

## ANNUAL ASTHMA SURVEY REPORT

A SNAPSHOT OF ASTHMA IN CANADA





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The Canadian asthma community is a diverse group of more than 3.8 million individuals living with asthma. It not only includes patients with asthma but countless others: family members, friends and caregivers.

As one of the most common chronic diseases in Canada, it's important that we maintain up-to-date knowledge about the realities of asthma care. Our annual asthma survey provides an opportunity to gain insight into the patient experience in Canada and hear directly from our community members. Canadians with asthma face unique challenges and the survey responses directly inform our strategy to ensure every Canadian with asthma gets the support they need.

Asthma Canada continues to advocate for Canadians with asthma to ensure asthma care for every individual includes an official diagnosis, with proper and accurate testing, followed by comprehensive management, including an Asthma Action Plan.

We know that people living with asthma continue to experience mental health challenges as a result of their symptoms, too. A large majority of respondents reported feeling anxious or stressed because of their asthma.



It is imperative that asthma care includes supports to address mental health needs.

There is still a clear disparity between people's perception of asthma control versus the clinical definition of control: a major barrier in optimizing asthma care. We are working diligently to end this misconception, and there is still more to be done.

Moving forward we will continue to amplify the voices of the asthma community, and address these issues head-on so that every Canadian with asthma can strive to lead a healthy, active and symptom-free life.

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**Vanessa Foran** President & CEO, Asthma Canada

## EXECUTIVE SUMMARY

Nearly 3.8 million Canadians are affected by asthma, a chronic lung disease which restricts the airflow into the lungs making it difficult to breathe. It is one of the most common chronic diseases in Canada. Many social and environmental factors trigger asthma symptoms causing shortness of breath, chest tightness, wheezing and coughing, which constrict the airways.

It is estimated that nearly 300 Canadians are diagnosed with asthma every day, and every year, four families lose a loved one to a fatal asthma attack.

Asthma Canada continues to listen to the voices of those living with asthma, providing continuous support and education. The 2021 Asthma Survey is the third annual survey conducted, focused on listening to the patient voice and raising awareness by highlighting the challenges and gaps that exist within the healthcare system for individuals with asthma.

Asthma can impact one's mental health to the point where individuals feel anxious and scared. Change in routine and uncertainty about the future during a global pandemic has left many emotionally stressed, too. The majority (76%) of people living with asthma reported having some form of health-related anxiety and 71% reported feeling emotionally stressed due to their asthma. Asthma impacts the quality of life of those affected by the disease and can have a devastating impact and cause challenges for individuals when completing daily activities or interacting with others in society. More focus needs to be given to the mental health and emotional well-being of individuals living with asthma.

Timely access to quality health care, treatment and education for proper asthma management and symptoms control is crucial to the wellbeing of Canadians with asthma. Yet, close to half (42%) reported that their current drug coverage is insufficient and 25% of people have skipped filling a prescription because they were not able to afford it.

### **Executive Summary**

Family doctors, pediatricians and emergency room doctors are the first to diagnose (71%) compared to asthma specialists (12%). However, the primary source for care and management for those living with asthma still continues to be a family doctor or pediatrician (59%), followed by an asthma specialist (24%). Issues of access, wait times to see a specialist, lack of information and education provided for managing asthma and referrals as well as follow-up after-emergency care are all priorities for our community. In a pandemic this continues to be more challenging and of concern when safety measures in place further lead to the decrease in utilizing the healthcare system out of anxiety or fear: thirty-nine percent of respondents in our survey had not gone to an appointment during the pandemic.

Survey results again showed that there is a clear disparity between people's perception of symptom control versus the clinical definition of control. This can be a major barrier in optimizing asthma care. While 83% of respondents believe their asthma is somewhat to very well controlled, (70% reported their asthma to be the same during COVID-19), 59% report trouble sleeping due to asthma symptoms and 64% report avoiding exercise or physical activities due to asthma symptoms—clear signs of uncontrolled asthma.

Consistent with both the 2019 and 2020 surveys, three at-risk groups were identified: Canadians between ages 18 and 24 (note in the 2019 survey this age group identified was between 18-34 years of age and in the 2020 survey this age group identified was 25-44 years of age); people living with Severe Asthma (note in 2020, this also include those living with moderate asthma); and those with an annual income less than or equal to \$29,000 (note in the 2019 survey the annual income was less than or equal to \$19,000, and in 2020, less than or equal to \$29,000).

There are various factors that can affect the burden of asthma, including the social determinants of health. Improving access to affordable medications, accurate testing and diagnosis along with early diagnosis and comprehensive management can lead to better quality of life for those living with asthma.

## SURVEY METHODOLOGY

Asthma Canada offers our sincere thanks and gratitude to all those who took the time to complete the survey. Feedback from our community is incredibly important to us.

The 2021 survey was launched online and shared with our Asthma Canada Member Alliance (ACMA) on May 3, 2021. Data collection period lasted for nine weeks, closing on July 4, 2021. We received a total of 256 responses with a 68% (174) completion rate. Criteria for participation was to be living in Canada and have asthma, or be a parent or caregiver to someone with asthma. Of those who had completed the survey, more than half (51%) of the survey respondents did not participate in the 2020 Asthma Canada Annual Survey compared to 16% who had participated and 33% who were unsure if they had participated. Nearly half (48%) of the respondents indicated that they had moderate asthma. The percentage of respondents indicating mild and Severe Asthma was 25% and 27% respectively.

The majority of the survey respondents (47%) were in the 45-64 years of age-group followed by the 25-44 group (23%) and 65+ (20%). Most respondents in the younger age groups (17 & under and 18-24) represented 6% and 4% of the respondents, respectively.

A majority (82%) of the respondents were from three provinces: Ontario (43%), British Columbia (27%) and Alberta (12%). Response from Quebec was only 5%. Responses from the Atlantic provinces was comparatively low, collectively accounting for just 8% of the respondents. Response from Manitoba and Saskatchewan was also low, representing 2% and 3%, respectively. No response was received from Nunavut, the Northwest Territories and the Yukon.

Less than half (38%) of the respondents reported that their income level was less than \$59,000 and 46% were living in a suburban area compared to 37% in urban areas, 16% in a rural area and 2% in a remote area.

Due to the small sample size interpretations must be made with caution.

## SURVEY FINDINGS

### **Quality of Life: The Impact of Asthma on Mental Health**

66 There is nothing as frightening as not being able to breathe."

An individual's overall health and well-being can be significantly impacted by asthma. The emotional impact can affect one's anxiety and stress levels. The 2021 survey indicated that a significant majority of respondents reported having health-related anxiety (76%) and (71%) reported feeling stressed due to their asthma. More than half of the respondents reported feeling like they were missing out on opportunities (52%) and less confident (52%) due to their asthma. Less than half (44%) reported feeling hopeless with regards to their health and well-being.

Mental health issues like depression and anxiety contribute to the quality of life among people with asthma, however there is not enough evidence to conclude that one causes the other. Other risk factors such as stress may may cause asthma symptoms to worsen and cause people with asthma to feel frightened. Stress is a daily part of life and it can be triggered by major stressors happening on one's live such as the loss of a job, increased financial obligations, death of a loved one, chronic illness or injury, relationship issues, too many deadlines, lack of support, or life changing events that might not be in one's control.

And of course, the lives of many have changed due to the COVID-19 pandemic. The pandemic has had a huge impact on the mental health and well-being of many living with chronic health conditions, including asthma. It is normal for some to feel concerned as more cases of COVID-19 are reported in their community. Strong emotions, uncertainty and unpredictability can create unhealthy amounts of fear and stress that can trigger an asthma attack. Each individual handles stress and anxiety in very different ways.

### Quality of Life: The Impact of Asthma on Mental Health

The survey specifically highlights higher reporting of health-related anxieties and feeling stressed among: Canadians between 18 and 24; people living with Severe Asthma; and those with an annual income less than or equal to \$29,000.

These results are similar to what was found in the 2019 survey and slightly changed in the 2020 survey where Canadians between 25 and 44 years of age and moderate and those with Severe Asthma had a higher reporting of health-related anxieties and feeling stressed.

Majority (73%) of the respondents aged between 18 and 24 reported feeling healthrelated anxiety due to asthma. In addition, a surprising 71% felt less confident, and 86% reported that they felt isolated or like they were missing out on opportunities due to their asthma. More than half of the respondents reported feeling stigmatized (57%) or hopelessness (57%) due to their asthma. Surprisingly, respondents between aged 25-44 also felt health related anxiety and stress due to their asthma 73% and 76%. These findings are similar to those from 2020.

Majority of the respondents with Severe Asthma reported feeling health-related anxiety (82%), isolated or like they were missing out on opportunities (80%), less confident (74%) and hopelessness (56%). Additionally, 80% of respondents with Severe Asthma reported feeling stressed due to their asthma and 63% stigmatized due to their asthma. Individuals living with Severe Asthma experience poorer quality of life and are at an increased risk of exacerbations, hospitalizations and death due to poor disease control and more often have poor mental health outcomes.

In addition, stressors such as job loss, increase in financial obligations or living in a low income household can also have a huge impact on a person's asthma. This can lead to lack of affordable housing, medications and working in precarious jobs with dangerous working conditions, subsequently leading to poor mental health and well-being.

### Quality of Life: The Impact of Asthma on Mental Health

When analyzing income-level, majority (77%) of the respondents with an annual household income of \$29,000 or less reported health-related anxiety due to asthma: the highest percentage among all the income groups. This group also had the highest proportion of respondents reporting feeling stressed (77%), isolated and missing out on opportunities (58%), less confident (50%) and stigmatized (42%) due to their asthma. These findings are similar to what was found in the 2019 and 2020 survey.

The fear of having an asthma attack can significantly impact those living with asthma. Less than half (49%) of respondents indicated that experiencing an asthma attack left them fearing for their life, majority of those who experienced this feeling were those who identified as having Severe Asthma (60%), compared to moderate (55%) and those with mild asthma (26%).



"Having asthma feels like I'm going to eventually die of an attack, so it's like knowing how you will die."

My very first attack was in the tub with the water running. The attack was paralyzing and I couldn't get out of the tub. My husband became concerned and entered the bathroom when I didn't answer him. He got me out of the tub and into a room with the window open where I was able to recover."

"In the summer of 2015, I had a near-fatal asthma attack. I was hospitalized for five days. Initially, I was asked about my final wishes and told that I may have to be intubated. I was alone and very scared. This traumatic incident is always on my mind."

"I have had a few instances in the past where I was very scared because I felt like I could not catch my breath."

"Eldest son passed away from an asthma attack due to anaphylaxis and youngest son has asthma and allergies too, so any attack fears us."

### Quality of Life: The Impact of Asthma on Mental Health

Asthma affects the person, but it also affects personal relationships with parents, spouses, coworkers and caregivers. This can have an emotional impact on the individual living with asthma. More than half (53%) of respondents felt that living with asthma interfered with the quality of their social interactions. This was felt more often by respondents with Severe Asthma (85%).



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"I've avoided going outside due to wildfire smoke."

"With the pandemic and the possibility of catching Covid-19 it has been quite the cause for concern. Leaving out mostly any activity outside or done in a group."

"I've avoided going outdoors on days that are very humid, days with poor air quality or days with extreme cold wind."

"Avoided outdoor activities on humid days in summer."

"I avoided walking, gardening, sitting out and enjoying the day."

### Quality of Life: Addressing Lack of Participation and/or Avoidance

Avoiding and lack of participation in outdoor/physical activities is alarmingly high in many people living with asthma, particularly those with exercise-induced asthma. This can have a negative impact on the psychological and social-wellbeing of those living with asthma. More than half (59%) of respondents indicated that in the past 12 months their asthma symptoms prevented them from participating in outdoor and/or physical activities. This was seen in 79% of respondents with Severe Asthma, 58% with moderate asthma and 40% with mild asthma.



It has been shown that people with Severe Asthma have poor quality of life that impacts their ability to complete daily activities, participate in outdoor and/or physical activities, loss in productivity at work or school and are limited in their leisure and lifestyle. The major limitation is not being able to participate in sports and vigorous activities and is more common in individuals with uncontrolled asthma. Based on the survey participant responses, the pandemic has not made it any easier for individuals living with asthma to complete daily activities.

### **Quality of Life: Absenteeism and Presenteeism**

Asthma is the leading cause of absenteeism (which is time taken off) and presenteeism (which is the loss in productivity) in school and work.

Absenteeism from school is more prevalent among low-income and racial/ethnic minority children and children in urban areas. Differences associated with asthma control such as access to and quality of health care, adherence to medication use, and social factors such as segregation and psychosocial stressors also contribute to absenteeism. In the past 12-months, 25% of respondents missed work or school because of their asthma symptoms, 47% with severe asthma and 57% were between the ages of 18 and 24 years old.

Similarly, the loss of productivity at school or work due to being sick or feeling unwell in individuals with asthma, can lead to a decrease in performance or quality of work or schoolwork. This is known as presenteeism, and it is often overlooked and it has been reported that productivity loss in work and school can be avoided by achieving and maintaining control of asthma, which can sometimes be difficult in individuals with Severe Asthma. Nearly one-third (32%) of respondents said the performance or quality of their work or schoolwork in the past 12 months was affected by their asthma symptoms, 48% with Severe Asthma, and 42% were between the ages of 18 and 24 years old. This can have a negative impact on the financial and emotional consequences burdening people with Severe Asthma and their families.

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"I've had to resign my job on medical grounds as my asthma has severely deteriorated in the past 4 years."

"While I was working from home, I had severe asthma symptoms and could not teach my classes as I could not breathe."

"I had to keep stopping what I was doing to take Ventolin. I teach so I couldn't sing/teach often without taking Ventolin. Couldn't do exercise with my students. Couldn't always take them outside to play."

### **Quality of Life: Diagnosis**

When an individual presents to their primary care doctor with respiratory symptoms, the best practice for diagnosing asthma includes completing a detailed history and examination for asthma, alongside conducting a spirometry test (a pulmonary function test that measures the amount of air you can breathe in and out).

Conducting a spirometry test is important to avoid under- diagnosing and overdiagnosing asthma. Over half of respondents (59%) had their asthma diagnosed through physical exam, followed by 46% of cases that were diagnosed through spirometry testing. A chest x-ray was used in 42% of cases. These results are similar to what was found in the 2019 and 2020 survey. More respondents are reporting that their asthma is diagnosed through spirometry testing.

Majority of the survey respondents (71%) indicated that their official diagnosis came from a family doctor/pediatrician or emergency room doctor, followed by 12% who said they were diagnosed by an asthma specialist/respirologist/allergist. Overall, 47% of respondents indicated that they were diagnosed in adulthood and 29% reported being diagnosed as an infant or at a preschool age (one to five years-old).

66 I had asthma educators many years ago when I first got diagnosed, so that helped."

#### **Quality of Life: Asthma Control**

Most people living with asthma say they have their asthma under control, yet their symptoms tell another story.

The results in this survey are similar to what was found in the 2019 and 2020 surveys. Nearly half (42%) of respondents indicated that their asthma was controlled to very well controlled, while 11% said their asthma was neutral. In addition, nearly half (41%) of respondents said their asthma was somewhat controlled, and 5% said their asthma was not controlled at all. However, when looking at the key parameters of asthma control nearly half of the respondents reported that they experienced trouble sleeping, used a rescue inhaler frequently, were less likely to participate in outdoor and/or physical activities, and missed work or school in the past 12 months due to their asthma symptoms. There is a clear difference between those reporting that their asthma was controlled compared to it being *actually* controlled.

### **Quality of Life: Asthma Control**

A majority (85%) of respondents with self-reported mild asthma and nearly 76% of those with self-reported moderate asthma indicated that their asthma is controlled. However less than half (40%) of those with self-reported Severe Asthma indicated their asthma is controlled.

More than half (62%) of respondents with an income level less than \$29,000 and (63%) of respondents with an income level between \$30,000-59,999 reported having trouble sleeping because of their asthma symptoms such as wheezing, persistent cough, shortness of breath or tightness of the chest. In addition, 70% of adults ranged from 45-64 years of age reported having trouble sleeping because of asthma symptoms. It has also been shown that those individuals whose asthma is not well controlled are more likely to use their rescue inhalers for quick relief of asthma symptoms rather than the long-term prevention provided by controllers. In this survey, 45% of respondents said they use their rescue inhaler more than twice a week and 50% use it before exercise.



The majority (70%) of respondents indicated that they felt their asthma was the same, even during a pandemic. However, 39% of respondents also indicated that they had not gone to an appointment or utilized the health care system because of COVID-19.

## **Quality of Life: Asthma Control**

Access to proper care and treatment during a pandemic is important, yet it is unclear whether the anxiety or stress of leaving the house due to COVID-19 was the reason for many not seeking medical care.

Asthma Control: Perception vs. Reality			
Respondents' perception of the level of their asthma control	Respondents' self-reported data on the key parameters of asthma control		
<ul> <li>More than a quarter (29%) indicated that they believe their asthma is 'controlled'; 13% indicated it is 'very well controlled'</li> <li>Nearly 11% indicated that they believe their asthma is 'neutral'</li> <li>Nearly half (41%) indicated that they believe there asthma is 'somewhat controlled'</li> <li>Only 5% of respondents reported that they believe their asthma is 'not controlled'</li> </ul>	<ul> <li>In the last 3 months, more than half (61%) of respondents have experienced trouble sleeping because of asthma symptoms such as wheezing, persistent cough, shortness of breath or tightness of the chest.</li> <li>Less than half (45%) of respondents said they use their rescue inhaler more than twice a week and 50% use it before exercise.</li> <li>Majority (64%) of respondents indicated that in the past 12 months their asthma symptoms prevented them from participating in outdoor and/or physical activities.</li> <li>In the past 12-months, more than a quarter (26%) of respondents missed work or school because of their asthma symptoms</li> </ul>		

#### **Quality of Life: Asthma Control & Asthma Action Plans**

Health care providers play a key role in the management of an individuals asthma. The symptoms of asthma can vary from time to time and situation to situation, therefore maintaining asthma control is they key to reducing the frequency of asthma symptoms and preventing asthma attacks. It is important to work with a health care provider to develop and Asthma Action Plan. An Asthma Action Plan is a personalized treatment plan that outlines steps a person with asthma needs to take to monitor the frequency of asthma symptoms and to avoid flare-ups and exacerbations. This plan should be developed in consultation with health care professionals to meet individual needs.

In this survey, 58% of respondents reported that they did not have an Asthma Action Plan, while 23% of respondents reported that they had one and either used it regularly or had not used it or updated it in a long time.

### **Quality of Life: Asthma Control**





In addition, those who self-reported as having Severe Asthma, 18% of respondents didn't have an Asthma Action Plan and 62% of respondents aged 25 and older did not have an Asthma Action Plan, compared to those younger than 17 years of age, where 24% did not have an Asthma Action Plan and 43% of those between 18 and 24 years.

### **Quality of Life: Vaccination**

Influenza is recognized risk factor for asthma exacerbations and asthma is associated with increased risk of flu complications and worse health outcomes. Therefore for people with asthma, vaccination is considered a routine part of proper asthma management. When asked their thoughts on vaccination, two-thirds (66%) of the respondents felt being vaccinated was important for the health of others in the community, 65% knew vaccines were effective and 64% felt vaccines were important for their health and generally did what their doctor or health care provider recommended. Thirteen per cent of respondents felt concerned about the serious side effects of vaccines.

Nearly three-quarters (70%) of the respondents had received the annual influenza vaccination while 10% refused the vaccine. Less than a quarter (18%) had received one dose of the pneumococcal vaccine while 24% had not because it was not available to the respondent or the cost was not covered; 6% missed receiving their vaccination due to the pandemic. Access to proper care and treatment during a pandemic is important, and can minimize respiratory complications and worse outcomes in those living with asthma.

When looking at how many respondents received the COVID-19 vaccination, more than half (64%) of the respondents had received one dose and were waiting for second dose (note the survey closed in early July 2021). Only 4% of respondents had refused the vaccine or did not plan to get the vaccine. Of those that reported having Severe Asthma 70% received the first dose, while 4% refused. When looking at age, for those younger than 17 years of age, 70% were not eligible to book vaccine appointment, as well as more than half (57%) of those 18-24 years of age. However, more than three-quarters of the respondents (78%) who were 45 and older were waiting for their second dose at the time they took the survey.



Sixty-four per cent of survey respondents indicated they felt receiving recommended vaccinations was important for the health of others in the community.

### **Management and Lifestyle: Affording Medication**

Those living in lower income households are not able to access affordable asthma medications.

Nearly (42%) of respondents indicated that their current drug coverage isn't enough to control their asthma symptoms and feel that they need a little to a lot more support and 54% of those respondents with an income level less than \$29,000 required a government drug plan compared to those in the \$30,000-\$59,000 income group. Individuals in the higher income group were more likely (31%) to pay out of pocket and received (33%) partial and government funding. In comparison to those who earned over \$90,000 were more likely (69%) to receive full or partial drug coverage by their employer.



Of these respondents who require a little to a lot more support in paying for their medication and helping to keep their symptoms under control, 55% had self-reported as having Severe Asthma and 44%, moderate asthma.

One quarter (25%) of respondents indicated that they have skipped filling a prescribed asthma medication because they were not able to afford it, compared to 75% who said they did not skip filling their asthma medication. Of those respondents who skipped filling a prescription for their asthma medication due to the inability to afford it, 44% of respondents were in the less than \$29,000 income level, similarly (42%) of respondents with an income level between \$30-59,000 also skipped filling a prescription due to cost.

#### **Management and Lifestyle: Affording Medication**

When looking at age variation, respondents between 45 and 64 years of age (32%) reported having skipped filling their prescription compared to (29%) of respondents who were 18 to 24 years of age and 28% 25 to 44 years of age. While those younger than 17 (10%) and those older than 65 (9%) skipped filling their asthma medication prescription. Similarly, those respondents who self-reported as having Severe Asthma, less than one-third (30%) indicated that they had skipped filling their prescription.





### **Management and Lifestyle: Affording Medication**



It is clear that additional assistance and funds are needed for individuals in the lower income bracket, those less than 44 years of age, and those with Severe Asthma to cover their asthma medication and treatment. Without proper asthma medication, it becomes difficult for individuals with asthma to control their asthma symptoms and are at risk of flare ups/exacerbations. Without assistance, people are forced to make decisions that might not be in the best interest of their health.

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"I take multiple medications. I sometimes can't afford all my inhalers and my general practitioner (GP) gives me samples."

"The cost of medication has caused me to miss medication."

"There are times when I don't have the coverage, and for a long time I had to come up with the money and submit the receipt afterwards. I wasn't always able to afford the medication. I would ask for samples from the doctor, but they didn't always have them."

"When I don't have benefits through my partner's work I can't afford the high costs of multiple medications each month. I tried to sign up for the Trillium Benefit but my deductible is really high and I can't afford it."

#### **Treatment and Emergency Care: Health Care Professionals**

Health care professionals play a key role in the education, management and treatment of asthma. Nearly three-quarters (71%) of respondents indicated that their asthma was first **diagnosed** by a family doctor, pediatrician or emergency room doctor, compared to 12% by a respirologist or allergist.

Similarly, more than half (59%) of respondents have their asthma **managed** primarily by a family doctor or pediatrician and 24% are managed by a respirologist or allergist. The continuity of care received from the onset of diagnosis can greatly impact the management and control of asthma long-term.

A majority (88%) of respondents indicated that they have timely access to a family doctor in their area and 57% were satisfied with their asthma-related care provided by a family doctor. Similarly, when asked about access to a respirologist or allergist, half (50%) of respondents indicated that they had timely access to a specialist or asthma clinic and 46% were satisfied with the asthma-related care provided by an asthma specialist, however, 40% also indicated that they didn't visit an asthma specialist for their asthma-related care.

When looking at the level of satisfaction of care provided by a family doctor and age group, more than half of the respondents who were 17 years of age and older indicated that overall they were satisfied with the care provided by their family doctor.



### **Treatment and Emergency Care: Health Care Professionals**

When looking at the level of satisfaction of care provided by an asthma specialist and age group, a majority (75%) of the respondents who were younger than 17 years of age indicated that overall they were satisfied with the care provided by their asthma specialist compared to 34% of respondents between 18-24 years of age.





"My family doctor is very good, but I prefer to see the respirologist."

"My wonderful general practitioner (GP) of 30 years retired 2 years ago...I am looking for a new GP and may go with a nurse practitioner instead because GPs are hard to come by in my neighbourhood."

"It took a very long time but I finally have my asthma somewhat managed, my lung specialist has been great."

"My family doctor helps me with all my problems and is always available."

"My family doctor has been more helpful to me than the specialist has. She makes time to answer my questions and concerns."

### **Treatment and Emergency Care: Health Care Professionals**

Lack of knowledge and inappropriate education about how to properly use an inhaler, whether a preventer or reliever inhaler, can lead to inadequate management of asthma, especially in an individual whose asthma is already not in control. It is important that health care providers provide this education.

A majority (80%) of respondents indicated that their health care provider helped them correctly use all of their current types of inhaler(s) or device(s) before they started using them, compared to 14% of respondents who reported that their health care provider did not help them correctly use all of their inhaler(s) or device(s).

When respondents were asked when filling their asthma prescription 'did the pharmacist ever check your inhaler technique,' in this case the numbers were reversed and 70% of respondents said no, their pharmacist did not teach them how to use an inhaler, while 23% said yes, they did.



Overall, nearly half (58%) of respondents were satisfied with the information and education they had received regarding their asthma care from their primary source of care. However, less than half (49%) still felt that not receiving information or education on managing their asthma prevented them from receiving the asthma care, support and treatment required. Therefore, quality of care and continuity of care provided by a health care provider is important for optimal asthma care.

#### **Treatment and Emergency Care: Barriers to Access and Care**

A majority (88%) of respondents indicated that they have timely access to a family doctor in their area and 57% were satisfied with their asthma-related care provided by a family doctor.



Similarly, when asked about access to a respirologist or an asthma clinic half (50%) of respondents indicated that they had timely access to a specialist or asthma clinic and 46% were satisfied with the asthma-related care provided by an asthma specialist, however, 40% also indicated that they didn't visit an asthma specialist for their asthma-related care.



It is also important to note that individuals aged between 18-24 are at a risk of not having timely access to specialized healthcare. More than three quarters (83%) of respondents indicated they had timely access to a family doctor, however only 33% had timely access to an asthma specialist. Similarly, those aged 45 and older reported having timely access to a family doctor (90%), however only half (50%) to an asthma specialist. The lack of coverage for critical medications and access to appropriate healthcare services can have an impact on individuals living with asthma. While coverage is an essential factor in access to care, barriers also prevent individuals with asthma from getting timely care to manage their asthma and prevent symptoms.

#### **Treatment and Emergency Care: Barriers to Access and Care**

## There were noticeable differences in attaining timely access to asthma care across the Canadian provinces.

Ninety-four per cent of the respondents living in Alberta, Manitoba, New Brunswick, Prince Edward Island and Saskatchewan indicated that they have timely access to a family doctor. In Ontario, this was slightly low (89%) compared to other provinces, similarly in British Columbia (85%), while in Quebec more than a half (56%) have timely access to a family doctor. In comparison, when respondents were asked if they had received timely access to an asthma specialist or an asthma clinic those living in Manitoba, New Brunswick, and Prince Edward Island were not able to access an asthma specialist or an asthma clinic directly and had to be referred by a physician. Since, the 2020 survey respondents have shown to have timely access to an asthma specialist or an asthma clinic.

Access to appropriate asthma care is dependent upon different factors, including socioeconomic and environmental factors that may be associated with poor asthma outcomes. The role of environmental factors and conditions can have an effect on the spread and transmission of COVID-19. This can also lead to barriers to accessing healthcare for those living with asthma. Over one-third (39%) of respondents indicated that they had not gone to an appointment or utilized the health care system because of COVID-19.

#### **Treatment and Emergency Care: Barriers to Access and Care**

According to the survey, the following prevented respondents from receiving the asthma care, support and treatment they required: long wait times to see a specialist (53%), inadequate air quality regulations for workplaces (51%), and lack of information/education on managing asthma (49%).

In gauging participants' perception of the most important barriers to good quality asthma care, we found that more than half (53%) of the respondents indicated that long wait times to see specialist prevents them from receiving asthma care, support, and treatment required. Many respondents also felt that they were not receiving adequate asthma care, support and treatment due to inadequate air guality regulations in the workplace. This can have a huge effect on those who are working long hours in precarious jobs and dangerous working conditions that trigger asthma symptoms, making it harder for those with asthma to manage and control their disease.

Parameter	Most of the time	Some of the time	Not at all
High cost of inhaler medications or devices	11%	24%	65%
High cost of newer medications like biologics	16%	16%	68%
No referral to a specialist	17%	25%	47%
Long wait times to see a specialist	28%	25%	47%
No local specialist	17%	15%	69%
Lack of information/education on managing asthma	17%	32%	51%
Difficulty in locating asthma or respiratory educators	19%	25%	56%
Inadequate air quality regulations for workplaces	24%	27%	<b>49</b> %

We had asked: How often have the following prevented you from receiving the asthma care support

#### **Treatment and Emergency Care: Accessing Emergency Care**

Many with uncontrolled asthma due to lack of treatment or of a primary care provider receive emergency care as their **only** source of care. A quarter (25%) of the respondents indicated that in the past 12 months, they had received unplanned or emergency care for their asthma.

Of these respondents, when asked whether they were satisfied with the following during their emergency care: wait-time, instructions, recommendations for follow-up care and overall care during the emergency, less than half (49%) of respondents indicated overall satisfaction with overall care received during the emergency, while 18% expressed dissatisfaction with wait-time and 13% with instructions/recommendations for follow-up care.



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"My asthma remains uncontrolled despite maximal treatment. I wind up at urgent care, emergency, or admitted about five times a year."

"I've attended emergency as my inhalers were not working."

"Allergies trigger asthma so badly we thought I had COVID. Went to the ER twice last year because of it."

"I probably should have, but I am too scared to go to the hospital. So far I have been able to live with the symptoms even though it can last a few days."

### Treatment and Emergency Care: Oral/Systemic Corticosteroids

In managing asthma, in particular Severe Asthma, oral and systemic corticosteroids play an important role. More than a quarter (28%) of respondents indicated that they had used an oral/systemic corticosteroid once or less per year and (29%) indicated they have never used or required an oral/systemic corticosteroid. However, a quarter (28%) indicated they have used an oral/systemic corticosteroid once or more per year.

More than a quarter (27%) of respondents with a household income of less than \$29,000 reported that they used an oral/systemic corticosteroid at least once or more per year. It was also noticed that 33% of respondents between 45 and 64 years of age reported using oral/systemic corticosteroids once or more per year. Not surprisingly, nearly half (49%) of those respondents who self-reported as having Severe Asthma, used oral/systemic corticosteroids once or more per year.



## Treatment and Emergency Care: Oral/Systemic Corticosteroids

Oral/systemic corticosteroids are used to manage uncontrolled asthma however the overuse of them can also lead to health-related adverse effects such as osteoporosis and bone fractures, cataracts, adrenal failure, diabetes, hypertension, and impaired immunity.

When asked if they had been prescribed oral corticosteroids in the past and if the health care provider who prescribed this medication explained the possible side effects of the medication, 50% said yes, while 27% said no and 9% were unsure. Of those who reported to have Severe Asthma, 72% of the respondents were told of the side effects. It is important to talk with a health care provider about potential side effects while using oral/systemic corticosteroids.

Overall, (32%) of respondents were prescribed oral corticosteroids by their primary healthcare provider, 23% by an emergency room physician. Nineteen per cent had never been prescribed oral corticosteroids.

### The Impact of the Global Pandemic on Asthma Care

When asked whether their asthma was controlled during the COVID-19 pandemic, 70% of respondents said their asthma was the same. Similar findings were found in those who self-reported with having mild, moderate or Severe Asthma and in all income groups. However, when looking at age, forty-three per cent of those between the age of 18 and 24 years reported their asthma was less controlled during COVID-19.

Many respondents commented about the changes they made when accessing medication because of COVID-19. They noted they were using the phone or online virtual platforms for health care appointments. Individuals living in low-income households or those who are unable afford internet service may have been greatly impacted by the social and physical restrictions placed upon them due to COVID-19, putting them at an even higher risk if they had to travel to pick up medications during a time when in-person exchanges were not recommended.

When asked if they used the healthcare system differently because of COVID-19, 39% of respondents reported they had not gone to an appointment during COVID and 27% visited their healthcare professional less frequently, while 4% had not seen a physician or visited the emergency department or hospital during COVID-19.

It is important that individuals with asthma have access to care when they need it.

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"All my appointments are on Zoom or the phone."

"I had great difficulty contacting my primary health care provider in the first year of COVID-19. My pharmacy also stopped returning my communications and I could no longer get onto the online site to order refills. I needed to start contacting my respirologist directly, and switched pharmacies in order to get my medication."

"Since the pandemic started, I have not gone for my regular check-ups with the respirologist. I did go for a pulmonary function test back in May 2020. I am stable and the respirologist did refill my medications when required."

"Masking and distancing have led to no viruses for a year. No asthma symptoms."

# CONCLUSIONS

Canadians living with asthma continue to face several challenges, and in this survey respondents continue to address how their mental health and wellbeing is affected on a daily basis because of their asthma. Even amidst a global pandemic, these results are consistent with results from our 2019 and 2020 surveys.

Inability to participate in day-to-day activities has an impact on an individual's performance in school or work. This can lead to overwhelming stress and anxiety, and feeling isolated or like they are missing out on things because of their asthma. This also negatively affects social interactions with friends, coworkers, family and caregivers. The stress of not being able to go to work or thought of underperforming can lead to poor health decisions because of the constant worry of not being able to afford medications.

Management of asthma is not only about the disease itself, but also social and environmental factors that contribute to poor health outcomes or health decisions made by individuals living with asthma. It is crucial that continuity of care for proper asthma control and use of medications is provided from diagnosis to ongoing management by a health care provider.

Similar to the 2019 and 2020 survey responses, an overwhelming majority of respondents said their asthma was moderately to very well controlled, yet a different story was told when the survey looked at how many times a rescue inhaler was used in a week, or whether they had trouble sleeping at night or if they were underperforming in school or work because of their asthma. Proper asthma management results in better overall asthma control, which prevents asthma attacks and long-term ramifications of poor disease control, such as airway remodelling.

## CONCLUSIONS

Developing an Asthma Action Plan and demonstrating proper inhaler technique at every doctor's appointment are key components in providing education and increasing an individual's knowledge as to how to best manage symptoms.

Those living with asthma continue to struggle with accessing specialized care, which most often requires a referral from a family doctor. However, in this survey 88% of respondents had timely access to a family doctor. Having timely access to a doctor or respirologist can decrease the number of visits an individual makes to the emergency department because of asthma symptoms or an asthma attack. The care provided in the emergency department is also quite stressful for those who have to wait a long time, or do not have proper follow-up care after the emergency visit.

Similar to the 2019 and 2020 survey results, the 2021 survey highlighted three key at-risk groups who are most vulnerable and impacted by asthma: individuals in the lower income bracket, young adults, and those with Severe Asthma. Supporting those in the most vulnerable population groups should be prioritized. Low-income households with individuals living with asthma are at a higher risk of their asthma worsening over time due to poor quality housing and living conditions.

Ongoing support is needed for those living with Severe Asthma who require more medical care and asthma medications that may not be readily available or affordable. In a pandemic this can be even more challenging and of concern when safety measures in place further lead to the decrease in utilizing the healthcare system out of fear and anxiety.

Policy changes should focus on improving access to affordable medications, accurate testing and diagnosis, and education during early diagnosis and management by health care professionals for all Canadians with asthma.

## POLICY RECOMMENDATIONS

#### **Specialized Care for Vulnerable Groups**

Improved support and care must be provided to vulnerable groups such as lowincome populations, young adults and those living with Severe Asthma. The prevalent models of care are not sufficient to meet the unique needs and challenges of these groups. An effort must be made to reduce the use of oral corticosteroids among people with asthma, and move toward personalized treatments. The care of young adults must be tailored to meet their needs and situation. Access to care and medications must be expanded for those in low income brackets.

#### **Improved Asthma Management**

It is vital that an effort to improve asthma management be made across Canada. We would like to see greater investments in patient education leading to better self-management through increased use of Asthma Action Plans, and a joint physician-patient effort to aim for zero symptoms. In this survey, 45% of respondents said they use their rescue inhaler more than twice a week. Specialist care must be made available in a timely fashion for those who require it. Additionally, those who go to ER need automatic referrals to specialists. Increased utilization of Certified Respiratory Educators would lead to improved management and patient education.

#### **Proper Diagnosis Standards**

Developing and implementing clear and uniform standards for proper diagnosis through pulmonary function testing such as spirometry must become an established protocol in basic asthma care.. Everyone with asthma or suspected asthma must have ready access to objective lung function testing and adequate training must be provided to all healthcare providers to conduct such tests.

## POLICY RECOMMENDATIONS

#### Access to Medication

The inability to access and afford medications has adverse effects on already vulnerable populations and leads to poor health outcomes. It is essential that all levels of government work to eliminate this barrier and establish consistent support across the country that enables access to prescription medications and offers choice in treatments based on health outcomes, not cost.

#### Access to care (virtual care vs. in-person care)

To overcome barriers to healthcare access, the use of virtual, video-based technology platforms for asthma care is a potentially useful format to deliver optimal asthma care directly into patient homes. Public health requirements during the pandemic like physical distancing can interfere with how those living with asthma might make decisions about their health. During the pandemic when restrictions are in place and travel to a primary care physician/specialist or to the pharmacist may be affected, new ways of delivering optimal asthma care should be explored.

## TIPS FOR OUR COMMUNITY



#### Ask for help when you need it

Complete control of asthma means living symptom-free. This means zero symptoms: no time lost from work, school and play, no limitations on exercise or activity, and no emergency room visits. Asthma Canada is here to help: our **Asthma & Allergy Helpline** offers bilingual and personalized support from Certified Respiratory Educators. Call **1-866-787-4050** or email *info@asthma.ca*.



#### **Create and follow an Asthma Action Plan**

Use a personalized Asthma Action Plan, developed with the health care professional who manages your asthma to achieve optimal control. Do not leave without a follow-up appointment. You can download an Asthma Action Plan by visiting <u>asthma.ca</u>



#### Advocate for yourself

It's essential to know your rights and advocate for quality care when you're living with asthma. You can learn more about self advocacy on <u>asthma.ca</u>



#### Get Involved

Join the Asthma Canada Member Alliance, share your story, donate to support the asthma community, connect on with Asthma Canada on social media.



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## ABOUT ASTHMA CANADA

Asthma Canada is the only national, volunteer-driven charity, solely devoted to enhancing the quality of life for people living with asthma and respiratory allergies. For more than 45 years, Asthma Canada has proudly served as the national voice for Canadians living with asthma.

Our mission is to help Canadians with asthma lead healthy lives through education, advocacy and research.

Our vision is a future without asthma.



Asthma & Allergy HelpLine 1.866.787.4050



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