his medication when he needs it. The pharmacy can run out of stock or a heavy snowstorm or flooding can prevent him from making the trip to the pharmacy.

Without his medication, Robert's life is endangered. It is a monthly stress he has to live with—a stress created by policies that look good on paper but work badly in practice.

“I think I'm getting the best I can out of the healthcare system right now,” says Robert, “but the whole healthcare system is not the way it should be.”

Major Findings of the Study

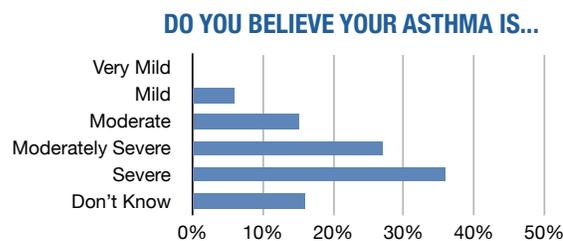
This study revealed five significant findings:

1. SA is not well-managed for most patients.
2. Inconsistent diagnoses and treatments impair the quality of care.
3. Patients are not equipped to manage their Severe Asthma.
4. Financial challenges create significant barriers to better health outcomes.
5. SA significantly impairs a patient's quality of life.

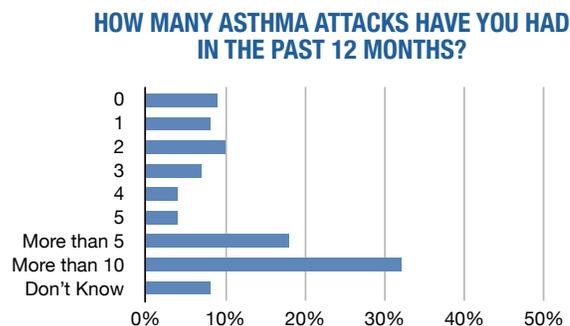
Finding 1: SA is not well-managed for most patients

SA is a regular—and often a sudden—health crisis for most of the respondents to the ASC study. The study found that:

- **For many, asthma is not controlled.** 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 8% don't believe their asthma is controlled at all.



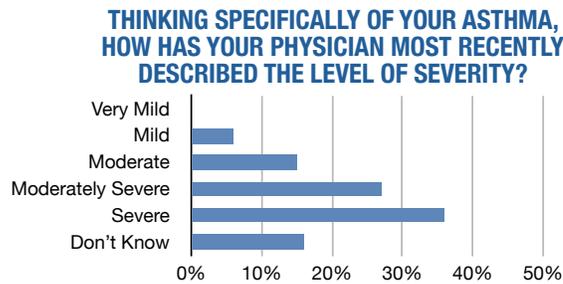
- **Asthma symptoms come on with little warning.** Most respondents (70.4%) say their symptoms come on with little or no warning. Only 3.1% indicate this doesn't happen at all.
- **Daytime symptoms are frequent.** Three-quarters of respondents experienced daytime symptoms (coughing, wheezing, chest tightness, shortness of breath) more than two days a week in the previous four weeks. Thirty-five per cent experienced these symptoms multiple times per day.
- **Asthma attacks happen as often as monthly for people with Severe Asthma.** Half of respondents have had more than five asthma attacks in the previous 12 months. A third of respondents have had more than 10 attacks.



Finding 2: Inconsistent diagnoses and treatments impair the quality of care

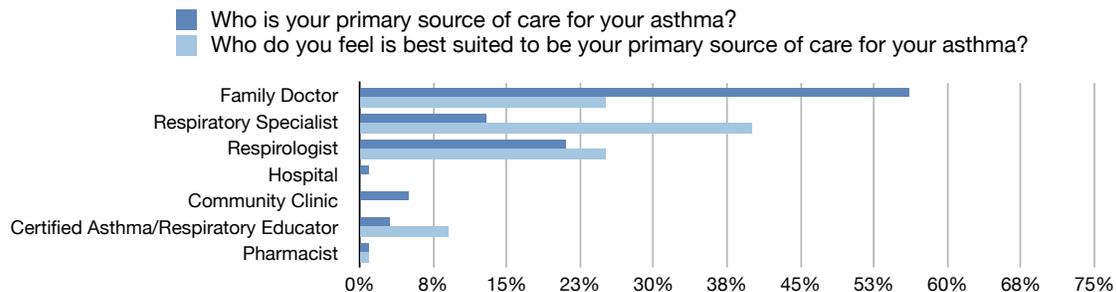
This study identified areas where the doctor-patient relationship thrives—and where it needs improvement.

- **Not all healthcare practitioners can appropriately identify SA.** All of the respondents to this study have SA, as identified by the Canadian Consensus Guidelines. But, when asked, 21% of respondents said their physician described their asthma as “Mild” or “Moderate.” More than a quarter (27%) reported that their physician described their asthma as “moderately severe.”



- **Most rely on family physicians for care, but would prefer a specialist if they could access one.** The ASC study showed that most respondents (56.7%) said their family doctor is their primary source of care for their asthma. Most (64.9%) said they felt a respiratory specialist or respirologist would be better suited as their source of primary care for their asthma.
- **Access to specialists is limited.** Only 31.6% of respondents said they had access to a respiratory specialist and only 41.1% had access to a respirologist. Only 33.7% indicated they had access to a community asthma clinic and only 22.1% had access to a Certified Asthma/Respiratory Educator. A third of respondents had access to a pulmonary lab.

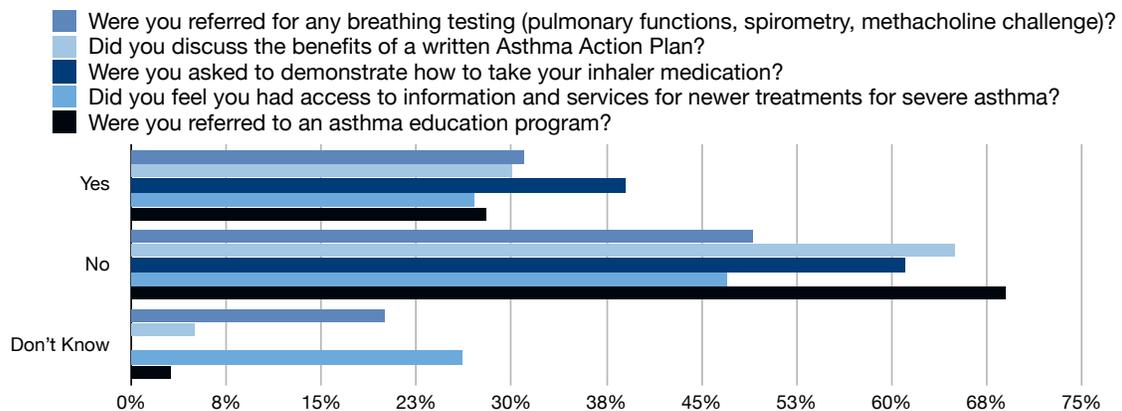
WHO IS YOUR PRIMARY SOURCE OF CARE FOR YOUR ASTHMA?





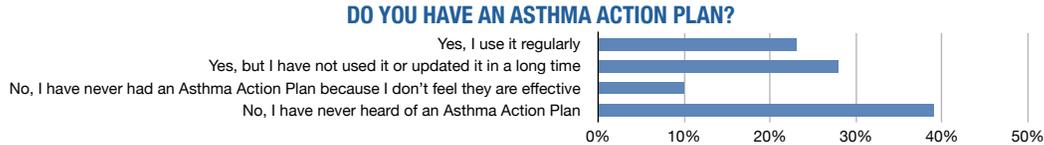
- **Healthcare professionals use inconsistent criteria and differing diagnostic techniques when diagnosing and grading asthma.** The ASC study showed that only half of respondents reported being given any lung function or other pulmonary tests prior to their diagnosis. Tests often don't include standard allergy testing or elementary objective lung function tests such as spirometry.
- **Asthma symptoms, control, treatment and management are not always discussed with healthcare providers.** Less than half of respondents said they discussed proper inhaler techniques (40%), Asthma Action Plans (30.5%) and the benefits and risks of an inhaled steroid medication (38.9%) with a healthcare professional in the past year. Only 27.4% of respondents were asked if they had any concerns about their medications. Only 62.2% of respondents agree that their doctor makes sure they are using their medication properly.
- **A surprising number of patients are not receiving information about the newest kinds of therapies for their asthma.** Only 27.4% of respondents felt that they had access to information and services for newer treatment options for SA. Patients knew little about new biologics available for treatment of SA and none had heard of bronchial thermoplasty despite its availability in several centres geographically near interview participants.

PRIOR TO YOUR DIAGNOSIS OF ASTHMA,



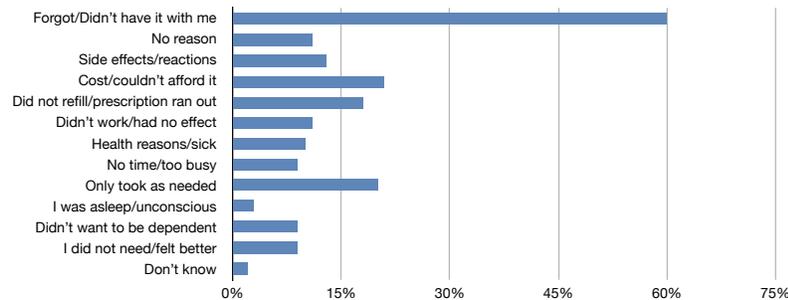
Finding 3: Patients are not equipped to manage their SA

- Most patients have no written plan to manage their asthma.** A variety of studies have shown that an Asthma Action Plan can help patients manage asthma at home. Despite the promotion of these plans by leading respiratory health organizations, only 23% of respondents use an Asthma Action Plan or an Asthma Diary and 39% have never heard of these tools. While many patients do not use a plan, 62% of respondents feel that an electronic version of an Asthma Action Plan would be most useful. Additionally, only 27.4% of respondents were referred to an asthma education program by their doctor.

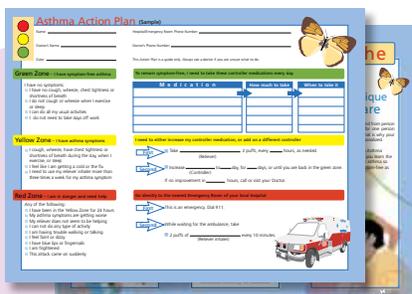


- Many respondents do not carry their reliever asthma medication with them.** A variety of reasons were suggested for this including not filling prescriptions, not having access to multiple inhalers or simply not expecting to encounter a trigger or predicting an exacerbation.
- Many respondents admit failing to use controller medications as prescribed.** More than half of respondents (57.9%) admitted to not taking their prescribed controller medication, with 32.8% missing prescribed dosages more than two days per week, and 16.4% of respondents missing prescribed dosages more than four days per week. Most often, patients expressed the belief that they were asymptomatic and not in need of their medication. Additionally others had given up on the medication because of repeated asthma exacerbations despite past use. Some cited unpleasant side-effects.

WHAT IS THE MAIN REASON YOU MIGHT STOP OR NOT TAKE THE CORRECT DOSAGE?



- Many patients are unsure about their therapy.** Only 17.5% of respondents use **Single Maintenance and Reliever Therapy** (also known as SMART), a combination inhaler that delivers both a maintenance drug and a quick relief drug. At the same time, 42.3% of respondents said they were unsure whether they use SMART. This fact indicates patients either don't know about the SMART option, or they are unfamiliar with the details of their treatment.
- Medical devices, such as spacers (useful for those using pressurized metered-dose inhalers) and peak flow meters (indicated for some patients) are not used by many SA patients.** A quarter of respondents did not know anything about asthma related medical devices such as a spacer or peak flow meter, and 42.5% of respondents were never given or prescribed any equipment of any kind.



What is an Asthma Action Plan?

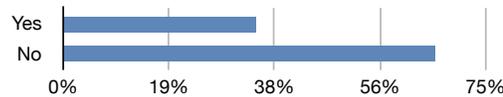
An Asthma Action Plan is a set of written instructions that help patients manage, track and treat their asthma. These plans assist patients in monitoring and adjusting medication for worsening asthma and are informative in situations where patients are not near their usual treatment facilities.

Finding 4: Financial challenges create significant barriers to better health outcomes

While most respondents use their asthma medication every day, many do not, and for different reasons.

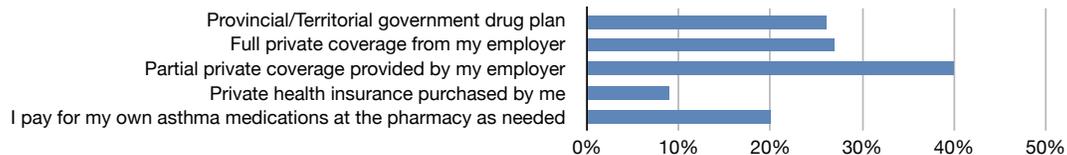
- **Many patients cannot afford the cost of their medication.** Of those who indicated their annual household income, more than a third of respondents (36.9%) reported it being under \$50,000. This appears to affect their ability to manage their asthma.

HAVE YOU EVER SKIPPED FILLING A PRESCRIBED ASTHMA MEDICATION BECAUSE YOU WERE NOT ABLE TO 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. Many of these people (29.5%) are currently taking alternative treatments for their asthma. Just over half of respondents (53.7%) have a “full coverage” drug plan and 40% say they only have “partial coverage.” Only 62.1% of respondents indicated their insurance plans sufficiently covered their treatment costs.

HOW IS THE COST OF YOUR MEDICATION COVERED?



The cost of asthma medication affects treatment

The high cost of asthma medication affects treatment. One respondent said in an interview that, “I have prescription coverage that will cover birth control, but it won’t cover my inhaler. Sometimes I just want to give up.”

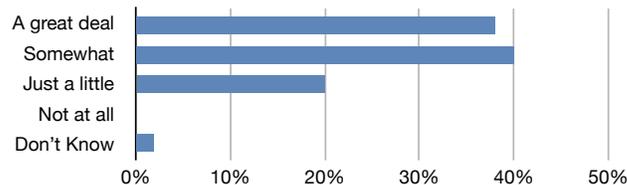
Another respondent describes having to rely on sample medication to maintain the treatment schedule: “My doctors help me with the cost by giving me samples of most of my inhalers, but when I have to pay for them, except for the Ventolin which is reasonably priced, I have to take on extra work to help pay for my medication.”

Finding 5: SA impairs a patient's quality of life

This research shows that SA impairs a patient's ability to live a full and healthy life.

- **SA limits physical activity.** Despite the fact that a clear majority of respondents (89%) agree that asthma was not a reason for avoiding physical activity, 71.4% experience limitations to their daily activities and exercise because of their asthma in the four weeks preceding the study.
- **SA 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.”

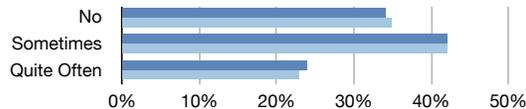
WOULD YOU SAY YOUR ASTHMA AFFECTED YOUR WORK OR SCHOOL PERFORMANCE?



- **Asthma creates social barriers for some patients.** More than half of respondents (64.6%) said they have felt stigmatized at some point because of their asthma, with 22.2% saying they feel stigmatized “quite often.” Similarly, 66% of respondents feel that their asthma interferes with the quality of their social interactions with others, and 23% feel this way “quite often.”

DO YOU FEEL LIVING WITH ASTHMA INTERFERES WITH THE QUALITY OF YOUR SOCIAL INTERACTIONS WITH OTHERS?

- Do you feel living with asthma interferes with the quality of your social interactions with others?
- Has your asthma ever caused you to feel stigmatized or isolated?



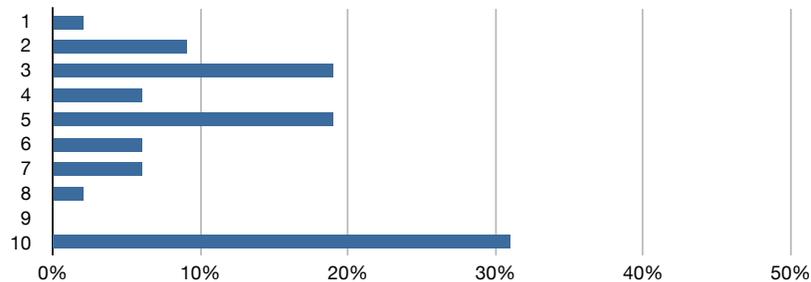
- **Asthma affects family members, too.** Most respondents (80%) reported that they, or a family member, experienced trouble sleeping in the last three months because of their asthma symptoms.
- **SA attacks tend to be lengthy and costly.** Approximately 30% of our respondents missed work or school because of their asthma. Of these, 65.9% missed five days or more. A third of those who missed work or school (31.9%) missed 10 days or more, amounting to approximately 10% of total respondents.



The Asthma Society of Canada has recently published a guide for maintaining a healthy, active life with asthma. Copies are available at asthma.ca

- **SA is an emergency condition for many patients.** Almost half of respondents (48%) visited an emergency room because of their asthma in the 12 months preceding the study. A third went more than once during this period. One in five had been admitted to the hospital because of asthma in the preceding 12 months, with one in ten having been hospitalized more than once.

APPROXIMATELY HOW MANY DAYS OF WORK OR SCHOOL DID YOU MISS IN THE PAST YEAR?



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)

One Patient's Story: Margaret's Journey with Severe Asthma

Severe Asthma, along with physical effects, strains one's emotional and mental wellbeing.

"I had fear of this getting worse, that I'm doing everything I'm supposed to and now have a sense of betrayal from my own body," says Margaret, a 55-year-old woman living in Toronto.

Margaret's SA inhibits several aspects of her life, such as the simple joy of spending time outdoors and being around her husband, who is a smoker.

"When I was in my mid-30s was when it really started getting worse," Margaret says. SA even affects her profession, as she suffered an asthma attack on her first day at a new workplace.

"I'm not out as much since my last hospitalization. I'm a lot more timid about going out and getting things, with the 'what if' in my head. Is it a good day? Bad day?"

An Ongoing Hardship

Margaret was diagnosed with SA when she turned 50.

The condition dates back to her childhood, when her family treated her mostly with home remedies. As she grew older, it became more apparent that Margaret suffered from asthma. A new family doctor treated her accordingly.

Margaret's current adversity rests in her inability to find a family doctor or respirologist in her community. Retirement and relocation have made it difficult to maintain regular doctor's appointments. Presently, Margaret consults with physicians at a nearby walk-in clinic, who say her asthma is controlled poorly.

Struggles with Healthcare

Through the years, Margaret's experiences with physicians have varied. Her symptoms have sometimes been treated as isolated allergic reactions. Other times, doctors have carefully explained treatment and medication options and referred her to Certified Asthma Educators.

Along with being upset by many doctors' lack of attention to and awareness of SA, the expense of her medications frustrates Margaret. Over the years, she has been treated with Ventolin, Advair, Beclovent, Qvar and Prednisone.

"I was frustrated that the medication was so expensive," Margaret says. To save money, she has tried to stretch her doses so that her medication would last longer.

Educating Others about SA

"I've tried to educate friends and family when I can but it's frustrating," Margaret says with regards to SA awareness.

In the same way SA complicates her professional life, SA also complicates Margaret's relationship with her husband because of his smoking habits. Smoke has a direct effect on Margaret's condition, and she feels the situation indicates her husband's lack of awareness regarding his impact on her. Avoiding smoke leads to isolation.

Margaret considers venturing outdoors a risk because of air quality and pollen. In all aspects of life, she makes an effort to educate others about the hardships of SA.

"I felt really guilty one day," Margaret confesses. "Somebody came in and said, 'I can't believe it, my niece just died from an asthma attack,' and I went, 'Yes! You finally get it!'"

Should loss of loved ones be the lesson people need before they understand the dangers associated with SA? Margaret doesn't think so. But in her experiences, it has taken extreme lessons before people change.



Patients, working together with healthcare providers and governments have the capacity to manage their asthma. Together we can aim for zero symptoms.



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 the overall health of employees



The Asthma Society of Canada's National Asthma Patient Alliance is a grassroots patient group whose aim is to increase patient awareness about how to achieve optimal asthma control. To join, call 1-866-787-4050 or email napainfo@asthma.ca.



Appendix: The Study Methodology and Research Team

About the Study

The study examined patients in four urban centres located in three provinces (Alberta, Ontario and Quebec) using a qualitative survey (n=24) involving a lengthy personal interview and a complementary on-line quantitative survey (n=200) to validate the results of the in-depth interviews. Participants were Canadian adults 18 years and older who live with controlled or uncontrolled SA, and who have been diagnosed with asthma by a physician. The indicators used to determine the severity of asthma were based on a variety of indices of asthma control such as those listed by GINA and reviewed by a team of expert advisors.

About Participants

The research team recruited people diagnosed with SA to participate in in-person interviews. A small number of interviews were accomplished over telephone.

Patient recruitment involved direct outreach to members of the National Asthma Patient Alliance (NAPA), through the Severe Asthma Network as well as promotion through local asthma clinics and relevant healthcare centres. Project staff distributed promotional posters through clinics and health centres in target cities and emailed relevant contacts with the goal of reaching as many potential participants as possible in the target cities. All interested participants were directed to the Eligibility Questionnaire that was available in English and French.

All potential participants were evaluated through a strict screening process and only qualifying applicants were contacted for the interview phase. All participants were given the option of anonymity or to withdraw as part of the online screening structure and provided with an additional consent form.

Who they are

- Seventy-five per cent of interviewed participants were between 30 and 60 years old. The largest group was between 50 and 59 years old. The next largest group was between 30 and 39 years old. The majority of interview participants (81%) were female.
- A quarter of participants were diagnosed with asthma before the age of five and another quarter of participants were diagnosed with asthma in their 30s. Nearly all participants were diagnosed with SA as adults.

Where they live

- The largest group of participants live in Ontario (42.2%), with the next largest groups living in Alberta (20.6%), British Columbia (15.7%) and Quebec (8.9%). The remaining 12.6% live in other parts of Canada. The study participants were largely from provinces in which the ASC has active relationships with asthma clinics and the most research partners and clinicians for patient recruitment. They also are the provinces in which most Canadians live.

What they earn

- Of the people who participated in this research study, most (69.9%) had a college or higher education background and many (42.7%) reported they had an annual household income of \$50,000 or higher (36.9% of respondents reported an annual household income of under \$50,000, and 24.3% said they had a household income of \$90,000 or higher).
- The respondents represented a diverse group, with nearly half (47.1%) employed on a full-time basis. Almost a tenth of respondents (8.8%) said a disability prevented them from working. The remaining participants identified themselves as employed part-time, retired, unemployed, a student or as a stay-at-home parent.

The challenges they face with asthma

- The majority of respondents to the study reported that they use asthma medications on a daily basis.
- Most respondents (83.5%) use their controller medication daily, with 71.1% using it at least twice per day.
- Many respondents (42.2%) use their reliever medication daily, with 28.8% using it at least twice per day.
- In the four weeks preceding the study, more than half of respondents (52.9%) used their rescue medication almost daily, with 22.2% requiring it several times per day.

The Project Team

The team that conducted the ASC study into SA include researchers, academics, clinicians and staff of the Asthma Society of Canada.

- **Dr. Robert Oliphant**
President and CEO, Asthma Society of Canada
- **Dr. Susan Wasserman**
Professor, Dept. of Medicine, Clinical Immunology and Allergy, McMaster University
Chairperson, Medical and Scientific Committee, Asthma Society of Canada
- **Darren Fisher**
Director, Partnerships, Asthma Society of Canada
Project Management
- **Rupinder Chera**
Researcher, Asthma Society of Canada
Project Investigative Lead
- **Noah Farber**
Director, Communications and Government Relations and Executive Director,
National Asthma Patient Alliance (NAPA)
Recruitment, Dissemination of results
- **Zach Simbrow**
Director, insightOut
Research Methodology Consultant

Expert Advisors

An advisory group representing the medical, clinical and academic perspectives provided expert advice on the project implementation strategies and helped the investigators create definitions, establish the project scope, address barriers and challenges, devise a methodology of data collection tools, ensure appropriate ethics approvals and recruit participants.

- **Dr. Dilini Vethanayagam**
Co-Investigator, Associate Professor, Department of Medicine (Respirology), University of Alberta,
Edmonton Regional Severe Asthma Center
- **Dr. Jason Lee**
Education Director, St. Michael's Hospital Clinical Immunology and Allergy, St. Michael's Hospital,
Private Practice Lecturer, University of Toronto Department of Medicine
- **Dr. Céline Bergeron**
Assistant Clinical professor, Department of Medicine, Université de Montréal, Pneumologist, Centre
hospitalier de l'Université de Montréal (CHUM)
- **Dr. Clare Ramsey**
Attending Physician, Respiratory Medicine and Critical Care Medicine, Health Sciences Centre
Assistant Professor, Department of Medicine, University of Manitoba

Ethics Review

This study, its methodology, survey instruments, patient recruitment and consent materials and all protocols regarding information storage and disclosure were reviewed and approved by Institutional Review Board Services (IRB). IRB services attests that the protocol and consent documents were approved and accord with good clinical practices, Health Canada regulations and the Tri-Council Policy Statement for Ethical Conduct of Research involving humans.

Additionally, standards based on the Member Standards for the Market Research Intelligence Association were also followed. General ethical standards and guidelines are approved by the Asthma Society's Medical and Scientific Committee for all research and programming and fall into the following categories:

- **Consent:** Research teams ensure that participants understand the purpose and key components of the study and what the information they provide will be used for. Participants have the right to be treated professionally and to withdraw from a study for any reason.
- **Professional conduct:** The utmost care is taken to uphold high standards of general competency in the design, execution, analysis, reporting, interpretation and consulting phases of any study. All activities abide by the prevailing legislation that applies to the research conducted.
- **Participant rights:** The research team protects the interests of participants' rights to confidentiality. The team ensures that records of research will be held for the appropriate periods and that these will be protected from theft, misuse and inadvertent destruction. All personal and identifying information is kept confidential and will only be used as identified and consented to.



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*“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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