

# Aspirin-Exacerbated Respiratory Disease

A Practical Guide for Patients and Providers



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# AERD 101

## Getting to Know AERD

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Aspirin-Exacerbated Respiratory Disease (also called Samter's Triad) is a chronic disorder of the immune system. It is also known as NERD (NSAID-Exacerbated Respiratory Disease) in some European countries.

### Clinical Components of the Condition

AERD is a medical condition that consists of three clinical features: asthma, sinus disease with recurrent nasal polyps, and a sensitivity to aspirin and other non-steroidal anti-inflammatory drugs (NSAIDs) that inhibit an enzyme called cyclooxygenase-1.

This sensitivity usually manifests as respiratory reactions that occur upon ingesting or inhaling an NSAID medication, and occasionally after applying it topically to the skin.

The exact cause of AERD is not known.

Approximately 7% of all adults with asthma and 14% of all adults with severe asthma have AERD. About 30% of adults with asthma and nasal polyps have AERD – estimated to be 1.2 million to 1.6 million people in the United States.

AERD can develop quite suddenly in adulthood, usually between the ages of 20 and 50, and there is no clearly understood trigger that causes the disease.

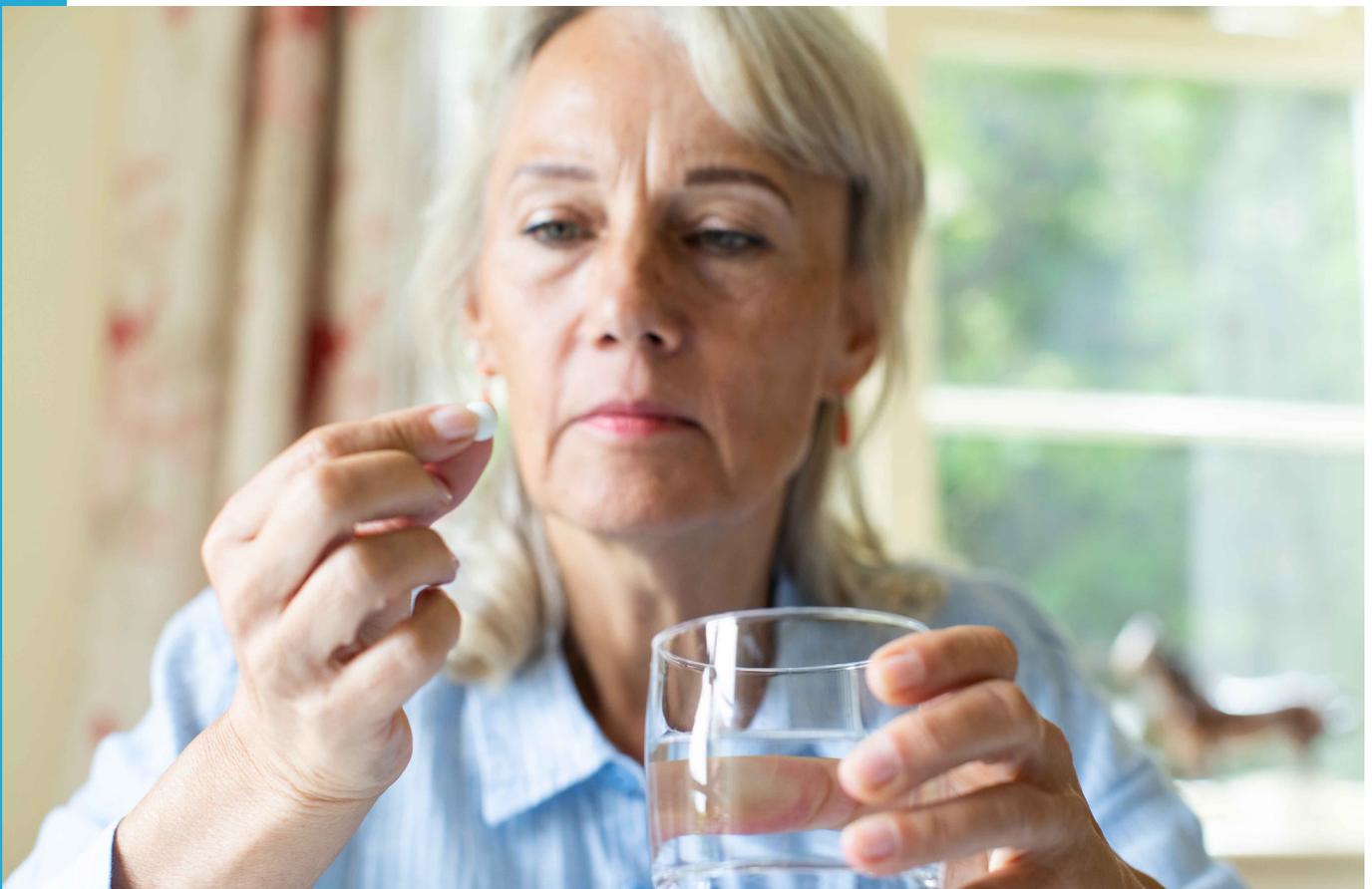
## Signs and Symptoms

People with AERD usually have asthma, nasal congestion and recurrent nasal polyps. Symptoms often do not respond sufficiently to conventional treatments.

Symptoms can include:

- Nasal congestion – prolonged severe sneezing
- Itchy, watery, red eyes
- Coughing, wheezing, chest tightness
- Headache or sinus pressure
- Nausea or abdominal pain
- Hives or a rash
- Alcohol intolerance

When someone with AERD takes aspirin or an NSAID, the severity of symptoms will vary widely from person to person.





# Understanding AERD

## Diagnosis

There is not a specific test for AERD. The diagnosis is a clinical one – if a patient develops asthma, nasal polyps and aspirin sensitivity – then that’s usually enough for a doctor to diagnose AERD.

A characteristic of AERD is that people develop respiratory reactions to aspirin and other NSAIDs. These reactions classically involve both upper respiratory symptoms (increased nasal congestion, frontal headache or sinus pain, and sneezing) as well as lower respiratory symptoms (cough, wheezing, chest tightness), but they can also induce skin flushing, rash, abdominal pain and occasionally vomiting.

Doctors may perform an aspirin challenge to confirm an AERD diagnosis.

People with AERD have high numbers of eosinophils, a type of immune cell that is involved in inflammation, in their nasal polyps. They often have elevated levels of eosinophils in their blood. Though the presence of an elevated eosinophil level is not required as part of the diagnosis, it can be a helpful additional insight.

## Treatment and Management

First, people with AERD should avoid aspirin and all other NSAIDs to prevent reactions. The drug acetaminophen is usually safely tolerated at low doses (up to 500 mg at a time or below 1,000 mg) to treat body aches, colds and fever.

Even with complete avoidance of NSAIDs, people will continue to have symptoms of asthma, nasal congestion and recurrent nasal polyps.

Most people with AERD will need to use daily medications to control their symptoms: inhaled corticosteroids for asthma, intranasal steroid sprays or steroid sinus rinses to help control nasal symptoms, and corticosteroid injections to treat nasal polyps. For patients with severe asthma, new injectable biologic medications may be helpful.

Several non-steroid medications are also available, specifically medications that inhibit the production (zileuton) or block the function (montelukast and zafirlukast) of leukotrienes, chemicals involved in immune responses that cause inflammation, swelling and tightening of airways.

Despite intensive medical therapy, the need for surgical removal of nasal polyps in AERD is very common, though unfortunately the rate of recurrence of nasal polyps after surgery is high.

Aspirin desensitization in order to initiate daily high-dose aspirin therapy can also be used as a treatment in some patients. In people with AERD, an aspirin desensitization procedure should be performed under the guidance of a physician and consists of administering gradually increasing doses of aspirin in a hospital or clinic that specializes in such treatment.

The goal of aspirin desensitization is to have the person begin long-term daily aspirin therapy, which in many people can decrease the regrowth of nasal polyps and reduce the need for corticosteroid medications. An added benefit of desensitization is that it allows patients to tolerate aspirin and NSAIDs again.

## Medications and AERD

If you have AERD, you should usually avoid COX-1 inhibitor NSAIDs including:

- Aspirin or salicylate-containing medications
- Ibuprofen
- Naproxen
- Ketoprofen
- Ketorolac
- Diclofenac

People with AERD can safely take the COX-2 inhibitor drug celecoxib as an anti-inflammatory or pain reliever.

Although AERD is not a rare condition, some healthcare providers may not be familiar with the long-term aspirin therapy. AERD specialists will provide their patients with a letter containing a brief description of AERD and its management with long-term aspirin therapy. This letter can then be taken with the patient when seeking healthcare with other providers (a sample letter can be found in the Resources section of this guide).

Some AERD patients choose to carry a card with them that outlines medications containing NSAIDs that inhibit the COX-1 enzyme. An example of a card is found here.

### NSAIDs & COX-1 inhibitors to avoid



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Patients with Aspirin-Exacerbated Respiratory Disease (AERD), or Samter's Triad, should completely avoid all non-steroidal anti-inflammatory drugs (NSAIDs) that inhibit the COX-1 enzyme.

This list includes most commonly available COX-1 inhibitors in the United States – the generic drug name in **bold**, followed by most of the brand names in *italics*. These medications should all be avoided. Please read all medication labels, and check with your healthcare providers to ensure that you are not mistakenly given a prescription for a medication listed below.

• **Aspirin or acetylsalicylate:**

*Excedrin*    *Aspergum*  
*Pepto-Bismol*    *Aspermin*  
*Alka-Seltzer*    *Aspir-Mox*  
*Anacin*    *Aspirtab*  
*Asperbuf*    *Arthropan*

• **Ibuprofen** (*Motrin, Advil*)  
• **Naproxen** (*Aleve, Anaprox*)  
• **Ketorolac** (*Toradol*)  
• **Diclofenac** (*Arthrotec*)  
• **Fluriprofen** (*Ansaid*)  
• **Salsalate** (*Amigesic, Argesic, Salflex*)

# The Patient Experience

## Andrea Reinhardt's AERD experience:



I lived without being able to smell for several years. If you want to know what it's like living with AERD, imagine having the worst cold you've ever had, but it never goes away, and then throw asthma and severe reactions on top of that.

My journey with AERD started when I was in my early 30s. I've had mild asthma since childhood, but suddenly something changed. I took Advil for a backache and had a severe asthma attack. I thought that was strange since I'd never had a problem taking Advil before. I figured that I had developed some sort of allergy to it. I avoided NSAIDs, but my asthma continued to get more severe and I ended up needing daily inhalers. I couldn't identify any triggers – I felt like my body was suddenly reacting to everything. Then I awoke one morning with a totally blocked nose and inability to smell or taste.

I saw an otolaryngologist (an ear, nose and throat specialist, or ENT) and an allergist. The ENT told me that I had nasal polyps and prescribed antibiotics and prednisone. The antibiotics did not help and the prednisone only helped short term. Fortunately, the allergist was aware of AERD and able to diagnose me based on my symptoms – asthma, polyps, and reactions to NSAIDs. I was prescribed Singulair®, which helped somewhat. I was given a multitude of antihistamines and nasal sprays, none of which helped much at all. I was back at the doctor's office every few weeks. They would prescribe prednisone and I would feel miserable again after finishing it. I lived without being able to smell for several years. If you want to know what it's like living with AERD, imagine having the worst cold you've ever had, but it never goes away, and then throw asthma and severe reactions on top of that.

I joined a support group online where I learned about budesonide rinses. My ENT prescribed the rinses and they were more helpful than any nasal spray I had tried. I also learned about aspirin desensitization, which no doctor had ever offered me before. I found a new allergist and was able to get desensitized a few months later. Finally, many of my issues began to improve. I could smell and breathe through my nose. My asthma was more controlled. My energy began to return.

At that point, I wanted to do something to help other patients. There is a lack of awareness of AERD and many doctors aren't up to date on the most effective treatments. A group of us decided to start The Samter's Society – a support group for patients, but also a place for people to find resources to manage the disease better.

I am feeling a lot more in control of the disease today than I used to be, but AERD never goes away. As patients, we often need to advocate for ourselves to get the best treatments, but there are things available that can help restore quality of life.

## Rhonda Nelson's AERD experience:



AERD doesn't stop us from doing things we enjoy. It just alters the way we do them.

I had never been diagnosed with asthma and I had never had problems with allergies. It started with a cold. I was taking cold medicine and I would wake up in the middle of the night and start coughing and wheezing for hours. That was really the first clue something was not right.

I was 33 when I was diagnosed. It took about a year to find a doctor who knew about AERD. I was seeing a physician who told me to undergo allergy shots, but my symptoms kept getting worse. Later, after my husband Wayne and I relocated, I started with a new allergist who diagnosed me immediately: 'You don't have allergies, you have AERD.' At the time, it was called Samter's Triad.

In hindsight, I was probably worsening my condition because I was taking medication that contained aspirin without knowing aspirin sensitivity was a symptom of AERD. It turns out delayed diagnosis and misdiagnosis are very common with AERD.

Now I have a treatment plan – it took a little bit of time to find the right combination of medications. I avoided aspirin and other NSAIDs, and later I underwent aspirin desensitization and daily aspirin therapy to reduce nasal polyp growth. I eventually had surgery to remove all of the nasal polyps. From that point on, I have kept my AERD under control. Thankfully, I'm not on a lot of medications now – I know that's not the case for many AERD patients.

One key factor – and it took me a whole lot of sinus infections to realize this – is it's important to do a daily nasal rinse. AERD patients tend to get a lot of sinus infections. Nasal rinses can keep your nasal passages clean and fend off a virus or bacteria.

An AERD diagnosis doesn't mean you have to give up things in your life. We travel a lot, I exercise, and I take horseback riding lessons. AERD doesn't stop us from doing things we enjoy. It just alters the way we do them. Also, if you suspect you have AERD, don't give up on finding a doctor who is knowledgeable about the disease and can give you an accurate diagnosis.

# Resources to Share

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## Sample Letter to Healthcare Providers about Aspirin Therapy

Dear Healthcare Provider,

This patient is under specialized care with a condition known as “Aspirin-Exacerbated Respiratory Disease” or AERD, previously known as Samter’s Triad. This is a unique condition in which patients usually suffer from asthma, sinus disease and nasal polyps, and develop hypersensitivity reactions to aspirin and other NSAIDs. It is further unusual because it is a condition in which, by definition, patients are allergic to aspirin but following an aspirin desensitization procedure, enjoy significant therapeutic benefit from taking aspirin every day. In AERD, patients have a significant burden of illness with high systemic corticosteroid requirements, high health care utilization for asthma exacerbations and sinusitis flares, and frequent sinus surgery. Many patients have a need for sinus surgery as frequently as every other year to control nasal polyp growth.

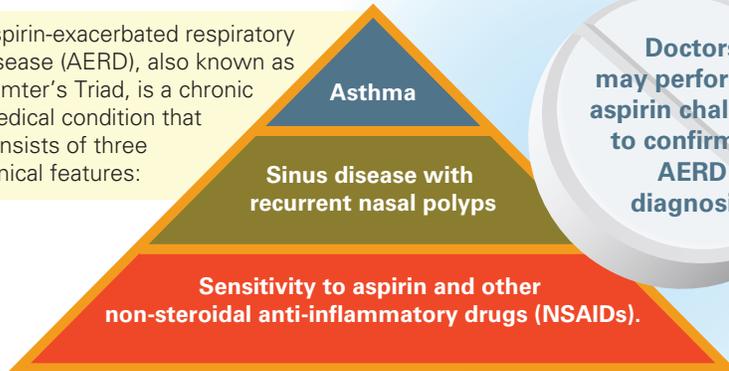
Daily aspirin therapy, at a dose of 650 mg-1,300 mg per day, has been shown in four double-blind, randomized-controlled studies, to control polyp regrowth and sinus inflammation. Although there are certainly risks of being on aspirin long-term, these risks are reviewed in a balanced discussion with patients in consideration of the burden of their underlying illness. Longitudinal studies show that the vast majority of patients on long-term aspirin therapy do not have bleeding complications or gastrointestinal ulceration.

We have heard from our patients that occasionally physicians have expressed concern over the high recommended dose of aspirin. Please be assured that the recommendation to place the patient on aspirin was done after a lengthy consultation and a shared decision-making process, and that an extensive risk/benefit discussion went into the decision. As with many other medications, aspirin therapy may have some safety concerns but also has a huge benefit on patient health outcomes.

# What Is AERD?



Aspirin-exacerbated respiratory disease (AERD), also known as Samter's Triad, is a chronic medical condition that consists of three clinical features:



Doctors may perform an aspirin challenge to confirm an AERD diagnosis.

## How Common Is It?



Between **1.2 million** and **1.6 million** people in the United States

## Raising Awareness

Many healthcare professionals and patients are unaware of AERD. This can lead to:

- Misdiagnosis or delayed diagnosis (sometimes a year or longer)
- Lack of adequate care, forcing patients to see numerous specialists before reaching an accurate diagnosis



## Fast Facts

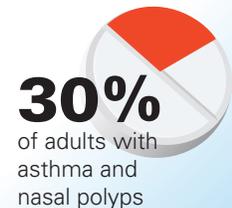
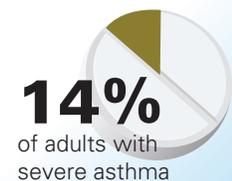
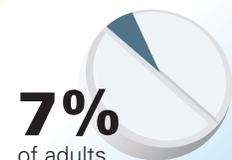
AERD typically develops between the ages of 20 and 50.

AERD requires specialized care.

It can cause life-threatening reactions to common medications such as aspirin, ibuprofen and naproxen.

AERD often causes a reduced or absent sense of smell.

75% of people with AERD have mild-to-moderate respiratory reactions when they drink alcohol.



## AERD Treatment

Avoid aspirin and other NSAID medications



Take prescribed medications to treat asthma and nasal polyps as directed



Consider surgical removal of nasal polyps



Consider aspirin desensitization



Consult with your doctor about your treatment and maintain an ongoing dialogue to best manage the disease.



The mission of Allergy & Asthma Network is to end the needless death and suffering due to allergies, asthma and related conditions through outreach, education, advocacy and research.

## AERD Web-Based Resources

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- Allergy & Asthma Network AERD:  
<https://allergyasthmanetwork.org/aerd-disease>
- The Samter's Society:  
<https://www.samterssociety.org/>
- Samter's Society Facebook Support Group:  
<https://www.facebook.com/groups/507118766355639/>
- AERD Partners – Brigham & Women's Hospital:  
<https://aerd.partners.org/>
- Penn Medicine – AERD Center:  
<https://www.pennmedicine.org/for-patients-and-visitors/find-a-program-or-service/ear-nose-and-throat/aerd-center>
- Scripps AERD:  
<https://www.scripps.org/medical-groups/scripps-clinic/services/immunology/services/specialized-services/aspirin-desensitization>

All content reviewed by Tanya Laidlaw, MD, and AERD patients