

# Breathe Easy



  
**Asthma.ca**  
Asthma Society of Canada

**SELF-ADVOCACY GUIDE FOR  
CANADIANS WITH ASTHMA**



## WHAT IS THIS HANDBOOK FOR?

This guide has been developed by the Asthma Society of Canada to help take you through complex Healthcare Systems as you live with asthma. You will learn about the people who can help you control your asthma. This booklet is for everybody, including people who were just diagnosed with asthma, people who have had asthma for decades, and parents, caregivers and friends of people with asthma.

### Healthcare Professionals –

*Anybody with medical training who can assist you with your asthma management and questions. There are many types of people with different training and skills, and they are all available to help you.*

*Part of this guide is to help you figure out who they are and where to find them. Please see page 22 for a list and descriptions.*

*We use the term ‘healthcare professional’ when talking about any professional who is able to help you.*

## HOW TO USE THIS HANDBOOK

There are many ways to use this booklet:

- ▶ Read it cover-to-cover
- ▶ Flip back and forth between sections
- ▶ Make notes in the margins
- ▶ Draw on the diagrams
- ▶ Mark the pages you think are important
- ▶ Share it with your friends, family and co-workers
- ▶ Use it to prepare for your medical appointments

We hope that the information helps you learn how you can manage your asthma properly. We hope it also inspires you to take control of your asthma and help those around you take care of theirs.

This guide has been created and reviewed by experts in the field of asthma care. The authors, reviewers and sponsors want you to discuss this information with your Healthcare Professionals. The information in this booklet will not replace expert medical advice and treatment. It is designed to help you make informed choices. Because your asthma is as unique as you are, a physician must diagnose your asthma and supervise your treatments for each condition you have.

## WHAT IS SELF-ADVOCACY?

Asthma is a chronic condition; it can be controlled but not cured. As you live with your asthma, you will need to learn about people and places to go to for help. Self-advocacy empowers you to get the support you need.

- ▶ Self-advocacy is about taking an active role in managing your asthma.
- ▶ Self-advocacy is about asking the right questions to the right people, and making sure you understand the answers you are given before making decisions about your care.
- ▶ Self-advocacy is about working with your Healthcare Professionals to help you set your goals and then meet them.
- ▶ Self-advocacy is about understanding your rights and responsibilities as a patient.
- ▶ Self-advocacy is about telling your family, friends, boss, co-workers and others what they can do to help you manage your asthma.

## ABOUT US

The Asthma Society of Canada is a national health charity. We are 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.



**Chronic** - *A condition that is always present. When you have reasonable control of your asthma and your breathing feels good on a daily basis, the main cause of asthma is still present in your airways that requires ongoing treatment.*

**Empower** – *Giving you the tools and the knowledge which allow you to actively participate in your own decision-making*

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## BECOMING A SELF ADVOCATE

Setting goals for living with asthma symptom-free

Before you become a self-advocate, you need to decide what your goals are. This will help keep you focused, and should answer the question: “**Why** do I want to control my asthma?” Pick something **specific** – your asthma is as unique as you are. Here are a few examples:

- ▶ I want to hike the Great Wall of China
- ▶ I want to go for a swim at the beach
- ▶ I want to stay out of the emergency department next year
- ▶ I want to dance with my daughter on her wedding day
- ▶ I want to run a half-marathon
- ▶ I want to sleep through the night
- ▶ I want to convince my son to quit smoking
- ▶ I want to become a police officer

You should never be limited from doing something you **know** you can **do** because of your asthma. Being a self-advocate helps you control your asthma so it won't control you.

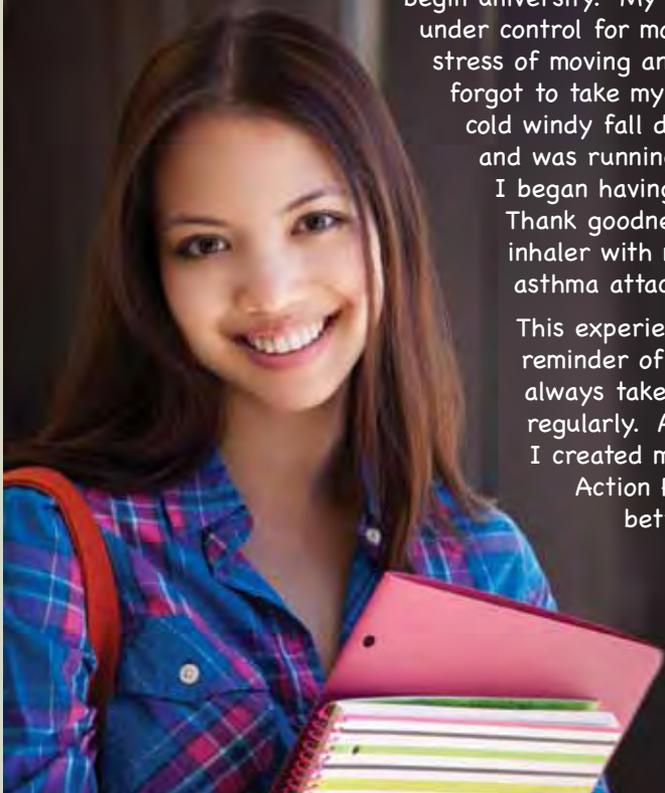
## AMY'S ASTHMA STORY

When I was eighteen years-old I began having trouble breathing. I would become short of breath while exercising, and would feel pain in my chest when around smokers. I visited my family doctor who diagnosed me with asthma. My doctor prescribed a daily medication, as well as a rescue inhaler to control my asthma. My doctor also encouraged me to try keeping an asthma journal, which would monitor the status of my condition and help me identify my asthma triggers.

After analyzing my journal, I found that my symptoms worsened around cigarette smoke and when I was around cats; but sometimes my symptoms would flare up just from being outdoors. My doctor referred me to an allergist who performed an allergy skin test, which was done by exposing a small area of my skin to controlled doses of an allergen. Fifteen minutes later, I learned that I was allergic to cat dander and pollen. In order to reduce my asthma symptoms I needed to avoid cigarette smoke and cats and lessen the time I spent outdoors on windy days.

When I was taking my daily inhaler and doing my best to avoid my triggers I found it was pretty easy to keep my asthma under control. Not long afterwards, I left home to begin university. My asthma had been well under control for months and with the stress of moving and starting classes I forgot to take my puffers regularly. One cold windy fall day I was late for class and was running across campus when I began having difficulty breathing. Thank goodness I had my rescue inhaler with me to prevent an asthma attack.

This experience was a good reminder of why I needed to always take my medication regularly. At my next Doctor's visit I created my very own Asthma Action Plan that helped me to better control my asthma.



## THE ROLE OF KNOWLEDGE

Knowledge is power in self-advocacy. Understanding the words that your Healthcare Professionals use will help you become more comfortable asking questions. If you don't understand something – ask! You should ask questions to make sure you understand exactly what choices you have as you manage your asthma.

You will find that the type of information you need will change over time. Start with understanding the big questions before you ask about the small details, but make sure that you keep asking for the information you feel is important!

### **Credible –**

*able to be trusted. For example, a website may not tell you all the facts. Some websites may actually be untruthful.*

## ABOUT THE INTERNET

If you type 'asthma' into a search engine, you may receive more than **35 million** results. Unfortunately, not all information on the internet is credible. For example, a website that sells flowers might tell you the good things about indoor houseplants for people with asthma. Those sites might not explain about how allergy and mould in plants can increase asthma symptoms.

You may read online about “a study” which was completed. In credible studies, the results often need to be checked through extra tests,



or repeated by someone else, before the science is accepted. Not all studies that you hear about have been verified.

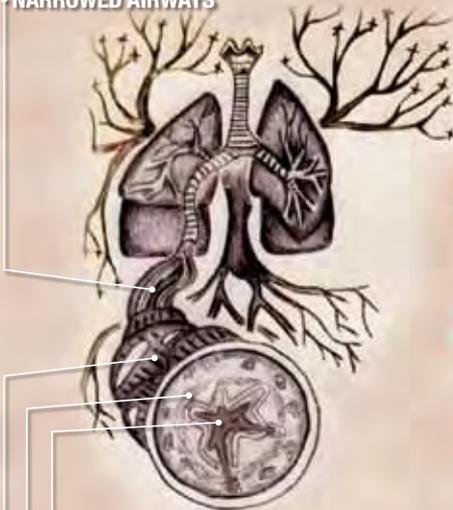
Try to determine the credibility of a website before you use the information. The most credible are government websites, and organizations that represent patients or focus on just a few health areas. Groups such as the Asthma Society of Canada or the Canadian Lung Association have Healthcare Professionals who review all their health information before it is published. A credible website will usually show a variety of

options for medications or products, rather than promoting a specific item.

If you find information on the internet that seems interesting to you, ask your Healthcare Professional before you spend money or make major changes. Never try any so-called “alternative treatments” before you talk to your Healthcare Professional about the risks involved.

## UNTREATED LUNG AIRWAY WITH ASTHMA

### NARROWED AIRWAYS



• DAMAGED AIRWAY PASSAGE WALL

• INFLAMMATION

• CONSTRICTED MUSCLES

## LUNG AIRWAY AFTER ASTHMA TREATMENT

### WIDENED AIRWAYS



• FURTHER DAMAGE TO AIRWAY WALL MAY BE PREVENTED

• REDUCED INFLAMMATION

• RELAXED MUSCLES

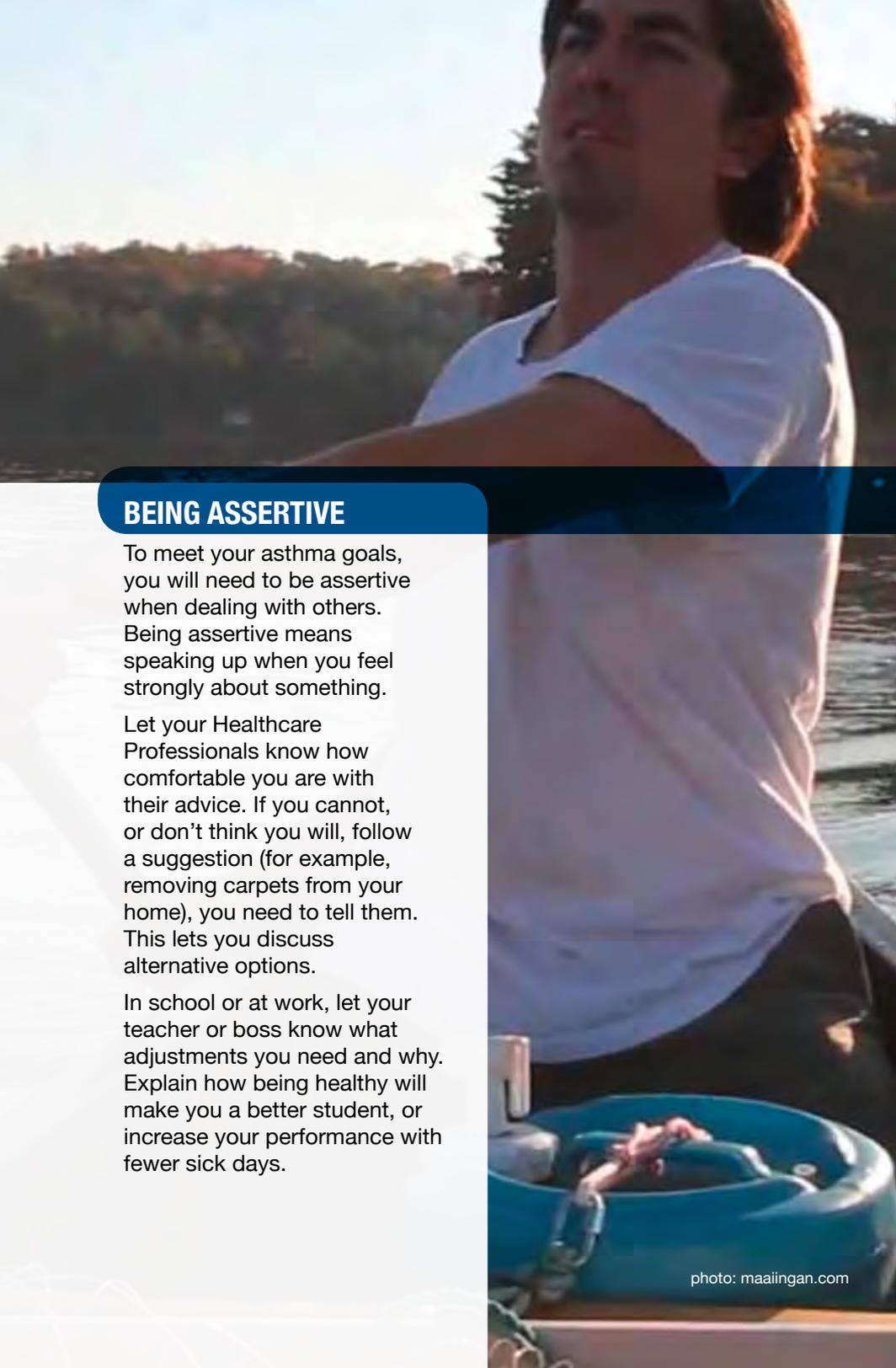
## KEEPING YOUR INFORMATION ORGANIZED

One of the easiest ways to help you manage your asthma is to keep all of your health information in one place. That way, it's easy to find when you visit your Healthcare Professional.

The things you should keep:

- ▶ All prescriptions and receipts
- ▶ A record of all healthcare visits and hospital forms
- ▶ Any forms you fill out about your asthma (such as drug plan information)
- ▶ Your Asthma Action Plan (Learn more about AAPs on page 20)
- ▶ This booklet, and other asthma information from the Asthma Society of Canada
- ▶ Your asthma diary or notes that you make:
  - ▶ write down any questions as soon as you think of them, so you don't forget before your next healthcare visit
  - ▶ to help discover your triggers, write down when and where you've experienced symptoms
  - ▶ to help discover your triggers and your current asthma control, write down when and where you required your reliever medication

Keeping all the information together helps you find information quickly when you need it, and helps you keep track of your progress towards your goal.



## BEING ASSERTIVE

To meet your asthma goals, you will need to be assertive when dealing with others. Being assertive means speaking up when you feel strongly about something.

Let your Healthcare Professionals know how comfortable you are with their advice. If you cannot, or don't think you will, follow a suggestion (for example, removing carpets from your home), you need to tell them. This lets you discuss alternative options.

In school or at work, let your teacher or boss know what adjustments you need and why. Explain how being healthy will make you a better student, or increase your performance with fewer sick days.

## A 9-STEP PROCESS TO REACH SELF-ADVOCACY

The Asthma Society of Canada has developed some steps you can take to help you control your asthma and then grow into an advocate for yourself and others.

- 1. Set a goal.** To advocate for yourself, you need to think about where you want to be in 1 year, 5 years or 10 years. If your asthma is a barrier, work towards eliminating the hurdles in your path. When you have a goal, you can clearly understand why each step is important.
- 2. Understand your medication.** Learn about what each of your medications is supposed to do for you, and how to take it properly. Take it as prescribed, and note any differences in your reaction to it (such as side effects, or if it's not working like your Healthcare Professional said it would). Keeping track of when you use your medication can also help you find your triggers.
- 3. Make lifestyle changes to avoid your triggers.** After you determine which triggers cause your asthma symptoms, work to remove them from the places you live, work and play. Taking steps to control your environment may show you how much of a difference one simple action can make.
- 4. Understand your healthcare options.** Learn which types of Healthcare Professionals can help you, and where you can find them. Ask questions to make sure you understand the advice you are being given.
- 5. Know where to go for support.** Controlling your asthma may not happen as quickly as you would like. Find resources through family, friends, the National Asthma Patient Alliance, or other community groups. Other people who have been in your situation can give you strength and tell you about their own experiences.
- 6. Let others know about your asthma.** With proper levels of control, your asthma will usually not be visible to others. Someone should know that you have asthma at each of the places you live, work, study and play. This is most important in case of emergency. Don't be afraid or embarrassed about your disease; and help educate others whenever possible.

**7. Help others help you.**

Some people can be in a position to make a difference, such as your family, your boss, or your friends. Let them know about your asthma triggers. You can suggest activities or changes which can help you stay symptom-free wherever you go.

**8. Become a resource.** With your asthma knowledge, help support someone else who has asthma. Let them know what has worked for you and how your approach to asthma management has changed since you were diagnosed. Help them ask the right questions to gain control of their asthma.

**9. Help change the world for others.** Use your knowledge to meet with decision makers like a politician, the CEO of your company, or your school principal. Become involved in policy decisions which affect not just you, but thousands of Canadians.



## THE LEVEL OF CARE YOU DESERVE

The goal of proper asthma management is control of your asthma. As a self-advocate, you need to be aware of what is achievable. Your asthma or your asthma symptoms should not limit you. Many people think that daily symptoms are normal for someone with asthma, and don't realize that better control is possible.

The [Asthma Management Continuum Consensus Summary](#) is used in Canada to help tell if your asthma is under control:

- ▶ Daytime symptoms fewer than 4 times per week
- ▶ No time lost from school, work, or regular activities due to asthma
- ▶ Nighttime symptoms fewer than 1 time per week
- ▶ No emergency room or hospital visits
- ▶ Use of your reliever medication fewer than 4 times per week
- ▶ Peak Flow readings at or above 90% of your personal best
- ▶ No exercise limitations

This is what you should be aiming for in your asthma management. For some people, it may be hard to look at this list and think that optimal asthma control is possible. But when you work together with your Healthcare Professionals, you can find the medications and life changes that will help you control your asthma.



## UNDERSTANDING THE HEALTHCARE SYSTEM IN CANADA

The Healthcare system in Canada is huge. It involves billions of dollars, millions of people, and hundreds of different pieces. It would be impossible to describe all the parts of the medical system in these pages, but here are some of the key pieces for you to know.

### WHO IS RESPONSIBLE?

Each province controls most areas of healthcare services. The provinces regulate doctors, operate hospitals, and give you a health card to use for other services.

The federal government gives the provinces some money for healthcare. In return, provincial governments must make some basic services free for all users in their province. Together, this is sometimes referred to as “Medicare”.

Finally, cities or regions are responsible for some local health clinics and public health programs. Cities or regions may also operate the ambulances which take you to the hospital in case of an emergency.

### SEEING A DOCTOR

About 85% of Canadians have a family doctor. Your doctor will see you for a regular check-up each year, and you can schedule additional appointments when you have a question or concern about your health.

If you don't have a family doctor, you can use a “walk-in clinic” or “urgent care” clinic. At these clinics, patients are treated in the order they arrive. You normally can't book an appointment in advance, so you might need to wait before you see a doctor. You may not always see the same doctor each time, but these clinics can help you get prescriptions, and any referrals that you might need.

*A doctor's office is called a “practice”. A doctor sets up a company and takes as many patients (customers) as they can see on a regular basis. The provincial government pays the doctor so that you don't have to.*

## EMERGENCY SITUATIONS

If you have an emergency, call 9-1-1 or go to the nearest hospital immediately. At a hospital, the nurses and doctors treat patients in the order of priority.

While you are at the hospital, you will be given any treatments that are necessary to make sure your health is no longer in danger. Sometimes, you may need to stay overnight, or for a few days in the hospital until you are well enough to go home.

## ASTHMA CLINICS

An asthma clinic may be located in a hospital or local health centre. At a clinic, you can speak to a Certified Asthma Educator, Certified Respiratory Educator, or other Health Professionals. These people focus only on asthma and lung health. Some clinics let you make your own appointments, but usually your doctor will need to give you a referral. An asthma clinic may ask you to come back for follow-up visits to make sure your asthma is under good control.

*Priority –*

*The people who need help the fastest, or the ones who need the most urgent care, will be seen first, even if someone else was already waiting.*





## PHARMACIES

Photo by Audrey Huntley

When you are given a prescription by a doctor, take that slip of paper to a pharmacy. Your pharmacist keeps a record of all the medications you are taking, and the number of repeats you have left. Your pharmacy also sells asthma devices, such as chambers, and peak flow meters.

The pharmacist gets paid by adding a “dispensing fee” to the cost of your medication. This is why it’s usually best to ask for all the medications you need at the same time, to save you money. In certain provinces, pharmacists can perform other services as well such as writing or adjusting some prescriptions.

### **Referral –**

*When a doctor or hospital suggests that you visit someone else who treats only specific conditions. Sometimes you cannot just phone and ask to make an appointment, your doctor must request one for you.*

### **Repeats –**

*The number of times you can refill the same medication at a pharmacy before you need to go back to a doctor to ask for a new prescription.*

## PUBLIC AND PRIVATE DRUG COVERAGE

You may not have to pay all the costs of your medication.

- ▶ About 58% of Canadians have coverage under a private drug plan
- ▶ About 14% of people have public drug coverage for all or most of their medications

Each province runs a different version of a public drug benefit plan for some people. The federal government also runs prescription drug coverage for First Nations and Inuit people, as well as other groups such as military veterans, prisoners in federal jails, and some refugee claimants in Canada. These plans usually cover most of the medication costs, but the user may have to pay a percentage or a set dollar amount.

You might also have private drug coverage. This is usually provided as a benefit from your job by your employer or by your union. Most universities and colleges also have a health plan included in your tuition. Sometimes, you might buy insurance yourself as an individual. A private company will collect premiums and pay most of your drug costs out of all the money they have collected. You will only have to pay a fixed price or a smaller percentage of the cost if you need medication. This type of plan helps protect you from unexpected high drug costs, especially in emergency situations.

**Public drug benefit plan –**  
*The government covers some or all of the cost of medications for the parts of the population who need it the most. This usually includes the very poor, the elderly, and people with very high drug costs.*

**Premium –**  
*A fixed dollar amount paid to the insurance company each month*

## HOW YOUR MEDICATIONS ARE MADE

Certain companies are known as research-based pharmaceutical companies. They spend millions of dollars making and testing different types of drugs, for common and rare conditions. When they get close to finding a new drug that might treat a disease in a better way, the companies run clinical trials with some patients.

The government then reviews the results of the clinical trial. They determine if the new drug works better than any existing treatments, and if the drug is safe enough to prescribe. If it is, the company that makes the drug is given something called a notice of compliance.

After several years, other companies are allowed to start making and selling drugs with the same active ingredients.

These are called generic pharmaceutical companies. If the medical parts of the drug are the same, the generic companies do not have to spend money on lots of extra clinical trials. Generic drugs are usually cheaper because those companies do not have to pay for research.

A patent and a notice of compliance determine how long a new drug can be sold by just one company. This system makes sure that some companies have protection to research new and better medicines. But it also makes sure that the protection expires so other companies can also start making the same medication at a lower price.

### **Clinical trials –**

*Testing a new drug on people when it is close to being finished. Half the people take the new drug, and half don't. Researchers measure the differences between the two groups to find out if the new drug is effective.*

### **Patent –**

*A legal term that allows only one company to make and sell a product for a set amount of time. It takes lots of money and testing to make new products. A patent helps encourage companies to do research by making sure that they can sell their new products before anyone else copies it.*

## WHAT TO ASK ABOUT

One of the most important steps in controlling your asthma is knowing exactly what you should be asking your Healthcare Providers about. Use this section as a guide for the topics and tools you should discuss at your next visit with your Healthcare Professional.

### SPIROMETRY TESTING

Spirometry is a quick test that shows how much air you can blow out of your lungs. You will be asked to take a deep breath, and blow as hard and fast as you can. You do this into a tube until your lungs are empty. A machine connected to the tube will also tell you how quickly you can breathe air out. This test helps with diagnosing asthma, and measuring your lung health on a regular basis. A spirometry test may be done in your doctor's office if they have a spirometry machine. If not, you can get the spirometry test done at your local hospital or asthma clinic

### ASTHMA ACTION PLAN

This is a written agreement between you and your Healthcare Professional, which can help you manage your asthma at home. You can find an example at [www.asthma.ca](http://www.asthma.ca), or your Healthcare Professional might have a different style which will have the same information. Your plan will help you understand what symptoms you should watch for, and what they mean when you feel them. It will also tell you which medication to take when you are in the “Green Zone” (feeling well), the “Yellow Zone” (feeling symptoms) and the “Red Zone” (in danger and need immediate help).





## **EXERCISE ROUTINES**

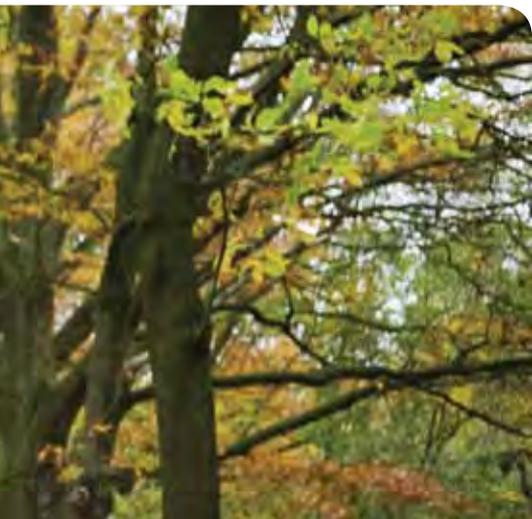
Being physically active is important for everybody. But it takes extra priority for someone with asthma. Some people don't know how to stay fit without experiencing asthma symptoms. This can lead to obesity (being very overweight) and can cause extra problems making your asthma even harder to control. To stay fit, make sure to get at least 2.5 hours of exercise per week (such as 30 minutes of exercise, 5 times per week). When you have control of your asthma, all activities should be possible. Until you get to full control, ask your Healthcare Professional which activities would be best for you.

## **TRIGGERS**

If you usually feel asthma symptoms when you are in a certain place (like at work), talk about this with your Healthcare Professional. Similarly, if you feel your asthma worsen when around pets, perfume or smoke. Your Healthcare Professional sees hundreds of patients and knows about asthma triggers. You can talk about how you can protect yourself, and how to remove many of these triggers from your life. You may also be sent for an allergy skin test to identify some of your triggers.

## **REFERRAL TO AN ASTHMA CLINIC**

If you don't have time to ask your Healthcare Professional all these questions in one visit, ask for a referral to an asthma clinic. There, you can schedule an appointment to speak only about your asthma. They will give you extra information and tips you can use to help manage your condition.



## WHO DOES WHAT IN YOUR ASTHMA NETWORK

### YOU

You are the most important part of your asthma Network. There are two main reasons for this:

- ▶ You are the person with asthma. It is your health which is the concern of everybody else who is trying to help you.
- ▶ Everybody else can help you only as much as you want to be helped.

This means that you must understand your asthma as a chronic disease which needs long-term care, not just a single appointment. You must be willing to hear what the Healthcare Professionals tell you, and ask questions until you understand. Most of all, you must be honest with the people around you. If you don't tell the whole truth about your symptoms, or the number of times you take your medications, the others around you are not going to be as effective at helping you control your asthma.

### YOUR DOCTOR

In Canada, family doctors (sometimes known as “general practitioners”) provide [primary care](#). Family doctors take care of the same patients for a long time, over years or decades. They treat people of all ages and with all conditions. The care is based on what they know about you, your family history, and the community you live in. Family doctors need to know about thousands of diseases and conditions which their patients may have, including asthma.

In certain cases, your family doctor may refer you to someone else for [secondary care](#). This is given by someone who has very detailed knowledge about a specific topic. You might know these doctors as [specialists](#). You may be referred to different types of specialists based on your individual needs. For example, if you have allergic asthma, your doctor might recommend an allergist. Other specialists are also listed on the following page.

### Stabilizing –

*A word used to describe how a health team brings a patient back to normal after an asthma attack or other injuries. It can also mean keeping a patient at a safe level, if there is a danger of getting worse.*

## **ALLERGIST**

An Allergist is a medical doctor who specializes in allergies and related conditions, including asthma. If you are referred to an allergist, he or she will have you go through a series of tests. These help figure out exactly what you are allergic to. An allergist can recommend treatments for your symptoms.

## **RESPIROLOGIST**

A Respiriologist is a medical doctor who focuses on lung diseases and breathing conditions such as asthma.

## **REGISTERED RESPIRATORY THERAPIST (RRT)**

Registered Respiratory Therapists have been specially trained to help people who have problems breathing. An RRT is commonly found in critical care areas (such as hospital intensive care units and emergency rooms). They can help in stabilizing a patient and giving you medicine when you can't take it yourself. An RRT can also perform lung testing, and give asthma education.

## **RESPIRATORY NURSE SPECIALIST (RNS)**

Respiratory Nurses are nurses who have gone through extra training in pulmonary (lung) health. They can help with asthma treatment, training, and education.

## **CERTIFIED ASTHMA EDUCATOR/CERTIFIED RESPIRATORY EDUCATOR (CAE/CRE)**

A Certified Asthma Educator/ Certified Respiratory Educator is a Healthcare Professional with special asthma training. After they write special exams, they can use the CAE or CRE title. They work in asthma clinics, hospitals, specialists' offices, and pharmacies among other places. CAE/CRE training allows them to give you personal advice about asthma, triggers, medication, diet, lifestyle, and Asthma Action Plans.



## PHARMACIST

Your pharmacist fills your prescription and gives you your medication. Most people see their pharmacist more often than their doctor. Your pharmacist looks at all your medications to make sure that the combination of different drugs will not cause extra side effects. Your pharmacist can also substitute different medications.

Your pharmacist should also be looking at your medication techniques on a regular basis. Your pharmacist can watch you take a dose, and help you fix any bad habits. Your drugs work better if you use the right technique. Asthma devices are also located at the pharmacy. Your pharmacist can help you choose the proper chamber or peak flow meter.

## FAMILY AND FRIENDS

Your family and friends may be your largest support group. Some will want to learn about asthma, and some may change their behaviours to help you. This could be by taking triggers away from the home, not smoking when you are around, or changing their exercise habits so you can join.

Unlike some other diseases, some people may get upset that they cannot “help” you more. Helping someone with asthma is not like pushing a wheelchair or learning how to give medicine. This is a normal reaction. Tell your friends that they are helping every time they help you avoid an asthma trigger, or encourage you with your Asthma Action Plan.

## NATIONAL ASTHMA PATIENT ALLIANCE (NAPA)

The National Asthma Patient Alliance is a patient group with members from across Canada. NAPA is supported by the Asthma Society of Canada. NAPA has three main goals:

- ▶ Increase awareness about how to control asthma
- ▶ Advocate on asthma issues and on behalf of Canadians affected by asthma
- ▶ Build a group of volunteers to improve asthma care and education

A free NAPA membership will help you connect to others across the country who have asthma, or who care for, and about, people with asthma. Together we will change public policy and make the world more asthma-friendly for you and your family. Also, the information you learn will help you understand more about your asthma, and help you teach others.

To learn more, please visit [www.asthma.ca/napa](http://www.asthma.ca/napa) or e-mail [napainfo@asthma.ca](mailto:napainfo@asthma.ca).

**Substitute** – *If two medicines have the same ingredients, your pharmacist can choose which one to give you. Always talk to your pharmacist if your medication has a different look or name than last time. Substitutes are used to stop side-effects, and can sometimes cost less.*



## SHARED DECISION MAKING

When you are talking about your options with your Healthcare Provider (like medications, or removing triggers from your home), you need to be part of the conversation, not just told what to do.

Your doctor, nurse, therapist, specialist, Certified Asthma Educator/Certified Respiratory Educator, or pharmacist have medical training, and know the most about these topics:

- ▶ What science says about asthma
- ▶ What is happening inside your body
- ▶ What types of treatments are available, and their positive and negative aspects
- ▶ What has worked for other people similar to you

But you have the most knowledge about these topics:

- ▶ How you feel today, how you have felt in the past, and how you want to feel in the future
- ▶ What side effects you don't like, and which ones are OK
- ▶ What behaviours you are willing and most likely to change

When you speak with your healthcare professionals, these points of view should be discussed until you both agree what should be done. You are not “right” and your Healthcare Professional is not “right” until you talk and decide **together** that something is right for you.

This doesn't mean that you should argue on purpose. But it does mean that you need to be clear and realistic about your expectations. For example, your Healthcare Professional may suggest a medication that you must take four times each day, at the same time every day. If it is not possible to take your medication when you are at work, let your Healthcare Professional know. If you don't, you may be buying a medication which will not work, and wasting your time and money.

To use another example, your allergist may advise you to remove pets from your home. If you know that you will not do this, let your allergist know. Be honest about your preferences and needs. Perhaps there is a different trigger you can try removing from your home first.

Shared decision making is very important with medications that may have side effects. Make sure you understand exactly what the side effects are, and

how much risk there is. If you are not comfortable with a drug, ask the Healthcare Professional if there are other choices. It's better to keep talking than to have a prescription that you do not want to use.





## HOW TO PREPARE FOR YOUR VISIT

A regular appointment should not be scary for you. Instead, it should be a chance to keep learning about how to improve your health. To prepare for your visit review this guide and bring it with you. Use it to decide if you think your asthma is under control, and get ready to speak to your Healthcare Professional about this.

Bring your medications with you, and your folder with all of your receipts. This will help your Healthcare Professional tell exactly how much medication you have been using, and if it seems to be working. Use the visit as a chance to check your technique – more than half of all asthma patients do not take their inhalers properly!

Write down your questions in a journal before you go to the office. This will help you remember everything that you wanted to ask, in case you forget.

Feel free to bring pictures about anything you want to discuss. It is easier to show your Healthcare Professional something than to describe it. This is most important with medication or triggers around your home, school or workplace.

Bring your Asthma Action Plan that you have worked on (see page 20).

Bring information you have about your drug plan coverage.



## HOW TO COMMUNICATE

Here are some tips for communicating with your healthcare team:

- ▶ Always be honest. Never “guess” at an answer that “seems right” when your Healthcare Professional asks you a question. All asthma is different, and your Healthcare Professional needs true information to help you control it in the future.
- ▶ Make sure to ask your most important questions first.
- ▶ If they are using medical words that you don’t understand, ask for a definition or a different way of explaining the same thing to help you understand.
- ▶ If your Healthcare Professional is giving you instructions, ask if you can repeat those instructions back to them in a way that makes sense to you. When you get it right, both you and your Healthcare Professional will know that you understand.
- ▶ Give as much detail as you can, especially if you are being asked questions about your symptoms or asthma attacks since your last visit. Keeping a journal can help you remember exactly when or where they happened and other details.
- ▶ Ask your Healthcare Professional if there are pictures, booklets, or something you can take to help you remember information once you leave the office.

## QUESTIONS TO ASK

In addition to the questions that you write in your journal, here are some other questions you should be asking during your visits:

- ▶ Does my Asthma Action Plan need to change?
- ▶ Am I taking my medications properly? (Show how you take it during your appointment)
- ▶ Should I have a(nother) Spirometry test?
- ▶ How many repeats of my prescription do I have left? Do I need more?
- ▶ Am I on the right medication for the best asthma control for me?
- ▶ Are there special physical activities that I should or should not be doing based on my asthma control?
- ▶ How can I learn more about asthma when I leave this office?
- ▶ When should I come back for my next check-up?

Here are some of the questions you should ask **every time you are prescribed a new medication**:

- ▶ What is this medication going to do for my asthma?
- ▶ What side effects can I expect? Is there any way to prevent them?
- ▶ How do I take it? (Ask for a demonstration for the proper way)
- ▶ How often do I need to take it?
- ▶ How will I know that it's working? Will I feel better immediately?
- ▶ When should I stop taking it?
- ▶ Will this be covered under my drug plan?
- ▶ How will this affect any other medications that I am taking?



## KNOW YOUR ASTHMA PATIENT BILL OF RIGHTS

To take control of your asthma, you must make sure you get the information that you need to make informed decisions about your asthma. This means knowing your rights, and what topics you should be asking about.

### As a patient with asthma, you have the right to:

1. **Strive for complete control of your asthma.** Complete control means exactly what it sounds like: a life free of symptoms and limitations. You should be aiming for:
  - ▶ Zero symptoms
  - ▶ Zero nighttime awakenings
  - ▶ Zero time lost from school, work and play
  - ▶ Zero exercise limitations
  - ▶ Zero emergency room visits
  - ▶ Zero time spent in hospital because of asthma
  - ▶ Zero side effects from asthma medications
2. **Discuss your personal targets in asthma management** with your doctor or health-care advisor
3. **Access accurate and up-to-date information/advice about asthma** and its management, and participate in decisions about your care
4. **Access appropriate medications** as needed
5. **Access asthma and health-care services in a timely manner**, including physician appointments and treatments in hospitals anywhere in Canada
6. **Access regular asthma assessments** with scheduled follow-up visits without waiting for an emergency
7. **Access Spirometry/lung-function testing** in the primary health-care setting
8. **Access referral to an allergist** for assessment and testing when required
9. **Access asthma education programs** anywhere in Canada
10. **Know which asthma triggers are present** in the places you live, work and play, and be free from exposure to avoidable allergens such as second-hand smoke, scents, and animal danders.

### **As a patient with asthma, you have the responsibility to:**

1. Take an active role in managing your asthma with the support of your health-care team
2. Stay informed about your asthma and know your numbers
  - ▶ What are your peak flow and Spirometry numbers?
  - ▶ How much rescue medication do you use?
  - ▶ How many triggers or allergies do you have?
3. Take control
  - ▶ Take your medication
  - ▶ Make and keep regular asthma appointments
  - ▶ Make emergency room visits unnecessary
4. Follow a healthy lifestyle that includes adequate sleep, balanced nutrition, and regular physical activity

### **Healthcare Providers have the responsibility to:**

1. Be familiar with the most current Asthma Consensus Guidelines
2. Update your knowledge about asthma, including its management on a regular basis through continuing medical education
3. Consider all patients' personal circumstances of asthma management to help them achieve asthma-control goals
4. Be 'partners in care' with patients by providing up-to-date information and advice
5. Build relationships with asthma patients based on mutual respect

### **Governments have the responsibility to:**

1. Ensure timely access to proper care for all patients with asthma
2. Ensure access to regular asthma assessments and Spirometry or lung-function testing in primary Healthcare
3. Ensure access to asthma education and self management programs
4. Ensure equality of asthma care by recognizing and removing cultural, linguistic and social barriers
5. Address outdoor and indoor environmental health issues affecting the health of patients with asthma







A NAPA membership puts you in touch with other Canadians who are working to increase awareness about asthma, improve asthma care, and build a volunteer network to support others affected by asthma. NAPA members also receive important updates and a quarterly newsletter.

To join the National Asthma Patient Alliance or for more information:

Online: [www.asthma.ca/napa](http://www.asthma.ca/napa)

E-mail: [napainfo@asthma.ca](mailto:napainfo@asthma.ca)

Phone: 1-866-787-4050

This booklet is also available online at [www.asthma.ca](http://www.asthma.ca)

The Asthma Society of Canada will review and update this resource in the future. Your feedback is welcome. Please e-mail your comments to [info@asthma.ca](mailto:info@asthma.ca)

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