



EOSINOPHILIC ESOPHAGITIS

A patient's guide to resources and hope



CONNECTING THE EOSINOPHILIC COMMUNITY

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Dear friends,

Eosinophilic esophagitis (EoE) is a chronic, allergic inflammatory disease of the esophagus (the tube connecting the mouth to the stomach). It occurs when a type of white blood cell — the eosinophil — appears in the esophagus in elevated numbers. Eosinophils are not normally found in the esophagus, and they cause injury and inflammation to the tissue. This damage may make eating difficult or uncomfortable, potentially resulting in poor growth, chronic pain, and/or difficulty swallowing. EoE is a chronic and lifelong disease, but with proper ongoing care and treatment those with EoE can manage their condition and lead a normal life.

This kit was developed by the American Partnership for Eosinophilic Disorders (APFED) to help those affected by EoE. APFED is a nonprofit organization that assists and supports patients and families affected by eosinophil-associated disorders, such as EoE, by providing education, creating awareness, supporting research, and promoting advocacy. This kit includes:

- **Getting started checklist.** Navigate a new diagnosis with this checklist to guide you as you learn.
- **FAQs.** Read answers to questions that are commonly asked by patients and caregivers.
- **Glossary.** Learn terms commonly used when discussing EoE.
- **Types of specialists.** Learn about the team of doctors or specialists that you may need to treat EoE.
- **Research progress.** Discover how EoE research is progressing and learn about recent discoveries.
- **Tips and strategies for successful diet management.** Explore practical strategies for diet management.
- **Tips for living well.** Access tried and true tips to help improve your quality of life with EoE.
- **Helpful resources.** Connect with others and tap into a supportive community.
- **Shop.** Spread awareness for eosinophil-associated diseases with items in APFED's Gift Shop.
- **Community fundraising.** Learn how to get involved and support the patient community.

We hope these resources will help you be better prepared to manage your EoE diagnosis. For more information, or for questions or support, please visit apfed.org or contact us at mail@apfed.org.

Sincerely,



Mary Jo Strobel
Executive Director
American Partnership for Eosinophilic Disorders (APFED)

EoE: Getting started checklist



A diagnosis of eosinophilic esophagitis (EoE) is life-changing and can feel overwhelming. Here are some tips to help you get started on your journey.

Educate yourself

- ✓ **Read the information in this kit.** The material inside is designed to help patients, families, and others understand EoE and how to manage it.
- ✓ **Watch educational videos and webinars about EoE.** APFED has an expansive e-library containing recorded interviews with experts answering commonly asked questions about EoE, conference presentations, and recorded webinars. To access this material, visit apfed.org, or visit our YouTube channel at youtube.com/APFED.

Find a doctor

- ✓ **Find the right doctor.** Managing a chronic illness requires a strong doctor-patient relationship. Find a doctor who is knowledgeable about EoE and with whom you are comfortable. APFED offers a list of self-identified practices offering care for patients with a variety of eosinophil-associated diseases at apfed.org/find-a-physician/.
- ✓ **Learn what specialists you might need.** EoE must be diagnosed and monitored by a gastroenterologist. Your gastroenterologist can help you determine which, if any, additional specialists you may need, such as an allergist/immunologist, a registered dietitian, a feeding therapist, or a psychologist who can assist with the emotional dimensions of chronic disease.

✓ **Ask your doctor(s) questions.** Before your next doctor's appointment, write down your questions. Some questions to consider include:

- What types of tests or procedures will be performed? How often will they need to be repeated?
- What treatments do you recommend, and why?
- How will it be determined if treatment is effective?
- Will I need to take (or continue to take) any medications? Are there any special instructions (e.g., dose, frequency, best time of day, how to administer)?
- Will I need to avoid certain foods? If so, what are appropriate substitutions?
- How can I determine that I'm getting adequate nutrition? Will I need supplemental nutrition? Will I need to work with dietitian?
- How will my information be shared/coordinated among the specialists involved in my care? Is a care coordinator available to help facilitate this?
- Will I need special accommodations at work or school?
- What type of research is happening now? Are there any clinical trials I might be eligible for?

Make a treatment plan

✓ **Develop a written plan to follow for diet management and prescriptions.** Make sure to include the dose, frequency, and any special instructions for administering medication(s), along with a list of any foods you might need to avoid.

✓ **Schedule follow-up visits.** Your health care provider may wish to repeat some tests or procedures more frequently than others to help determine if you are benefitting from the treatment plan.

Build a support system

✓ **Find a support group.** While APFED does not have affiliated support groups, we provide a list of self-identified community-led support groups at [apfed.org/find-support](https://www.apfed.org/find-support). Some groups host in-person meetings in their communities; others connect patients and families through social media.

✓ **Join our online support community.** APFED's online community "Eos Connections" on the Inspire Network is found at [apfed.inspire.com](https://www.apfed.inspire.com). Join the EoE board to connect with other patients and caregivers for peer-to-peer support.

EoE: Frequently asked questions



The following are questions frequently asked by patients and caregivers about eosinophilic esophagitis (EoE).

What is EoE?

Eosinophilic esophagitis (EoE) is a chronic, allergic inflammatory disease of the esophagus (the tube connecting the mouth to the stomach). It occurs when a type of white blood cell — the eosinophil — accumulates in the esophagus, causing inflammation and damage to the tissue. This damage may make eating difficult or uncomfortable, potentially resulting in poor growth, chronic pain, and/or difficulty swallowing.

What causes EoE?

While the exact cause of EoE is not yet known, the general belief is that it's typically caused by an immune response to specific foods. Many patients with EoE have other allergic conditions, such as environmental allergies, IgE-antibody mediated food allergies, asthma, and/or eczema.

What are the symptoms?

Symptoms of EoE may vary from one individual to the next and often differ depending on age. Infants and toddlers may refuse their food or exhibit poor growth, malnutrition, or weight loss. School-age children may have recurring abdominal pain, trouble swallowing, and/or vomiting. Adolescents and adults most often have difficult or painful swallowing. Their esophagus may narrow and cause food to become stuck (impaction), causing a medical emergency.

How is EoE diagnosed?

To diagnose EoE, a gastroenterologist will perform an upper endoscopy by inserting a small tube called an endoscope through the mouth. The esophagus, stomach, and the first part of the small intestine are examined for tissue injury and inflammation, and the esophageal wall is examined for thickening. A patient may have EoE even if the esophagus looks normal during endoscopy. Small tissue samples are taken (biopsies) for a pathologist to analyze under a high-powered microscope. If eosinophils are present in the samples, the pathologist will count how many are visible. Increased numbers of eosinophils (usually >15 eosinophils per high powered microscopic field) is highly suggestive of EoE. An endoscopy with the biopsies is the only reliable method of diagnosing EoE at this time, although less invasive diagnostic and monitoring methods are currently under investigation.

What types of treatments exist?

Current treatment options for EoE include swallowed topical corticosteroid therapy (fluticasone or a budesonide mixture/slurry), proton-pump inhibitors (acid suppressors), an elimination diet therapy, or a combination of these therapies. Repeat endoscopies with biopsies are needed to monitor the effectiveness of the treatment plan.

Elimination diet therapy involves removal of suspected or known food triggers. For some patients, elemental nutrition may be recommended as a supplement, or for full nutrition. Elemental diets consist of special amino acid-based formulas that do not elicit an allergic response. If a patient has difficulty drinking sufficient amounts of formula and/or the doctor believes it is necessary for other reasons, there may be the need for placement of a temporary feeding tube (called nasogastric) or a more long term alternative (called a G-tube).

Who has EoE?

EoE is increasingly being diagnosed in children and adults. Based on a 2014 study, it was estimated that there are fewer than 100,000 EoE cases in the US. Males and females of all ages and ethnic backgrounds are diagnosed with EoE, although a higher incidence is seen in males.

What will happen if EoE is left untreated?

Left untreated, EoE may cause scar tissue to form in the esophagus and cause problems with swallowing including food impactions.

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EoE: Glossary



Acid reflux: A condition causing contents from the stomach to come back up into the esophagus; often accompanied by a painful sensation behind the breast bone called "heartburn."

Allergen: A normally harmless substance, such as pollen or foods, that triggers the immune system to overreact in response. In some types of reactions, the body responds immediately and releases a chemical called Immunoglobulin E (IgE). In other reactions, called "cell-mediated," the reaction can be delayed as immune cells in the body errantly attack the substance.

Allergy: An abnormal immune system response to any stimulus, including food, pollen, or insect stings. The classic working definition used by most physicians only includes immediate response allergic reactions (IgE-mediated).

Amino acids: The building blocks of all proteins. Some amino acids also function as chemical signals, such as neurotransmitters that help transmit messages along nerves.

Antibody: A protein produced by the immune system that fights against foreign substances or toxins, called antigens.

Antihistamine: A medication that blocks the action of histamine, a compound released by cells in response to allergic and inflammatory reactions. Histamine subtype 1 blockers (H1 Blockers) are used to treat allergic reactions such as hives, allergic rhinitis, and/or eczema; decrease nausea and dizziness associated with motion sickness or chemotherapy drugs; and help with sleep problems. (Non-sedating antihistamines are relatively new and are used for daytime allergy sufferers.) Histamine subtype 2 blockers (H2 Blockers) reduce acid effects and are prescribed for stomach ulcers, heartburn, and acid reflux.

Atopy: The genetic predisposition to develop allergic diseases including eczema, rhinitis, asthma, and conjunctivitis. This inherited tendency, which runs in families, is associated with hypersensitivity to certain foods, pollen, and other common allergens.

Biopsy: Small tissue samples that are taken from the inner layers of the esophagus, stomach, and small and large intestines during endoscopy and colonoscopy procedures. A pathologist analyzes the samples under a high-powered microscope.

Clinical trial: Research studies performed in people to evaluate effectiveness and safety of medical, surgical, or behavioral interventions. Clinical trials may involve evaluating new medications in people before the Food and Drug Administration has approved the drug. The trials may involve a placebo group (inactive "medicine") to see if the new medication offers an advantage over current treatments. Some trials are "open label," in which all participants receive active medications or experimental treatments.

Corticosteroid (aka "steroid"): A type of medication that is a synthetic version of cortisol or other hormones. When based on cortisol, this type of medication suppresses the immune system and may be used to treat allergies, asthma, eosinophil-associated diseases, autoimmune diseases, some forms of cancer, organ transplant rejection, and other diseases. It also may be prescribed to provide adrenal gland support in cases of adrenal insufficiency.

Dysphagia: Difficulty swallowing liquid or solid food.

Eczema: An inflammatory skin condition that causes redness, scaling, and often itching. May be related to allergies, infection, diabetes, or environmental changes.

Elemental formula: Hypoallergenic, nutritionally complete liquid nutrition. These formulas are made from amino acids, which are the building blocks of protein, and can be consumed by mouth or through feeding tubes. Elemental formulas decrease the symptoms of food allergy, eosinophil-associated gastrointestinal diseases, Inflammatory Bowel Disease, and other conditions.

Elimination diet: A diet in which specific foods are eliminated to decrease the chance of an allergic reaction.

Endoscope: A tube with a light and a camera on the end of it that is used to view the esophagus, stomach, part of the duodenum, the intersection of the small and large intestine, and the entire large intestine. Endoscopes usually contain a biopsy port for the collection of tissue samples during procedures. The procedure in which an endoscope is used is called an endoscopy, esophagogastroduodenoscopy, or EGD.

Eosinophil: A type of white blood cell that is part of our immune system, because they help us fight off certain types of infections. They are produced in the bone marrow and migrate throughout the body. Elevated levels of eosinophils may be found in the blood and/or tissue, often as the result of an allergic response. Many conditions may cause abnormally high levels of eosinophils, including certain parasitic infections.

Eosinophil-associated disease: When a person has elevated numbers of eosinophils in their digestive system, tissues, organs, and/or bloodstream, without a known cause. These diseases are chronic and require long-term management.

Eosinophilia: High numbers of eosinophils in the blood.

Eosinophilic esophagitis (EoE): A chronic, immune/antigen-mediated, esophageal disease characterized clinically by symptoms related to esophageal dysfunction and histologically by eosinophil-predominant inflammation.

Esophageal dilatation: A procedure that dilates, or stretches, a narrowed part of the esophagus (esophageal stricture). This can be done with dilators called bougie dilators or with a balloon.

Esophagus: The muscular tube that connects the back of the mouth to the top of the stomach that carries food from the mouth to the stomach. The upper third of the esophagus is usually referred to as the proximal esophagus, or cervical esophagus. The middle third of the esophagus may be referred to as the thoracic esophagus. The lower third of the esophagus is usually referenced as the distal esophagus.

Fibrosis: The formation of excess fibrous tissue, usually in response to damage or injury.

Food challenge: Exposure to a food with the aim of determining whether it will elicit an immunological, allergic, or clinical response.

Food trial: Relative to EGID, the introduction/reintroduction of a food, typically for a specified period of time and subsequently evaluated via endoscopy, with the aim of determining whether it is considered to be a "food trigger," resulting in clinical symptoms and/or histological abnormalities (e.g., eosinophil-predominant inflammation).

High power field (HPF): A term used to describe the area examined under a microscope.

Histamine: A chemical the body produces in response to an allergic reaction. It also mediates several other biological activities in the body. There are four histamine receptors (H1-4) that are found on cells. Antihistamines, like Benadryl®, block some of the histamine receptors, and may relieve symptoms of the allergic reaction.

Immunoglobulin antibodies: Proteins produced by the body's immune system that attach to foreign substances so the immune system can destroy them. They may attach to bacteria, viruses, fungi, cancer cells, and animal dander. There are five major types of antibodies. IgA antibodies are found on mucosal surfaces such as the GI tract, airway, nose, mouth, and in body fluids such as tears and saliva. IgE is the allergy antibody. IgG, IgM, and IgD are the other immunoglobulin types. See also *antibody*.

Inflammation: Swelling of a tissue. It is part of the body's response to tissue injury, irritation, or damage. Inflammation can occur anywhere in the body and from many different causes.

Narrowing: Narrowing of a tubular or hollow structure in the body, such as the esophagus.

Protein: Amino acid containing molecules encoded by genes. A nutritional component required by the body to sustain life. Protein is made up of amino acids that have been connected in a variety of configurations depending on the type of protein. Whole food proteins are believed to play a role in eosinophilic esophagitis. See also *amino acid*.

Stricture: An abnormal area of narrowing in the digestive system; may occur in areas such as the esophagus or colon.

Tube feeding: Any form of feeding of liquid nutrition through a tube, such as a gastrostomy tube (GT).

This list of definitions was compiled and edited by APFED in cooperation with members of its Medical Advisory Panel.

For more definitions of terms about eosinophil-associated diseases, visit apfed.org/glossary/.

EoE: Types of specialists



People with eosinophilic esophagitis (EoE) may have more than one doctor or specialist involved with their care. These specialists may include:

Allergist

Specializes in the diagnosis and treatment of allergic disorders, including asthma, allergic skin rashes, allergic rhinitis, and food allergies.

Gastroenterologist

Specializes in diagnosis and treatment of disorders of the digestive system, including the liver and pancreas.

Immunologist

Specializes in the diagnosis and treatment of diseases involving the immune system. Some immunologists are also called environmental medicine specialists.

Occupational Therapist (OT)

Specializes in interventions to help patients develop, recover, or maintain meaningful activities, despite physical or health challenges. In children with EoE, an OT may recommend feeding therapy to address oral motor function and sensory issues related to food.

Psychologist

Specializes in wellness and provides strategies to cope with anxiety, depression, and other mental health issues related to chronic health conditions.

Registered dietitian (RD)

Specializes in organizing food and nutrition plans and can help provide strategies for identifying allowed foods, recognizing hidden ingredients, and determining appropriate food substitutes to maintain a balanced diet.

Often time, “registered dietitian” and “nutritionist” are terms that are used interchangeably, however, while both professions are related, education, credentialing, and licensing may differ between the two. All RDs are nutritionists, but not all nutritionists are RDs.

EoE: Research progress



Eosinophilic esophagitis (EoE) was first identified as a disorder in medical literature in 1995. Prior to that, scientific literature contained only rare, individual reports. Since then, research into EoE has greatly expanded, vastly improving our understanding of the condition and how to diagnose and manage it. Today, professional consensus guidelines are available to give the medical community a roadmap to direct a patient's diagnosis and treatment. Because EoE research is advancing at a rapid rate, the progress described below is a snapshot of current progress and should not be considered exhaustive.

Recent, pivotal findings

- Several pathways that regulate allergic responses have been identified, and a number of genes that play a role in EoE have been discovered. One such gene — known as calpain14 (CAPN14) — was found expressed primarily in the esophagus and has a strong association with EoE. These pathways may provide new directions to diagnose, monitor, and treat EoE in the future.
- Scientists identified three distinct subtypes of EoE, each having different clinical features and molecular pathways. There are specific genes associated with each of these subsets, and researchers are working to better understand these to guide development of targeted, personalized therapies.
- In the July 2018 issue of *Gastroenterology*, a consensus group of multi-disciplinary clinicians and researchers from 14 countries updated existing medical guidance and removed the requirement that patients try a proton pump inhibitor (PPI) before a diagnosis of EoE was made.

Ongoing areas of research

- **Genetic and environmental factors.** Studies have shown that close relatives, such as siblings of those with EoE, are at higher risk of developing the condition, suggesting that genetic factors play a role. On the other hand, studies of twins and of population databases have suggested that environmental factors play a strong role. More research is needed to help us better understand if EoE is more strongly driven by genetic factors or by environmental factors.
- **Gene identification.** Researchers are actively expanding upon knowledge of the genes that control EoE. Basic and clinical research to identify the genes and their role in EoE is an ongoing area of research.

- **Natural history.** Science is continuing to expand our knowledge on the natural history of EoE and the long-term consequences of this disease. If you receive a diagnosis relatively quickly, there is a lower prevalence of strictures or food impaction.
- **Improved diagnostics/monitoring.** Scientists are looking to develop novel and less invasive ways to diagnose EoE and monitor EoE activity. Examples of work in this area include identification of biomarkers in blood or feces, advanced technologies such as a transnasal endoscope, special imaging methods, and EndoFLIP, which is a new technology designed to help measure the flexibility or stretch of the esophagus.
- **Therapeutic options.** At this time, while there are effective medical therapies for EoE, none have been approved by the FDA. Primary management includes dietary therapy and corticosteroids used “off-label,” meaning these drugs were developed to treat other conditions but have not been indicated for use in EoE. Researchers are studying the efficacy of less restrictive diets and trials studying novel methods to administer budesonide, including an effervescent oral tablet and a viscous suspension. More information about clinical trials and investigational therapies can be found on the “Investigational therapies” page of this kit.

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Investigational therapies

Improved treatment options for EoE are an area of ongoing study.

Existing pharmaceuticals that were assessed for treatment of EoE and determined to be ineffective or limited by side effects include systemic corticosteroids, leukotriene antagonists, mast cell stabilizers, immunomodulators, and biologics such as anti-IgE and infliximab.

Recent research has identified a number of investigational drugs that may treat EoE. Currently, clinical trials are exploring the efficacy and safety of these potential new treatments, and investigators are working to understand how EoE develops, improve diagnosis and monitoring methods, and strengthen treatment protocols.

As of press-time, research efforts included studies to determine efficacy of less restrictive diets, and two Phase 3 clinical trials were studying novel steroids: a budesonide effervescent oral tablet and a budesonide viscous suspension. Other therapeutic targets include:

- **IgE (immunoglobulin E)** binds to mast cells and basophils and triggers a release of mediators when it is cross-linked with an allergen.
- **IL-5 (interleukin 5)** promotes eosinophil maturation, growth, and recruitment from the bone marrow to the blood stream. Studies to date include mepolizumab and reslizumab, both which showed moderate reduction of eosinophil infiltration of the esophagus, but without significant reduction in symptoms. These two therapies were recently approved for treatment of eosinophilic asthma. Another IL-5 therapy that works on the IL-5 receptor alpha, benralizumab, destroys eosinophils. As of press time, study results were not yet published.
- **IL-4 (Interleukin 4)** plays a major role as T helper (TH) cells turn into TH2 cells, which drive most allergic responses. It also stimulates epithelial cell expression. Dupilumab is a therapy targeting the IL-4 receptor alpha chain and study results indicate it can be effective in improving dysphagia. Preliminary study results also indicate that this medication can be effective in patients who don't respond to steroids. It is currently being studied in multi-center, randomized trials in adults.
- **IL-13 (Interleukin 13)** plays a role in the decrease of esophageal barrier function and can affect esophageal remodeling. A randomized trial in adults with EoE using RPC4046, a therapy that targets IL-13, showed significant improvement in endoscopic features of the esophagus and improvement of dysphagia. This potential therapy continues to be an area of research.
- **TSLP (thymic stromal lymphopoietin)** plays a role in setting off eosinophilic response. When the action of TSLP was blocked in a mouse model, it prevented eosinophilic inflammation and food impaction. Tezepelumab is an anti-TSLP monoclonal antibody which has been shown to reduce asthmatic responses in humans. It is unclear if this therapy may be helpful for patients with EoE, and more research is needed.

- **Eotaxins** are produced by epithelial cells, and may also be activated by eosinophils, mast cells, and fibroblasts. Eotaxin aids in the recruitment and migration of eosinophils. Researchers have found that mice without an eotaxin receptor are protected from developing EoE. This is a potential future target for an EoE therapy in humans.
- **CRTH2 molecules (chemoattractant receptor-homologous molecule 2)** are receptors that play a role in cell chemotaxis and activation. In an 8-week trial of adults with an oral CRTH2 antagonist, researchers noted reduced density of esophageal eosinophilia. However, it did not improve symptoms nor endoscopic features when compared to placebo.
- **TGFB-1 (transforming Growth FactorB-1)** plays a critical role in fibrosis and it alters the epithelial barrier function. Targeting TGFB-1 may be useful for patients who have persistent symptoms and fibrosis. One study underway is a multi-center trial of losartan (angiotensin receptor blocker), which was shown to inhibit the effects of TGFB-1 in experimental models.

Clinical trials

Clinical trials for EoE are now enrolling! Learn more about clinical trials at clinicaltrials.gov and apfed.org/clinical-trials.

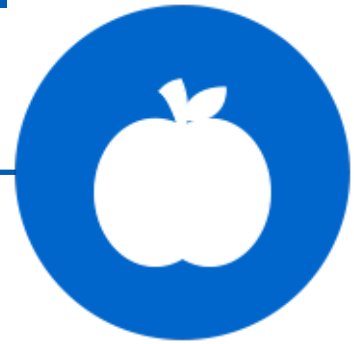
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EoE: Tips and strategies for successful diet management



Dietary restrictions or elimination diets are common for families managing eosinophilic esophagitis (EoE) and cooking with limited ingredients can be a challenge. These tips and practical strategies will help those who are new to elimination diets.

Be aware of what foods to avoid. Keep a list of the foods that you or your child cannot eat. Carry it with you to navigate food choices as you learn your new diet. Ask questions when eating foods prepared by others. Remember: when in doubt, do without!

Focus on what you can eat. Embrace the opportunity to expand your palate and discover new foods. Look for unprocessed or natural foods to add to your diet. In time, it will become easier to put meals together.

Read ingredient labels thoroughly. Read ingredient labels carefully. Ask your doctor about avoiding packaged foods that include advisory statements (e.g., “may contain”) for ingredients that you are avoiding. Check labels every time you purchase a food to ensure ingredients have not changed.

Plan meals in advance. Take time to create a menu for the week. Prepare meals in advance if you are able, so that if you are rushed or don’t have time to cook during the week, you will have something ready-made.

Allow extra time at the grocery store. Shopping may take longer than normal. Plan your trips to the store accordingly and know it will get easier with time.

Learn new recipes. There is a wealth of recipes available to help those with dietary restrictions. APFED has a number of recipes online at apfed.org/recipes, and several other websites offer food allergy-friendly recipes, too. Many specialty cookbooks are also available. One such cookbook, “*The Elimination Diet Cookbook*,” may be ordered through APFED’s website at apfed.org/shop.

Learn how to cook with substitutions. Many recipes can be successfully adapted with a few substitutions, even for commonly used ingredients, such as wheat, milk, or eggs. Most allergy-conscious cookbooks or websites include substitution ideas, depending on the dish.

Know where to find specialty ingredients. Preparing food for someone with a restricted diet often calls for specialty or hard-to-find ingredients. If you can't find an item at a local grocery store, ask the manager about ordering it. Otherwise, there are a number of online specialty food companies that offer an array of unique ingredients and products.

Be creative by modifying existing recipes. Once you get the hang of preparing food using ingredient substitutions, you will find that many recipes can be successfully adapted with a few modifications. Substitution lists can be found on apfed.org, or on websites that focus on allergy-friendly cooking.

Consult with a registered dietitian (RD). A registered dietitian can help you navigate your new diet and ensure your nutrient and caloric intake is adequate. An RD can also help you to identify safe foods and teach you how to make appropriate substitutes. Ask your health care provider for a recommendation for a local dietitian who is knowledgeable about elimination diets. If you do not have access to a local dietitian, telehealth services (web-based consultation) may be an option.

Choose restaurants wisely. When you must eat food prepared by someone else, such as in a restaurant, explain your dietary restrictions and seek the manager's help. Some restaurants have menus and allergy information online. Look for simply-prepared foods that contain few ingredients.

Plan for social situations. For parties or social gatherings that involve food, consider eating at home prior so that you aren't tempted to eat something that you shouldn't have. Alternately, offer to bring a dish or two so that you know you will have something safe for you and/or your child to eat.

Focus on non-food activities. Remember to stay positive and be healthy. A positive attitude goes a long way to successful diet management of EoE. Focusing on non-food activities can help.

Involve your child. If you are teaching a child a new diet, involve them in the process. Explain that some foods may be making him or her sick. Teach them the names of the foods that they are avoiding and what they look like. Let them know that they should only eat foods given to them by adults you trust. Involve them in label reading and give them a sense of control by offering choices ("You may eat this or this. Which would you like?" or "Would you like your formula in the red cup or the blue cup?")

EoE: Tips for living well



If you or someone you love is diagnosed with eosinophilic esophagitis (EoE) it is important to:

Stay informed. Subscribe to APFED's e-newsletter at apfed.org for regular updates, news, and events of interest to the eosinophilic patient community.

Connect with others. Connecting with the EoE patient community for emotional support and guidance is invaluable. For a calendar of local and national events, visit apfed.org. Stay connected 24/7 with other EoE patients on APFED's online community "Eos Connections" on the Inspire Network at apfed.inspire.com, and on our Facebook page at facebook.com/apfed.

Take care of yourself. Follow your treatment plan and your doctor's recommendations. Keep your prescriptions filled and schedule (and stick with!) your follow-up appointments.

Focus on what you can control. Feeling sad, anxious, or even angry about a disease is okay. In fact, it's normal. Rather than letting these feelings overwhelm you, acknowledging and expressing them can help give you a sense of control. Seek professional counseling if you need help coping with a chronic illness.

Know your rights in the workplace and school. Become familiar with your legal protections at work or your child's rights at school:

- **Family and Medical Leave Act** allows employees to take up to 12 weeks of unpaid leave each year for medical or family emergencies. This applies to employers that have 50 or more employees. Learn more at dol.gov/whd/fmla/.
- **Americans With Disabilities Act of 1990 (ADA)** was amended in 2008 to expand the rights of disabled individuals. ADA requires employers to make reasonable accommodations for disabled workers who meet their definition of "disabled." This may include additional time off or modified work schedules. As amended, ADA applies to employers that have 15 or more employees. Learn more at ada.gov/ada_intro.htm.
- **Section 504 of the Rehabilitation Act of 1973** prohibits discrimination against people with disabilities in programs that receive federal funding. It creates the framework to ensure children receive reasonable accommodations at school, such as time to make up missed work and absences without penalty when related to their disorder. Every school-age child, whether meeting the definition of disabled or not, is legally entitled to a free, appropriate, and meaningful education. For more information, visit the website for the Office for Civil Rights at <https://www2.ed.gov/about/offices/list/ocr/504faq.html>.
- APFED offers a school advocacy toolkit that includes information and templates for 504 planning at apfed.org/advocacy/school-advocacy.

Share your story. Everyone whose life has been touched by an eosinophil-associated disease has a story to share, and we can all learn from one another! In our newsletter, on our social media pages and on our website, APFED highlights perspectives from patients and family members who live with EoE and other eosinophilic disorders. We'd love to hear from you, too! Send your story to mail@apfed.org.

Join us. Become a member of APFED to help support our work. For more information about membership benefits or to make a donation to APFED, visit apfed.org.

Elemental diet tips

If your doctor has prescribed elemental formula either for partial or full nutrition, the following strategies will help you incorporate formula into your lifestyle.

- **Plan ahead.** If you will be away from home for an extended period, bring enough formula to ensure easy access. Elemental formulas are available as powders that you mix into water and in premixed, single-serve packages. If your formula is powdered, you may either prepare it and bring it with you in a small cooler or pre-measure the amount of powdered formula you will need and pack it into a small container to mix later. Consider storing extra formula in places that you may frequent, such as school, work, or friends' houses.
- **Keep an eye on your supply.** Pay attention to how much formula you have on hand so that you can reorder more before you run out.
- **Shake it up.** Change the texture of formula by adding ice and pulsing for a few seconds in a blender to create a shake. You may drink it right away or freeze it for a few hours to make a frozen treat.
- **Ask your doctor what foods or ingredients may be allowed.** Some ingredients may be permitted on an elemental diet, such as pure cane sugar and candies made with pure sugar, and artificial flavorings and sweeteners. Ask your health care provider for a list of acceptable additives.
- **Experiment with flavors.** Many formulas are available in different flavors, such as chocolate, vanilla, or fruit flavors, but you may also add allowed ingredients (e.g., juices, extracts). Formula manufacturers may offer recipes to help you create flavor and texture variety with their product. Check their websites for more information.
- **Increase a child's acceptance** of formula with praise and positive reinforcement, fun glasses or containers with lids, and colorful straws. Stick with a feeding routine so that the child knows what to expect.

EoE: Helpful resources



Check out these resources for those affected by eosinophilic esophagitis (EoE).

Online support



Eos Connections: APFED's online support community on the Inspire Network provides a forum for patients, caregivers, and family members to connect with others for support and to share information. Join the conversation today at apfed.inspire.com.



Facebook: Follow APFED on Facebook at facebook.com/APFED.

You may also wish to follow the Facebook page for National Eosinophil Awareness Week (3rd week of May) at facebook.com/NationalEosinophilAwarenessWeek.

Support groups



Support group directory: As a courtesy, APFED provides a list of eosinophilic support groups that are volunteer-led (APFED does not have affiliated support groups). Groups provide emotional and educational support and information about local programs, services, and events for families and individuals with eosinophil-associated diseases. Find a support group at apfed.org/support-groups.



Support group development assistance: APFED offers resources to help patients and caregivers start their own support groups. We publish an e-newsletter for support group leaders to highlight similar efforts across the U.S., provide ideas to make the most of meetings, and share news of interest with community members. For more information, contact mail@apfed.org.

Videos



Watch educational videos and webinars about EoE on APFED's YouTube channel at youtube.com/user/APFED and website at apfed.org/videos-and-webinars.

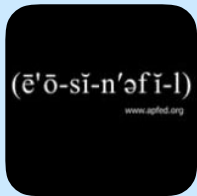
Additional information

In addition to the American Partnership for Eosinophilic Disorders (APFED), the following non-commercial organizations/websites also have resources available about EoE, rare diseases, and/or special diets.

- American Academy of Allergy Asthma and Immunology
aaaai.org/conditions-and-treatments/related-conditions/eosinophilic-esophagitis
- American Autoimmune Related Diseases Association, Inc.
aarda.org/diseaseinfo/eosinophilic-esophagitis-eoe/
- American College of Allergy, Asthma & Immunology
acaai.org/allergies/types/food-allergies/types-food-allergy/eosinophilic-esophagitis
- American College of Gastroenterology
patients.gi.org/topics/eosinophilic-esophagitis/
- American Gastroenterological Association
gastro.org
- Asthma and Allergy Foundation of America | Kids with Food Allergies
aafa.org | kidswithfoodallergies.org
- Children's Digestive Health and Nutrition Foundation
cfhnf.org
- Consortium of Eosinophilic Gastrointestinal Disease Researchers (CEIGR)
rdcrn.org/cegir
- Food Allergy & Anaphylaxis Connection Team
foodallergyawareness.org
- Food Allergy Research & Education
foodallergy.org
- Genetic and Rare Diseases (GARD) Information Center | National Institute of Health (NIH)
rarediseases.info.nih.gov/diseases/9142/eosinophilic-enteropathy
- GI Kids | North American Society for Pediatric Gastroenterology, Hepatology and Nutrition
gikids.org/content/5/en/eosinophilic-esophagitis
- Global Genes
globalgenes.org
- International Eosinophil Society
eosinophil-society.org
- National Organization for Rare Disorders
rarediseases.org/rare-diseases/eosinophilic-esophagitis/
- North American Society of Pediatric Gastroenterology and Nutrition
naspghan.org

SHOP APFED

Shop for eosinophil-associated items and resources at apfed.org/shop.



Eosinophil gear

Spark conversations and raise awareness with the phonetic spelling of eosinophil on your phone, a t-shirt, or a bracelet



Find your way t-shirts

Raise awareness for how APFED helps patients and families navigate their eosinophil journey with our t-shirts



Awareness pins

Spread awareness for eosinophil-associated diseases by wearing our Eosinophil Awareness pins



Educational materials

Inform people about eosinophil-associated disorders



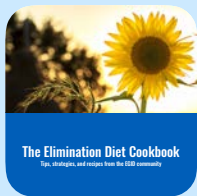
Support hope cooler

Make eating on the go easier with our fully insulated cooler



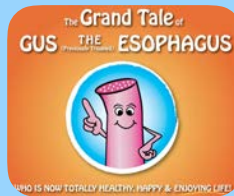
Notecards

Spread hope, thanks, and holiday cheer with our collection of notecards



Elimination Diet Cookbook

Learn tips, strategies, and recipes for managing an elimination diet



Children's books

Help children learn through reading books with lively illustrations



Living Well book

Learn about EGID, and get coping tips and ideas for school and work

COMMUNITY FUNDRAISING

Fundraising can be a fun and rewarding way to support APFED and make a difference for those living with eosinophil-associated disorders! Every dollar makes a difference.



TURN YOUR PASSION INTO ACTION

Do you play a sport? Love to scrapbook? Enjoy card games? Turn your passion into action by coordinating a fundraising event to support research, education, and awareness of eosinophil-associated diseases.

In addition to providing critical support to APFED, these events also raise disease awareness in local communities. Best of all, you may choose specific APFED programs and services that you would like to support or direct proceeds to a general fund.

APFED will work with you to make your event a success! Check out some of the community fundraisers that volunteers have organized:

- Golf tournament
- APFED Hope on the Horizon Walk for EOS
- Office donation collection (donate lunch or coffee break money)
- 10% community day at a local business
- Home-based retail party proceeds donation
- Social media campaign to ask friends and family to support APFED

Visit apfed.org/fundraise to explore ideas and learn how APFED puts your donations to work. APFED can help by providing flyers, donation request letters, and press releases, as well as letting other community members know about your event.

Apfed

American Partnership
for Eosinophilic Disorders

Connecting the Eosinophilic Community

For more information about fundraising, please visit apfed.org/fundraise or email fundraise@apfed.org.



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apfed.org

This kit is made possible thanks to our partnership with

