

Your Guide to Managing Eosinophilic Esophagitis (EoE)



Asthma and Allergy
Foundation of America



Kids with Food Allergies



Eosinophilic esophagitis [EE-oh-sin-oh-FILL-ick uh-sof-uh-JIE-tis] - “EoE” for short – is a chronic (long-term) allergic or immune condition of the esophagus. It can make eating difficult and painful. EoE affects people of all ages, genders, and ethnic backgrounds. About 1 in 2,000 people have EoE.¹

EoE causes swelling in your esophagus. The esophagus is the tube that moves food from

your mouth to your stomach when you swallow. EoE happens when a large number of white blood cells called eosinophils [EE-oh-sin-oh-FILLS] collect and damage the inner lining of the esophagus.

EoE may potentially result from an immune response to food. In some cases, environmental allergens (such as pollen, mold, dust mites, etc.) can also trigger EoE. Sometimes, triggers are not clearly identified.

Common signs and symptoms of EoE include:

Infants	Children	Adults
<ul style="list-style-type: none"> • Poor appetite and won't feed • Coughing with feeding • Reflux that isn't helped by medicine • Nausea and vomiting • Spitting up while arching the back (a sign of pain) • Poor growth, weight loss, malnutrition 	<ul style="list-style-type: none"> • Trouble swallowing or a feeling of food getting stuck • Food flows back into the esophagus (regurgitation) with reflux that medicine often doesn't help • Nausea and vomiting • Getting full early while eating • Older children may have chest pain and impaction (food gets stuck in the esophagus) • Failure to thrive (poor growth or weight loss) • Stomach pain 	<ul style="list-style-type: none"> • Trouble swallowing • Food gets stuck in the esophagus (impaction) • Food flows back into the esophagus (regurgitation) with reflux that medicine often doesn't help • Chest pain • Heartburn

1. EoE. (n.d.). American Partnership for Eosinophilic Disorders. Retrieved May 8, 2023, from <https://apfed.org/about-ead/egids/eoe/>

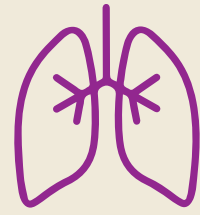
Diagnosing EoE

EoE cannot be diagnosed by symptoms alone. While your primary care doctor can refer you to a specialist (allergy or gastroenterology) to assess your symptoms, the formal diagnosis of EoE is done by a gastroenterologist (GI doctor) using a test called an upper GI endoscopy, or EGD. You might hear it referred to as a “scope.” During this procedure, the doctor will take photos and small tissue samples, or biopsies, of the esophagus (and possibly stomach and small intestine) to look for eosinophils.

EoE can be tricky to diagnose for many reasons:

- Symptoms can vary from person to person and between age groups.
- People with EoE may have learned to manage their symptoms. They may cut food into smaller pieces, drink liquids when eating dry foods, put off meals, and avoid pills.
- Eosinophils can be found in the esophagus for other diseases as well.

If EoE goes untreated, it can lead to long-term damage to the esophagus. The tube can narrow and tighten – called a stricture – which can make it harder to swallow and pass food through to the stomach. The esophagus may need to be stretched by a GI during an endoscopy.



Related Conditions

Many people with EoE may also have a personal or family history of allergies, asthma, allergic rhinitis, or eczema. These conditions are often caused by type 2 inflammation. When you have type 2 inflammation, you may have more than one allergic condition. Not all people with EoE have underlying allergies.

If you have more than one condition, it's important to treat all of them so you can keep all conditions well-controlled and have a better quality of life.

An allergist can help you manage your allergic conditions, including EoE.

On average, it takes about one to five years to be diagnosed with EoE. It is often originally misdiagnosed as conditions such as gastroesophageal reflux disease (called GERD or acid reflux), anxiety, or lactose intolerance.



Treating EoE

There is no cure for EoE, but you can manage it. A team of health care professionals can work with you to help you manage EoE:

- Allergist and immunologist
- Gastroenterologist
- Primary care doctor (including pediatrician or family medicine)
- Nurse
- Dietitian
- Psychologist, therapist, or counselor

Your health care team can help you set your goals for treatment. They will likely include:

- Helping heal the lining of the esophagus
- Managing existing narrowings (“strictures”) of the esophagus
- Preventing or reducing risk of long-term complications
- Improving symptoms and quality of life

EoE is treated through a combination of diet changes and medicine to control the inflammation.



Diet

EoE may sometimes be triggered by food. Many children and adults with EoE respond well to changes in their diet. Dry or dense foods may be hard to swallow until the esophagus is healed.

While diet therapy is often a recommended treatment, it is not the only treatment to consider. Elimination diets may have slightly weaker evidence for effect than use of steroids alone. Diet therapy needs to be very carefully considered in the context of your life and your preferences for how you wish to live your life.



Elimination diets

There are different versions of elimination diets which may involve removing one, two, four, or as many as six food groups from your diet.

- Your doctor can help you decide if you need an elimination diet
- Certain people with EoE improve after removing animal milk from their diet
- If symptoms persist after removal of milk, a person may need to avoid additional foods such as wheat, eggs, soy, peanuts/tree nuts, and fish/shellfish. However, there is no evidence that starting with just milk elimination has better results than starting with a 4 or 6 food elimination diet.

Elemental formula diets

In certain cases, more extensive food elimination is recommended. In these cases, the diet is managed with a special non-allergenic formula (a type of medical food). This is most often used in very young infants or in children and adults with more severe disease.

- May be recommended for people with severe disease or malnutrition
- Made of special amino acids (protein building blocks) that help avoid allergic responses
- Provide complete nutrition while helping you manage EoE
- May be given through a feeding tube to infants, children, or adults
- Examples include Neocate®, EleCare®, PurAmino™, Alfamino™

See the resources section on page 8 of this guide to learn where to get information on medical formulas for food allergies and EoE.



Nutrition with EoE

Nutrition is critical for people with EoE, especially children. Poor nutrition can affect oral motor skills, growth, and social development. You can work with your doctor to find the best balance between treatment, nutrition, and quality of life.

A registered dietitian nutritionist, especially one who specializes in food allergies or EoE, may be able to help. They will help you compare the nutrition you or your child needs with foods you or your child can eat. This will help to determine if you need to adjust the diet (if possible) and/or add supplements or medical formula.

You will likely work together to create a meal plan. The dietitian should give you meal ideas, a list of foods to eat, and a list of foods to avoid.

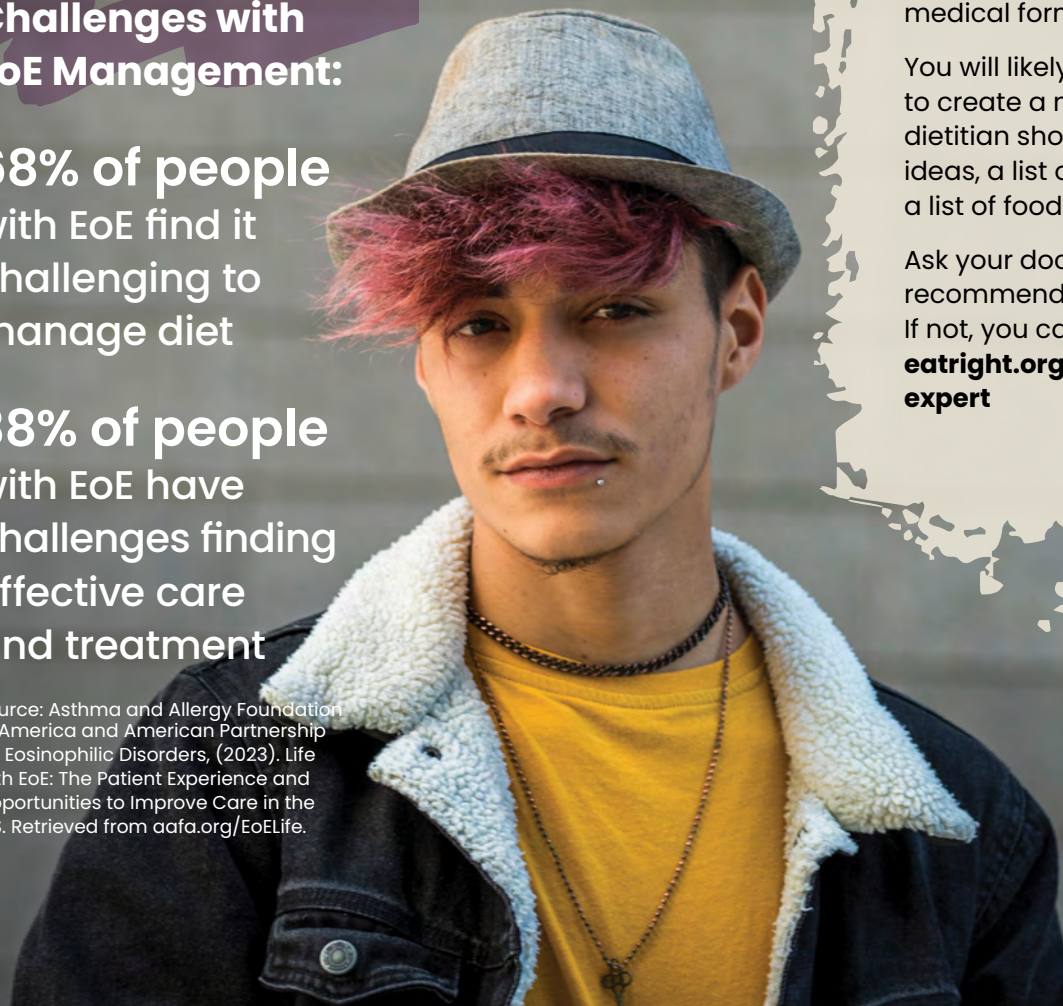
Ask your doctor if they have a recommendation for a dietitian. If not, you can search for one: eatright.org/find-a-nutrition-expert

Challenges with EoE Management:

68% of people with EoE find it challenging to manage diet

38% of people with EoE have challenges finding effective care and treatment

Source: Asthma and Allergy Foundation of America and American Partnership for Eosinophilic Disorders, (2023). Life with EoE: The Patient Experience and Opportunities to Improve Care in the U.S. Retrieved from aafa.org/EoELife.



Medicines and Treatments

While diet changes can help, this is not the only treatment option and is not always the initial treatment option chosen. Medicines can also help manage and reduce symptoms associated with EoE. Some treatments also target the underlying inflammation that causes EoE. Here are the most common treatments for EoE:

Proton pump inhibitors (PPI)

Older guidelines for EoE treatment recommended doing trial of PPI (for up to 8 weeks) *before* a diagnosis could be made. These recommendations have changed in recent years and this is no longer necessary. PPIs:

- Are pills or liquid medicines that reduce acid production in the stomach
- Treat acid reflux
- Can reduce eosinophils in the esophagus (can be used in children as young as 1 year old)
- Can control trouble swallowing
- Are often tried first before elimination diets or steroid treatments because this treatment is available over-the-counter
- Are generally safe, but long-term use may increase risk of nutritional deficiency, gut infections, or bone fractures

Topical corticosteroids

Corticosteroids help control inflammation in the esophagus. The dose sometimes can be lowered to a smaller amount once EoE is under control.

- Most used drug treatment for EoE
- Often taken from an asthma inhaler (fluticasone or budesonide) using a “puff and swallow” technique
- Can also be used to make a thickened slurry from the liquid medicine that is normally used in nebulizers and then swallowed to coat the esophagus
- Considered safe and are taken at doses similar to asthma – like any steroid, this should be monitored by a doctor because of concerns for higher risk of thinning bones, mood problems, infections, or diabetes

Esophageal dilation

Over time, EoE can cause scarring in the lining and narrowing of the esophagus, making swallowing difficult. Dilation:

- Helps enlarge the space in the esophagus in people with EoE-related strictures or recurring problems with swallowing to make swallowing easier
- Is a procedure that is usually well-tolerated
- Improves symptoms in nearly nine of 10 people but doesn't improve the number of eosinophils that cause inflammation



Biologic therapy

Biologics are a type of treatment that target a specific cell or protein to block inflammation pathways.

- Dupilumab (DUPIXENT®) is approved by the Food and Drug Administration (FDA) for people 12 and older with EoE weighing more than 88 pounds
- Indicated as a possible first- or second-line therapy
- DUPIXENT® comes in a pre-filled syringe or auto-injector and is given by a doctor in the office or self-administered at home
- Dupilumab side effects include injection site reactions, respiratory infections, joint pain, conjunctivitis (eye infection or inflammation), and herpes viral infections



Impact and Support

Managing EoE can mean removing foods from your or your child's diet, buying specialized formulas, managing medicines and treatments, and adapting social plans. It can have a costly impact on social, emotional, and financial health. This can reduce quality of life. People with EoE may be anxious about issues, such as:

- Physical health
- Financial burden of treatment and hospital visits
- The impact on relationships and social life
- Missing school or work due to frequent medical appointments

Understanding the burden of EoE and getting support can help you manage the impact. With management, treatment, and support, people with EoE can live full lives.

Managing Stress and Anxiety

It's natural to feel stressed and anxious about managing EoE. Some ways to manage stress include:

- Educating people closest to you so they understand what EoE is, what causes it, and how they can help
- Talking with your health care team about impact and where to find resources
- Talking with a counselor or therapist if you're having trouble dealing with your feelings or stress
- Consulting a dietitian who specializes in food allergies and/or EoE
- Using resources, education, and support from a patient advocacy organization such as the Asthma and Allergy Foundation of America (AAFA) and Kids with Food Allergies (KFA)

Managing EoE at School

If your child has EoE that is triggered by food, you can work with your child's school to manage their condition. Schools want your child to have a quality education in a safe environment. Start by talking with the staff at your child's school about ways they can help your child avoid foods that trigger EoE symptoms.

Every student with EoE should have a school health care plan. This plan lists your child's common symptoms, medicines, and what to do if they have symptoms. It may also outline what school staff should do to prevent symptoms.

Three of the most common types of school health care plans are:

- Emergency care plan (ECP)
- Individual health care plan (IHCP or IHP)
- Section 504 accommodation plan (also known as a "504 plan")

Children with EoE need to avoid eating their trigger food(s). Many schools already have policies in place to manage food allergies and conditions like EoE. Partner with the school to set up a school health care plan. It is an important part of your child's EoE management plan. Your child's health care plan may include accommodations such as:

- Making sure school staff has a list of safe foods for your child
- Modifications to allow your child to be part of school-sponsored field trips and extracurricular activities
- Absences without penalty when related to EoE
- Privacy and confidentiality

Finding Support

Medical and dietary treatment alone may not be enough to help you deal with the stress of managing EoE. It's important that you find additional support and resources. Here are several resources to help you manage EoE:

AAFA community – aafa.org/join

Join our online support community for support for adults with allergic conditions, including EoE, pollen allergy, asthma, and more.

KFA community – kidswithfoodallergies.org/join

Join our online support community for families managing food allergies, EoE, and related conditions. When you join our community, you'll also receive notifications about news, research, food recalls, and educational information to help you manage your child's condition.

Formula/Medical Foods for Food Allergies – kidswithfoodallergies.org/formula

Learn more about different types of formula options available, as well as information on what to do if you can't afford these expensive medical formula foods.

KFA School Zone – kidswithfoodallergies.org/school

Find information, resources, downloadable handouts, and forms to help you work with your child's school to manage their EoE. Our School Zone also includes resources for school staff and teachers.

Safe Eats® Allergy-Friendly Recipes – kidswithfoodallergies.org/recipes

Search our collection of more than 1,500 recipes that can be made free of several of the most common allergens. You can search to meet your dietary needs or browse by category.

Allergy-Friendly Foods – kidswithfoodallergies.org/foods

Search our collection of allergy-friendly foods from several different allergy-friendly food companies. You can search for foods free of your allergens or by type of food.

About the Asthma and Allergy Foundation of America (AAFA)

Founded in 1953, AAFA is the oldest and largest nonprofit patient organization dedicated to saving lives and reducing the burden of disease for people with asthma, allergies, and related conditions through research, education, advocacy, and support. AAFA offers extensive support for individuals and families affected by asthma and allergic diseases, such as food allergies and atopic dermatitis (eczema). Through its online patient support communities, network of local chapters, and affiliated support groups, AAFA empowers patients and their families by providing practical, evidence-based information and community programs and services. AAFA is the only asthma and allergy patient advocacy group that is certified to meet the standards of excellence set by the National Health Council. For more information, visit: aafa.org and kidswithfoodallergies.org

