Asthma

A NEW WAY TO

SUPPORT FAMILIES

Welcome to the Missouri Developmental Disability Resource Center (MODDRC). You are receiving this letter with an enclosed packet of information because a request was made by you (or someone on your behalf) to the MODDRC.

We have compiled information from a number of sources and have included them in this packet, which is divided into the following sections:

- **Overview of a specific disability, special health care need, or other major topic**
- **Current practices**
- **Personal Stories**
- **Family support, advocacy and services**
- **Missouri Service Systems**

The MODDRC, which has now expanded to include Missouri's Family-to-Family Health Information Center, seeks to inform and connect individuals with disabilities or special health care needs and/or their families to peer support. We also provide opportunities for leadership development and volunteerism. When contacting the MODDRC, you are connecting to staff that have first-hand knowledge about disability related issues because they have the experience of living with the disability, either as an individual, parent or family member.

Thank you for using the MODDRC. This packet of information is one of the many ways that the MODDRC can support you in your journey with disability. We hope you will connect with us again.

Missouri Developmental Disability Resource Center/Family-to-Family Health Information Center is housed within Missouri's University Center for Excellence in Developmental Disabilities Education, Research and Services (UCEDD) at the University of Missouri-Kansas City, Institute for Human Development.

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Overview

The purpose of this section is to help you gain a better understanding of a specific disability or special health care need. It is intended to provide a basic explanation of the disability and possible causes and characteristics.

If you would like more in-depth information on this topic, other topics of information or if it is not the topic you requested, please feel free to contact us again.

Overview: Asthma

Most of us take our breathing for granted. It's not something we even think about. But for more than 22 million kids and adults in the United States[1], a lung condition called asthma (**az**-muh) makes ignoring their breathing impossible.

Asthma usually appears in childhood and can last a person's lifetime. It causes tightness in the chest, shortness of breath, coughing, and wheezing (a whistling sound during breathing). With asthma, coughing often happens during the night or early in the morning.

When a person inhales, air travels into the body through their nose or mouth, through the trachea (**tray**-kee-ya) or windpipe, and into the bronchial (**bron-**kee-ul) tubes in their lungs. But people who have asthma have swollen, or inflamed, airways that produce mucus – a sticky, thick liquid. Their airways are very sensitive to certain things like dust, allergens, cigarette smoke, cold weather, or exercise. When someone with asthma comes into contact with one or more of these things, his or her lungs may react by tightening muscles around the airways (see diagram below). This tightness, combined with the swelling and mucus, makes it difficult for air to move through. When this happens, it is called an asthma attack, flare-up, or episode. For most people with asthma, this happens from time to time.

Lots of things can set off an asthma attack . Cold, dry air may cause problems for one person with asthma, while another may not be bothered at all. Cigarette smoke can be a major cause of symptoms, including smoke from someone else smoking around them, called "secondhand" smoke. Even things like perfumes, air fresheners, household cleaning products, mold, colds and flu, animal dander, and cockroaches can make breathing harder for some people. It is important for each person with asthma to find which of these "triggers" bother them. Then they can make a plan to stay away from the things that cause their attacks and/or manage their symptoms with medicine and the help of their doctor. (See Current Practices section for more information on this topic.)

Asthma is not contagious, but it does run in families. A child with asthma may have a parent or other relative who has asthma or did as a child. Teens who are overweight are more likely to have it, and it affects more boys than girls.[2]
No one knows for sure what causes asthma, but scientists think it may be from several factors combined, including:

- a family history of asthma or allergies
- infections of the lungs in childhood, and

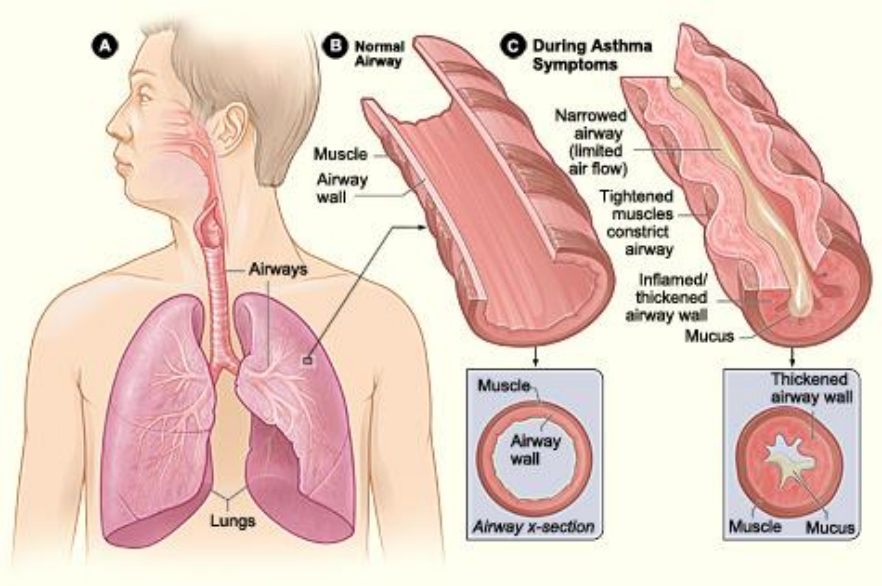


Figure A shows the location of the lungs and airways in the body. Figure B shows a cross-section of a normal airway. Figure C shows a cross-section of an airway during asthma symptoms.

[1] (National Heart Lung and Blood Institute, 2010)

[2] (Nemours Foundation/KidsHealth, 2010)

- exposure to some kinds of allergens or viruses at a very young age, while the immune system was still developing

A doctor can diagnose asthma by looking at a person's medical and family history, performing a physical exam, and by looking at results from special tests, such as:

- **Spirometry** (spi-ROM-eh-tree) – this test measures how fast a person can breathe out as well as how much air can be breathed in and out. Sometimes a person will take medicine and take the test again to see if the results change for the better. This is also called a Lung Function Test.
- **Bronchoprovocation** – uses spirometry tests given after exercise or exposure to other asthma triggers
- **Chest x ray or an EKG** (electrocardiogram) – used to rule out other diseases or to check for a possible foreign object in the airways

A doctor will also check for and rule out other possible reasons for asthma-like symptoms, including reflux disease, problems with the vocal cords, or sleep apnea.

Some children diagnosed with asthma may outgrow their symptoms. Some will not. For those that continue to live with asthma, the goal is to gain good control over flare-ups through a personal "asthma action plan". (see Current Practices section for more information) A person with controlled asthma will:

- have fewer symptoms like coughing and trouble catching his/her breath
- need rescue medicines less
- have better lung function
- be able to be more active without problems
- sleep better
- have fewer attacks and less chance of going to the hospital for medical treatment

With the help of a good doctor, most people can control their asthma, bringing more freedom to life – for those with asthma as well as their families.

Learning about asthma can be confusing.
Don't be afraid to ask questions of your doctors, other families who have gone through it too, and our staff here at the Missouri Developmental Disability Resource Center/Family-to-Family Health Information Center. We're here to help.

Works Cited

National Heart Lung and Blood Institute. (2010). Retrieved March 23, 2010, from National Institutes of Health/US Department of Health & Human Services: http://www.nhlbi.gov/health/dci/Diseases/Asthma/Asthma_WhatIs.html

Nemours Foundation/KidsHealth. (2010). Retrieved March 23, 2010, from KidsHealth.org: http://www.kidshealth.org/teen/asthma_basics/what/asthma.html

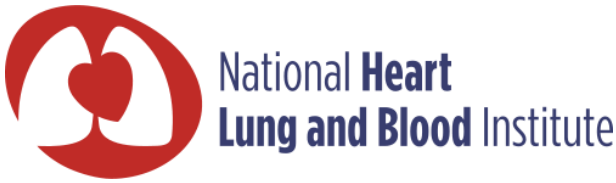
Current Practices

The purpose of this section is to provide you with the most current techniques and procedures for supporting people with developmental disabilities or special health care needs. These could include such things as:

- Information on therapies
- Medical treatment
- Accommodations
- Interventions

If you would like more information on current practices, please feel free to contact us again.

On the following pages, you will find more information on asthma from sources the MODDRC regards as respected and trustworthy. All information has been reprinted with permission and is for educational purposes only. For more information regarding your personal situation, please consult your team of medical professionals.



How Is Asthma Treated and Controlled?

Asthma is a long-term disease that can't be cured. The goal of asthma treatment is to control the disease. Good asthma control will:

- Prevent chronic and troublesome symptoms such as coughing and shortness of breath
- Reduce your need of quick-relief medicines (see below)
- Help you maintain good lung function
- Let you maintain your normal activity levels and sleep through the night
- Prevent asthma attacks that could result in your going to the emergency room or being admitted to the hospital for treatment

To reach this goal, you should actively partner with your doctor to manage your asthma or your child's asthma. Children aged 10 or older—and younger children who are able—also should take an active role in their asthma care.

Taking an active role to control your asthma involves working with your doctor and other clinicians on your health care team to create and follow an asthma action plan. It also means avoiding factors that can make your asthma flare up and treating other conditions that can interfere with asthma management.

An asthma action plan gives guidance on taking your medicines properly, avoiding factors that worsen your asthma, tracking your level of asthma control, responding to worsening asthma, and seeking emergency care when needed.

Asthma is treated with two types of medicines: long-term control and quick-relief medicines. Long-term control medicines help reduce airway inflammation and prevent asthma symptoms. Quick-relief, or "rescue," medicines relieve asthma symptoms that may flare up.

Your initial asthma treatment will depend on how severe your disease is. Follow up asthma treatment will depend on how well your asthma action plan is working to control your symptoms and prevent you from having asthma attacks.

Your level of asthma control can vary over time and with changes in your home, school, or work environments that alter how often you are exposed to the factors that can make your asthma worse. Your doctor may need to increase your medicine if your asthma doesn't stay under control.

On the other hand, if your asthma is well controlled for several months, your doctor may be able to decrease your medicine. These adjustments either up or down to your medicine will help you maintain the best control possible with the least amount of medicine necessary.

Asthma treatment for certain groups of people, such as children, pregnant women, or those for whom exercise brings on asthma symptoms, will need to be adjusted to meet their special needs.

Follow an Asthma Action Plan

You can work with your doctor to create a personal written asthma action plan. The asthma action plan shows your daily treatment, such as what kind of medicines to take and when to take them. The plan explains when to call the doctor or go to the emergency room.

If your child has asthma, all of the people who care for him or her should know about the child's asthma action plan. This includes babysitters and workers at daycare centers, schools, and camps. These caretakers can help your child follow his or her action plan.

See the National Heart, Lung, and Blood Institute's (NHLBI's) Asthma Action Plan for a sample plan by visiting (www.nhlbi.nih.gov/health/public/lung/asthma/asthma_actplan.htm).

Avoid Things That Can Worsen Your Asthma

A number of common things (sometimes called asthma triggers) can set off or worsen your asthma symptoms. Once you know what these factors are, you can take steps to control many of them.

For example, if exposure to pollens or air pollution makes your asthma worse, try to limit time outdoors when the levels of these substances are high in the outdoor air. If animal fur sets off your asthma symptoms, keep pets with fur out of your home or bedroom. The NHLBI offers many useful tips for controlling things that make your asthma worse.

If your asthma symptoms are clearly linked to allergies, and you can't avoid exposure to those allergens, then your doctor may advise you to get allergy shots for the specific allergens that bother your asthma. You may need to see a specialist if you're thinking about getting allergy shots. These shots may lessen or prevent your asthma symptoms, but they can't cure your asthma.

Several health conditions can make asthma more difficult to manage. These conditions include runny nose, sinus infections, reflux disease, psychological stress, and sleep apnea. Your doctor will treat these conditions as well.

Medicines

Your doctor will consider many things when deciding which asthma medicines are best for you. Doctors usually use a stepwise approach to prescribing medicines. Your doctor will check to see how well a medicine works for you; he or she will make changes in the dose or medicine, as needed.

Asthma medicines can be taken in pill form, but most are taken using a device called an inhaler. An inhaler allows the medicine to go right to your lungs.

Not all inhalers are used the same way. Ask your doctor and other clinicians on your health care team to show you the right way to use your inhaler. Ask them to review the way you use your inhaler at every visit.

Long-Term Control Medicines

Most people who have asthma need to take long-term control medicines daily to help prevent symptoms. The most effective long-term medicines reduce airway inflammation.

These medicines are taken over the long term to prevent symptoms from starting. They don't give you quick relief from symptoms.

Inhaled corticosteroids

Inhaled corticosteroids are the preferred medicines for long-term control of asthma. These medicines are the most effective long-term control medicine to relieve airway inflammation

and swelling that makes the airways sensitive to certain substances that are breathed in. Reducing inflammation helps prevent the chain reaction that causes asthma symptoms. Most people who take these medicines daily find they greatly reduce how severe symptoms are and how often they occur.

Inhaled corticosteroids are generally safe when taken as prescribed. They're very different from the illegal anabolic steroids taken by some athletes. Inhaled corticosteroids aren't habit-forming, even if you take them every day for many years.

But, like many other medicines, inhaled corticosteroids can have side effects. Most doctors agree that the benefits of taking inhaled corticosteroids and preventing asthma attacks far outweigh the risks of side effects.

One common side effect from inhaled corticosteroids is a mouth infection called **thrush**. You can use a spacer or holding chamber to avoid thrush. A spacer or holding chamber is attached to your inhaler when taking medicine to keep the medicine from landing in your mouth or on the back of your throat.

Work with your health care team if you have any questions about how to use a spacer or holding chamber. Rinsing your mouth out with water after taking inhaled corticosteroids also can lower your risk of thrush.

If you have severe asthma, you may have to take corticosteroid pills or liquid for short periods to get your asthma under control. If taken for long periods, these medicines raise your risk for cataracts and osteoporosis (OS-te-o-po-RO-sis). A cataract is the clouding of the lens in your eye. Osteoporosis is a disorder that makes your bones weak and more likely to break.

Your doctor may have you add another long-term control asthma medicine to lower your dose of corticosteroids. Or, your doctor may suggest you take calcium and vitamin D pills to protect your bones.

Other long-term control medicines

Other long-term control medicines include:

- Inhaled long-acting beta2-agonists. These medicines open the airways and may be added to low-dose inhaled corticosteroids to improve asthma control. An inhaled long-acting beta2-agonist shouldn't be used alone.
- Leukotriene modifiers. These medicines are taken by mouth. They help block the chain reaction that increases inflammation in your airways.
- Cromolyn and nedocromil. These inhaled medicines also help prevent inflammation and can be used to treat asthma of mild severity.
- Theophylline. This medicine is taken by mouth and helps open the airways.

If your doctor prescribes a long-term control medicine, take it every day to control your asthma. Your asthma symptoms will likely return or get worse if you stop taking your medicine.

Long-term control medicines can have side effects. Talk to your doctor about these side effects and ways to monitor or avoid them.

Quick-Relief Medicines

All people who have asthma need a quick-relief medicine to help relieve asthma symptoms that

may flare up. Inhaled short-acting beta2-agonists are the first choice for quick relief.

These medicines act quickly to relax tight muscles around your airways when you're having a flareup. This allows the airways to open up so air can flow through them.

You should take your quick-relief medicine when you first notice your asthma symptoms. If you use this medicine more than 2 days a week, talk with your doctor about how well controlled your asthma is. You may need to make changes in your asthma action plan.

Carry your quick-relief inhaler with you at all times in case you need it. If your child has asthma, make sure that anyone caring for him or her and the child's school has the child's quick-relief medicines. They should understand when and how to use them and when to seek medical care for your child.

You shouldn't use quick-relief medicines in place of prescribed long-term control medicines. Quick-relief medicines don't reduce inflammation.

Track Your Asthma

To track your asthma, keep records of your symptoms, check your peak flow number using a peak flow meter, and get regular asthma checkups.

Record Your Symptoms

You can record your asthma symptoms in a diary to see how well your treatments are controlling your asthma.

Asthma is "well controlled" if:

- You have symptoms no more than 2 days a week and they don't wake you from sleep more than 1 or 2 nights a month.
- You can carry out all your normal activities.
- You take quick-relief medicines no more than 2 days a week.
- You have no more than one asthma attack a year that requires you to take corticosteroids by mouth.
- Your peak flow doesn't drop below 80 percent of your personal best number.

If your asthma isn't well controlled, contact your doctor. He or she may need to change your asthma action plan.

Use a Peak Flow Meter

This small, hand-held device shows how well air moves out of your lungs. You blow into the device and it gives you a score, or peak flow number. Your score shows how well your lungs are working at the time of the test.

Your doctor will tell you how and when to use your peak flow meter. He or she also will teach you how to take your medicines based on your score.

Your doctor and other clinicians on your health care team may ask you to use your peak flow meter each morning and keep a record of your

results. It may be particularly useful to record peak flow scores for a couple of weeks before each medical visit and take the results with you.

When first diagnosed with asthma, it's important to find out your "personal best" peak flow number. To do this, you record your score each day for a 2- to 3-week period when your asthma is under good control. The highest number you get during that time is your personal best. You can compare this number to future numbers to make sure your asthma is under control.

Your peak flow meter can help warn you of an asthma attack, even before you notice symptoms. If your score falls to a number that shows that your breathing is getting worse, you should take your quick-relief medicines the way your asthma action plan directs. Then you can use the peak flow meter to check how well the medicine worked.

Get Asthma Checkups

When you first begin treatment, you will see your doctor about every 2 to 6 weeks. Once your asthma is under control, your doctor may want to see you anywhere from once a month to twice a year.

During these checkups, your doctor or nurse will ask whether you've had an asthma attack since the last visit or any changes in symptoms or peak flow measurements. You will also be asked about your daily activities. This will help them assess your level of asthma control.

Your doctor or nurse also will ask whether you have any problems or concerns with taking your medicines or following your asthma action plan. Based on your answers to these questions, your doctor may change the dose of your medicine or give you a new medicine.

If your control is very good, you may be able to take less medicine. The goal is to use the least amount of medicine needed to control your asthma.

Emergency Care

Most people who have asthma, including many children, can safely manage their symptoms by following the steps for worsening asthma provided in the asthma action plan. However, you may need medical attention. Call your doctor for advice if:

- Your medicines don't relieve an asthma attack.
- Your peak flow is less than half of your personal best peak flow number.

Call 9–1–1 for an ambulance to take you to the emergency room of your local hospital if:

- You have trouble walking and talking because you're out of breath.
- You have blue lips or fingernails.

At the hospital, you will be closely watched and given oxygen and more medicines, as well as medicines at higher doses than you take at home. Such treatment can save your life.

Asthma Treatment for Special Groups

The treatments described in this section generally apply to all people who have asthma. However, some aspects of treatment differ for people in certain age groups and those who have special needs.

Children

It's hard to diagnose asthma in children younger than 5 years old. Thus, it's hard to know whether young children who wheeze or have other asthma symptoms will benefit from long-term control medicines. (Quick-relief medicines tend to relieve wheezing in young children whether they have asthma or not.)

Doctors will treat infants and young children who have asthma symptoms with long-term control medicines if the child's asthma health assessment indicates that the symptoms are persistent and likely to continue after 6 years of age. (For more information, see "How Is Asthma Diagnosed?")

Inhaled corticosteroids are the preferred treatment for young children. Montelukast or cromolyn are alternative options. Treatment may be given for a trial period of 1 month to 6 weeks. The treatment usually is stopped if benefits aren't seen during that time and the doctor and parents are confident the medicine was used properly.

Inhaled corticosteroids can possibly slow the growth of children of all ages. If this slowed growth occurs, it usually is apparent in the first several months of treatment, is generally small, and doesn't get worse over time. Poorly controlled asthma also may reduce a child's growth rate.

Most experts think the benefits of inhaled corticosteroids for children who need them to control their asthma far outweigh the risk of slowed growth.

Older Adults

Doctors may need to adjust asthma treatment for older adults who take certain other medicines, such as beta blockers, aspirin and other pain relievers, and anti-inflammatory medicines. These medicines can prevent asthma medicines from working properly and may worsen asthma symptoms.

Be sure to tell your doctor about all of the medicines you take, including over-the-counter medicines.

Older adults may develop weak bones from using inhaled corticosteroids, especially at high doses. Talk to your doctor about taking calcium and vitamin D pills and other ways to help keep your bones strong.

Pregnant Women

Pregnant women who have asthma need to control the disease to ensure a good supply of oxygen to their babies. Poor asthma control raises the chance that a baby will be born early and have a low birth weight. Poor asthma control can even risk the baby's life.

Studies show that it's safer to take asthma medicines while pregnant than to risk having an asthma attack.

Talk to your doctor if you have asthma and are pregnant or planning to get pregnant. Your level of asthma control may get better or it may get worse while you're pregnant. Your health care team will check your asthma control often and adjust your treatment as needed.

People Whose Asthma Symptoms Occur With Physical Activity

Physical activity is an important part of a healthy lifestyle. Adults need physical activity to maintain good health. Children need it for growth and development.

In many people, however, physical activity may set off asthma symptoms. If this happens to you or your child, talk to your doctor about the best ways to control asthma so you can stay active.

The following medicines may help to prevent asthma symptoms due to physical activity:

- Short-acting beta2-agonists (quick-relief medicine) taken shortly before physical activity can last 2 to 3 hours and prevent exercise-related symptoms in most people who take them.
- Long-acting beta2-agonists can be protective up to 12 hours. However, with daily use, they

will no longer give up to 12 hours of protection. Also, frequent use for physical activity may be a sign that asthma is poorly controlled.

- Leukotriene modifiers. These pills are taken several hours before physical activity. They help relieve asthma symptoms brought on by physical activity in up to half of the people who take them.

- Cromolyn or nedocromil. These medicines are taken shortly before physical activity to help control asthma symptoms.

- Long-term control medicines. Frequent or severe symptoms due to physical activity may indicate poorly controlled asthma and the need to either start or increase long-term control medicines that reduce inflammation. This will help prevent exercise-related symptoms.

Easing into physical activity with a warmup period also may be helpful. You also may want to wear a mask or scarf over your mouth when exercising in cold weather.

If you use your asthma medicines as your doctor directs, you should be able to take part in any physical activity or sport you choose.

People Having Surgery

Asthma may add to the risk of having problems during and after surgery. For instance, having a tube put into your throat may cause an asthma attack.

Tell your surgeon about your asthma when you first consult him or her. The surgeon can take steps to lower your risks, such as giving you asthma medicines before or during surgery.

Can Asthma Be Prevented?

Currently, there isn't a way to prevent asthma from starting in the first place. However, you can take steps to control the disease and prevent its symptoms.

- Learn about your asthma and how to control it.

- Follow your written asthma action plan. (See the National Heart, Lung, and Blood Institute's Asthma Action Plan as a sample.)

- Use medicines as your doctor directs.

- Identify and avoid things that make your asthma worse (as much as you can).

- Keep track of your asthma symptoms and level of control.

- Get regular checkups for your asthma.

Living With Asthma

Asthma is a long-term disease that requires long-term care. Successful asthma treatment requires you to take an active role in your care and follow your asthma action plan.

Learn How To Manage Your Asthma

Partner with your doctor to develop an asthma action plan. This plan will help you to properly take your medicines, identify your asthma triggers, and manage your disease if asthma symptoms worsen. Children aged 10 or older—and younger children who can handle it—should be involved in developing and following their asthma action plan.

Most people who have asthma can successfully manage their symptoms at home by following their asthma action plans and having regular checkups. However, it's important to know when to seek emergency medical care.

Learn how to use your medicines correctly. If you take inhaled medicines, you should practice using your inhaler at your doctor's office. If you take long-term control medicines, take them daily as your doctor prescribes.

Record your asthma symptoms as a way to track how well your asthma is controlled. Also, you may use a peak flow meter to measure and record how well your lungs are working.

Your doctor may ask you to keep records of your symptoms or peak flow results daily for a couple of weeks before an office visit and bring these records with you to the visit.

These steps will help you keep track over time of how well you're controlling your asthma. This will help you spot problems early and prevent or relieve asthma attacks. Recording your symptoms and peak flow results to share with your doctor also will help him or her decide whether to adjust your treatment.

Ongoing Care

Have regular asthma checkups with your doctor so he or she can assess your level of asthma control and adjust your treatment if needed. Remember, the main goal of asthma treatment is to achieve the best control of your asthma using the least amount of medicine. This may require frequent adjustments to your treatments.

Most people who have asthma are able to manage the disease. They have few, if any, symptoms and can live normal, active lives.

If it's hard to follow your plan or the plan isn't working well, let your health care team know right away. They will work with you to adjust your plan to better suit your needs.

Get treatment for any other conditions that can interfere with your asthma management.

Watch for Signs That Your Asthma Is Getting Worse

Your asthma may be getting worse if:

- Your symptoms start to occur more often, are more severe, and/or bother you at night and cause you to lose sleep.
- You're limiting your normal activities and missing school or work because of your asthma.
- Your peak flow number is low compared to your personal best or varies a lot from day to day.
- Your asthma medicines don't seem to work well anymore.
- You have to use your quick-relief inhaler more often. If you're using quick-relief medicine more than 2 days a week, your asthma isn't well controlled.
- You have to go to the emergency room or doctor because of an asthma attack.

If you have any of these signs, see your doctor. He or she may need to change your medicines or take other steps to control your asthma.

Partner with your health care team and take an active role in your care. This can help control asthma so it doesn't interfere with your activities and disrupt your life.

Information courtesy of the National Heart Lung and Blood Institute and the National Institutes of Health.
For more information and planning tools, visit: www.nhlbi.nih.gov/health/public/lung/index.htm#asthma

KidsHealth
KidsHealth.org

Traveling and Asthma

Your child's asthma shouldn't stop you from planning a family vacation, sending your child to stay with friends for a week, or signing your child up for sleepover camp. With some careful preparation and communication, you and your child should be able to enjoy all the benefits of life away from home.

Before you travel, make sure that your child's asthma is well controlled. If it's been flaring up, you should check in with the doctor. Your child might need a change in medications or might need to see the doctor before you leave.

Before You Go

When packing, be sure to include your child's rescue and controller medications. Keep them handy, not buried in the car trunk. And if you're flying, be sure to take them in your carry-on luggage. That way, you'll have them if your child needs the medications during the flight and later, if your checked bags go astray.

You'll also want to pack your child's peak flow meter, if he or she uses one, and your child's health insurance card. Your child's asthma action plan is a great item to bring along as well. By having a copy, you'll have the names of medicines, dosage information, and your child's doctor's phone number, just in case.

If you're traveling abroad, it's a good idea to have a letter from your child's doctor that describes your child's diagnosis, medications, and equipment. This can help you with airport security or customs. It's also smart to have the generic names of your child's medicines, in case they're called something else in another country.

If your child uses a nebulizer, you might want to invest in a portable version. Many of these can be plugged into the cigarette lighter in a car. If you'll be traveling abroad, make sure you have the adapter you need to use it.

Rolling Along

Buses, trains, and cars may contain many of the same potential allergens as your home, including dust mites and mold that are trapped in the upholstery or the ventilation system. You can't do much about the bus or train, but if you're traveling by car, try this: Run the air conditioner or heater, with the windows open, for at least 10 minutes. This will help reduce mold and dust mites in the car.

If pollen counts or pollution levels affect your child's asthma and are high during your trip, travel with the windows closed and the air conditioner on.

Taking to the Sky

The air quality on planes may affect your child's asthma. Although all flights within the United States are smoke free, some international flights are not. On these flights, make

Breathe Easy at Camp

Your child doesn't have to miss out on sleepover camp because of asthma. Just communicate carefully with the camp director and your child's counselor. Also, in many parts of the country, the American Lung Association has special asthma camps with nurses and doctors on staff.

sure when you reserve your seats that you're as far from the smoking section as possible.

The air on planes is also very dry, so you should make sure your child drinks plenty of water while you're in the air. Many airlines permit the use of battery-operated nebulizers (except during takeoff and landing), but check on this in advance. Nebulizers aren't routinely included in aircraft emergency kits due to their bulky size. But inhalers with spacers have been shown to be as effective as nebulizers in treating asthma and might be easier to keep on hand when traveling.

Your Home Away From Home

Your child's triggers will determine what steps you need to take to prevent asthma flare-ups where you're staying. If pollen or air pollution triggers your child's asthma — and you're traveling to a region with high readings — you may want to schedule a trip during times of the year when pollen counts and smog levels are lower.

If dust mites or mold are a problem and you'll be staying in a hotel, check to see if there are any rooms that have been allergy proofed. Requesting a sunny, dry room away from the hotel's pool might also help. If animal allergens trigger your child's asthma, request a room that has never had pets in it. And you should always stay in a nonsmoking room.

If you'll be staying in a rented cottage or cabin that's near the beach or in a forest, ask that it be thoroughly aired out before you arrive. Make sure any friends or family you'll be staying with know about your child's asthma triggers before you arrive. Although they won't be able to clear away all dust mites or mold, they can dust and vacuum carefully, especially in the room in which your child will sleep.

If scented candles, potpourri, aerosol products, or wood fires bother your child, ask your hosts to avoid using them. You should also ask that no one smokes inside while your child is there.

Because it can take months for animal dander to be effectively removed from a room, even if a pet isn't allowed in there, you probably won't want to stay with friends or family who have a pet if animal dander is a trigger for your child.

Wherever you'll be staying, you may want to bring your child's pillow and possibly even a blanket from his or her bed to make sure your child has some hypoallergenic bedding.

Time zone changes can be tricky. When traveling, try to have your child take his or her medicine at the usual home time. Upon arrival in another time zone, remember to adjust the dosage times to the local clock.

Activity Savvy

If your child's asthma is well controlled, you should be able to plan any sightseeing, hiking, or other leisure activities. Just keep your child's asthma triggers in mind when planning what you'll do. For example, avoid lots of walking or hiking when the air pollution or pollen counts are likely to be high or if the weather is going to be extremely cold and dry. If you'll be camping, keep your child away from the fire.

A ski vacation or hiking trip aren't out of the question. But make sure you plan for plenty of rest (indoors if possible), carry your child's rescue medication at all times, and be prepared to change your plans if your child is struggling with his or her asthma.

As at home, if anyone else will be supervising your child, you should make sure that person knows about your child's asthma and is familiar with his or her asthma action plan.

Solo Adventures

If your child will be traveling alone (for example, going to sleepover camp or to stay with friends or family), make sure that you prepare him or her, as well as any adults who will be taking care of your child. It's extremely important that his or

her counselor or chaperone is familiar with and has copies of your child's asthma action plan, list of medications, and emergency phone numbers. You'll also want to provide written (and notarized) permission for the counselor or chaperone to care for your child in an emergency.

Make sure you sit down with your child before the trip to go over the asthma action plan and what he or she should do in an emergency. Your child should be familiar with any asthma triggers, should know how to administer his or her medication, and should be able to recognize the signs of a flare-up.

Telling your child that you've let the adults who will care for him or her know what to do during a flare-up should also help relieve any nervousness your child feels. And of course, you should reassure your child that he or she isn't different from other kids because of the asthma and that he or she should be able to join in on all the fun while traveling.

If your child hasn't been taking his or her controller medications and has been relying on rescue medication to control his or her asthma, it might not be a good idea to let your child go away alone, especially for an extended period of time. You'll want to discuss this with your child's doctor.

Most of all, be sure that your child still takes his or her medicine and tries to avoid triggers. If your child tries to ignore asthma during a trip, he or she could end up in the emergency department — and that's no place to spend a vacation.

Reviewed by: Elana Pearl Ben-Joseph, MD
Date reviewed: June 2007

Nemours.

Personal Stories

The purpose of this section is to provide you with the perspective of parents, family members and those living with the disability or special health care need. These stories give you insight of what life was like growing up and what life looks like now, as well as some of the joys and challenges that were experienced.

Written personal stories are one way of connecting to others who have similar experiences. Another way of connecting with others is through the Sharing Our Strengths peer support network. This service of the MODDRC provides you with an individualized match specific to what you want. This may include being matched to mentors with a similar disability experience, a mentor located in a similar part of the state or around a specific issue. If you are interested in being matched or in becoming a mentor for someone else, please contact us.

Planning Makes Perfect

Personal perspective of Beth, mother of an 8 year old girl with Asthma

Our daughter, Emma, was born five weeks early. Besides being tiny and having low muscle tone, she appeared to be in good health. But as she grew and developed, we noticed a cough that just wouldn't go away. It was a sharp, "barking seal" cough, and occasionally she would cough to the point of vomiting. She saw the doctor numerous times and each time it seemed to be "just a cold", or "bronchitis", or "watch her for a few days; she should be fine."

Finally, we saw a pediatric ENT/allergist. She diagnosed her as having a milk allergy, which seemed to bring on her cough-variant asthma (as we would find out years later it was called). We took her off all dairy products (you'd be amazed how many things have milk protein in them!), and within a couple of days, her cough had improved. We continued on that route until winter came.

Then, the sharp, bitter cold brought on her cough again. Due to insurance changes, we had to see yet another physician, and this time we sought out an asthma specialist. He started her on Pulmicort (an inhaled steroid), albuterol, and Zyrtec, all of which worked well for a year or so. Then we tried Singulair instead of Zyrtec, since it wasn't working as well as it had previously. We attributed some of that to Emma growing and her body changing enough that perhaps the Zyrtec just wasn't right for her any longer.

We noticed that the albuterol was making her shaky. She was taking this by mouth through an inhaler with a spacer. We tried nebulized albuterol, but still she was shaky and jittery from it. The doctor then tried nebulized Xopenex, with is a brand name for a variation on albuterol that has a slightly different isotope, which tends not to make kids quite so shaky. The doctor explained it to Emma this way: "Imagine that we took the albuterol and put it in the washing machine, and washed out the 'bad' part of albuterol that makes you shaky, and what was left is the Xopenex."

Emma has done well on those meds, and is a happy, healthy, and thriving 3rd grader. She is able to manage her medications with minimal parental supervision, and can tell more information about how to use a nebulizer than most adults know! She has meds at school as well as at home, and we have a small bag we take with us when we are going to be away from home for awhile. In that bag, we keep her nebulizer tubing and mask, the air compressor, her medication, and an adapter that plugs into the console in the car so that she can have a treatment while we are traveling. I also typed up the instructions for her meds and we leave them in the bag for when Emma visits grandparents or spends the night with a friend.

While I am no medical expert, I have been down the slippery slope of childhood asthma for almost nine years now, and I'd like to save other families from having to jump through the hoops we did just to get our daughter the right treatment. Here is my advice:

- Don't let anyone tell you your child will be just fine if you have a gut feeling otherwise. Seek medical advice.
- Do your research on pediatric asthma. Ask questions and educate yourself about your child's condition. There are books and websites that can fill in the gaps where the physician's information may leave off. Talking to other parents of children with asthma is often helpful.
- Read books about asthma with your child and/or visit interactive websites that can help you teach your child about asthma, as well teaching him/her how to manage meds once old enough to start doing so.

- Educate your child's teachers if necessary. Have an asthma action plan on file at school.

- Post the action plan at home somewhere, too. It's handy to know where it is in the middle of the night when your child has a flare-up and the treatment procedure is still new to you.

- Educate your family members (grandparents, etc.) on what to do if your child has a flare-up while in their care.

- Support your child. S/he may be sick and tired of being sick and tired! Reassure your child that you'll find the answers together, and that there are lots of people in the world who deal with asthma while living happy, normal lives.

Emma's turn:

Sometimes it's not fun in the winter. The cold, dry air messes with me. It's not fun. Asthma treatments are not that fun either, but I'm glad I have them. They make it easier to breathe.

My advice for other kids with asthma is:

- Don't run really hard if it hurts your chest.
- Make sure you take your medicine.
- Do your nebulizer treatments, if you have them.

Family Support, Advocacy and Services

The purpose of this section is to provide you with a listing of organizations specifically designed to meet the support needs of individuals with developmental disabilities or special health care needs and their families. This listing includes parent organizations, support groups or other advocacy organizations.

Support for Families

Sharing Our Strengths (SOS) Peer Support Network
215 W. Pershing Road, 6th floor
Kansas City, MO 64108
Toll free: 800-444-0821
Web: http://www.sharingourstrengths.com

SOS is a statewide support network of parents, family members, individuals with developmental disabilities or special health care needs, and professionals who are matched with peer mentors to share experiences, offer emotional support and to network with others. You can request an individual parent to parent or peer support match with another parent or individual who has experienced similar circumstances.

St. Louis Chapter
Asthma & Allergy Foundation of America
1500 South Big Bend, Suite 1S
St. Louis, MO 63117
Phone: 314-645-2422
Web: www.aafastl.org
Email: aafa@aafastl.org

American Lung Association in Missouri
1118 Hampton Ave.
St. Louis, MO 63139
Phone: 314-645-5505
Email: jdirkers@breathehealthy.org

National Heart Lung and Blood Institute
NHLBI Health Information Center
Attn: Web site
PO Box 30105
Bethesda, MD 20824-0105
Phone: 301-592-8573
Web: www.nhlbi.nih.gov
Email: nhlbiinfo@hnlbi.nih.gov

American Academy of Allergy, Asthma and Immunology
555 East Wells St., Suite 1100
Milwaukee, WI 53202-3823
Phone: 414-272-6071
Web: www.aaaai.org/patients.stm
Email: info@aaaai.org

Greater Kansas City Chapter
Asthma & Allergy Foundation of America
9140 Ward Parkway – Suite 120
Kansas City, MO 64114
Phone: 888-542-8252
Web: www.aafakc.org
Email: info@gafakc.org

St. Louis Regional Asthma Consortium
Salus Center
3545 Lafayette, Suite 300
St. Louis, MO 63104
Web: www.asthma-stlouis.org
Email: lreinhart@asthma-stlouis.org

US Environmental Protection Agency
US EPA/Office of Radiation and Indoor Air
1200 Pennsylvania Ave. NW
Mail Code 6609J
Washington, DC 20460
Phone: 202-343-9370
Web: www.epa.gov/asthma/

NeedyMeds, Inc.
PO Box 219
Glouchester, MA 01931
Web: www.needymeds.org
Email: info@needymeds.com

Find help with the cost of medicine

Missouri Service Systems

The purpose of this section is to provide you with a listing of agencies focused on areas such as educational, medical care or social services to individuals with developmental disabilities or special health care needs. This includes listings such as state or local agencies, hospitals, clinics or education systems.

Missouri Service System Contacts

In Missouri, Asthma education and program funding fall under the Department of Health and Senior Services. This department also manages the following:

Children with Special Health Care Needs (CSHCN) Program
Healthy Children and Youth (HCY) Administrative Case Management Program
Physical Disabilities Waiver (PDW) Administrative Case Management Program
Adult Head Injury Program

For more information about Missouri programs related to asthma or the programs listed above, please contact your regional office listed on the map.