The Asthma Society of Canada’s

Asthma Action Study

Canadian Adults with Severe Asthma
Asthma Consumer Research and Advocacy Program

EXECUTIVE SUMMARY
“Having an asthma attack... It’s like, somebody’s strangling you. It’s fearful to think someone might be strangling you and you have no control over stopping them.”

“You’re not living. You are kind of half living, or you only have half a life.”
Study Overview

The Asthma Society of Canada’s Asthma Action Study was undertaken to determine the unmet needs of Canadians with asthma. This is the largest survey the Society has undertaken that looks specifically at the knowledge, attitudes and behaviour of adults toward asthma and asthma management. POLLARA Strategic Public Opinion & Marketing Research conducted telephone interviews and obtained a national sample of 1000 adults with physician diagnosed asthma. The sample was weighted to obtain a representative gender distribution across Canada of adults living with asthma. The sample error was plus or minus 3.1% in 19/20 cases. Surveys were conducted in French and English and were conducted between March 8th and March 16th, 2005. The following summary reflects some of the preliminary results from this survey.

Quality of Life Impact on Canadians with Asthma

The Asthma Action Survey found that Canadians with asthma are not having their basic needs met. Instead of living a normal lifestyle, many are accepting a much lower quality of life. Asthma affects an estimated three million Canadians and the Asthma Action Survey found that two-thirds of adults are experiencing frequent symptoms and are compromising their quality of life unnecessarily. One-third of adult respondents are having serious symptoms on a daily basis. The reality is that many asthma patients experience daily symptoms such as breathlessness, chest tightness, coughing, and wheezing. These symptoms will keep them from a restful sleep and often will lead to work or school absenteeism. For the 240,000 Canadians with the severest form of asthma, it means incapacitating asthma exacerbations, multiple emergency room visits and the fear of dying with the next attack. Instead of living a normal life, many are compromising their lifestyle and accepting a much lower quality of life. Like all Canadians...they simply want to live a life free of any symptoms.

The Economic Burden of Asthma

From an economic perspective, it is very alarming that Canadians with severe asthma are missing twice as much time from work and school than other asthmatics. Specifically, 41% of severe asthmatics told us that it affected their work or school performance a great deal and another 37% said it affected their performance to a lesser degree. Overall, there was no severe asthmatic that was unaffected. In 1990 the Canadian provincial governments spent almost 650 million dollars caring for asthmatics – of which the most severe asthmatics generate the majority of the care costs. Twelve percent of the survey respondents indicated that they had missed an average of 34 work days due to their asthma. From an employer and productivity perspective, asthma triggered absenteeism is generating more than 8,160,000 lost work days each year.


“I really still don’t feel that I’m on top of the situation. My fourteen year old son is the one who’s the sickest… there are times I think, he’s not going to make it in life….That he’s going to die someday. I’m not sure I should be feeling that way. Sometimes I think I haven’t been aggressive enough about seeking medical help.”
“I have been disabled since 1995, because of my asthma.”

“Most people know other people who have asthma and if you don’t have it they don’t understand how incapacitating it can be.”

“I realize that it’s going to get worse, not better. And that it might come to a point where I won’t be able to do anything but sit in a chair.”
The Disconnect in the Asthma Care System in Canada

The Asthma Action Study clearly illustrates that Canada’s health care system is failing many of those with asthma. Canadian asthma experts developed the Asthma Management Guidelines for the diagnosis and management of asthma in 1996, and revised them in 1998, 2001 and 2005 with the goal of reducing the burden of asthma. Still, within the past year, one in every five severe asthmatics needed to visit an emergency department. On average, these same asthmatics revisited the emergency department three more times in the same year. The daily reality for severe asthmatics is serious symptoms that lead to attacks so bad they cannot speak. Many fear that they may die from their disease.

In addition to this, the stunning reality is that 90% of the asthma deaths and 75% of asthma hospital admissions are entirely preventable.

There is a clear disconnect between what asthmatics are doing to manage their disease, and what they say they want. Survey results found that patients want their asthma to go away, yet they remain complacent about their current therapy. Patients identified the desire to lead a normal life as the main driver for taking their medications; however, with current therapies, asthma patients are treating symptoms and not addressing the uncontrolled nature of the disease itself, which can lead to the need for acute care.

There is a treatment gap in asthma, one that affects severe asthmatics in particular. Reliever medications -- normally saved for rescue treatment --- are being used chronically by these patients. This is distressing because there is a direct correlation between using reliever medications and being out of control, which can lead to injury through long-term inflammation. One reason patients may be using relievers inappropriately is because they perceive to have had poor results with their controller medication and, in some cases, have lost faith in them. Another reason may be due to lack of medication efficacy. For those with severe asthma, limitations in the efficacy of their therapy can lead to misuse and abuse of medications.

While at present, there is no cure for asthma, there are self-management strategies that asthmatics can take to manage their condition. Yet the Asthma Action Study found that those with asthma are often not managing their disease effectively.

The Asthma Action Study points to a need among patients for newer treatment options that are more convenient and more effective in managing their condition. Indeed, patients in the survey showed a preference for a monthly treatment.

For the overwhelming majority, effective management is available but patients are not benefiting - either because they are not aware that their asthma is so poorly controlled and they need help, or because they do not understand what causes asthma, the available treatments and how to prevent symptoms. This reality must change as soon as possible.

“I think what scares me most is (asthma) takes away my life.

“I’ve just accepted that this was all there was for all these years. You know it’s something you just have to live with.”

“When I wake up, the first thing I have is my inhaler. I keep one beside my bed, one beside the chair I sit on to watch TV and one beside the kitchen counter. You have to be aware of it. (I think about it) all the time. It can be very scary.”
“One of my sons.... was so sick for years and I (eventually) went to a specialist and he said that his lungs were scarred.

I had no idea that there would be long term damage to his lungs (that) can stay with him forever. I didn’t...understand that.”

The healthcare system doesn’t support us (people with asthma) that well. If you are not proactive, you are in trouble.”
Reforming the Canadian Asthma Care System

The majority of asthmatics could live normal, symptom-free lives if they were to adopt the proper formula for asthma control. Yet, it is apparent from the survey results that the current standard of care for asthmatics is lagging far behind the recommended national guidelines. In order to save the lives of severe asthmatics and help them improve the quality of their lives, there are several reforms required to Canada’s current asthma management system. The asthma care system is failing many Canadian asthmatics, in particular, those Canadians with the most severe symptoms.

What Needs to Happen...

Breathing Tests: Objective measures such as breathing tests, are essential to confirm the diagnosis of asthma and to assess the level of control. Sadly, only about half of all physician-diagnosed Canadian asthmatics have been referred to a pulmonary function lab for a breathing test.

Specialist Referrals: Patients with severe or difficult to manage asthma should be referred to a specialist, such as a respirologist or allergist, so that they can be assessed and treated for possible related disorders, or unidentified exacerbating factors. Only half of the very severe group reported being referred to a respirologist. Similarly, only about half had been referred to an allergist despite the fact that allergy plays a major role in the disease process.

Asthma Action Plans: Asthma action plans are instructional tools that help individuals with asthma recognize and manage their triggers and symptoms. Even though written asthma action plans have been repeatedly promoted in the Asthma Management Guidelines for the past ten years, 83% of those surveyed reported that they have not had a conversation about such an attack management plan with their physician. This failure in communication eventually compromises the asthmatic’s quality of life.

Patient - Doctor Communications: Asthmatics often have concerns about their prescribed asthma medication, yet only one-third (34%) reported that a health care practitioner had discussed the risks and benefits of inhaled steroid medication with them. Similarly, less than one-quarter (24%) of respondents stated that a health care practitioner had asked them about their concerns and fears about taking their asthma medication.

Medications: There remains a huge gap in the patients knowledge of which medications should be taken to manage and prevent asthma symptoms. A majority of asthmatics continue to rely on symptom relief medications invented some 35 years ago. Asthmatics need to be supported so they can begin to understand the difference between symptom prevention medications and symptom relief medications. For Canadians with severe asthma and for those individuals who can not afford their medications, governments must come forward with programs that will pick up their abnormally high medication expenses.

Asthma Education Access: Asthmatics are not receiving the asthma self-management education that is so critical to the successful management of asthma. In one of the most surprising revelations of the Asthma Action Study, very few asthmatics – some 15% - had had access to an asthma education program. Asthmatics deserve the opportunity to acquire the knowledge necessary to cope effectively with their chronic disease. Educational resources and face-to-face counselling must be made available in local, regional and national asthma learning centers.
Chart 1 - **Referrals (Overall)**

Q. Has the doctor who treats you for your asthma, ever referred you to the following.

Chart 2 - **Functioning at Work or School**

Q. Has your asthma affected your school or work performance in the past year? If so, by how much?

Chart 3 - **Patient Education (Overall)**

Q. In the past year has any healthcare professional...

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**Conclusion**

The Asthma Action Study was undertaken to determine the burden of asthma in Canada and identify the unmet needs of Canadians with asthma. Our goal at the Asthma Society of Canada is to help asthmatics achieve an active, asthma managed life. All of our efforts aim to help asthmatics adopt behaviour changes that lead to a normal, symptom-free lifestyle. The findings of the Asthma Action Study will help the Society deliver the best available self-management education and asthma control information. It will also guide our advocacy activities so that the Society remains a strong, clear and effective voice for Canada’s three million asthmatics.