Eosinophilic Disorders Explained



Quick glance

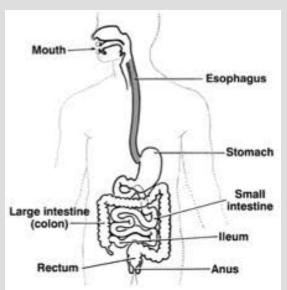
- Eosinophilic gastrointestinal disorders (EGIDs) are relatively new but their incidence is rising.
- EGIDs have no cure, but treatment is available.
- Generally children are diagnosed; however, the adult incidence is on the rise.
- Males are more commonly affected than females.
- Eosinophilic oEsophagitis (EoE) is the most common EGID.
- EGIDs can be painful, and difficult to diagnose.
- Ongoing management is required.
- ausEE provides free information and support for those affected.



What is an oesophagus and what does it do?

- The oesophagus* is the organ that connects the mouth to the stomach.
- It is the way we get our food from our mouths to our stomachs.
- Think of it as a 'transporter of food'.





*In North America the spelling is 'esophagus'.



What is an eosinophil?

- An eosinophil is a type of white blood cell that helps the body fight off certain infections and parasites.
- Normally eosinophils do good things.





Eosinophils in the oesophagus

- Sometimes the eosinophils think that food* is a foreign invader (like a parasite) and they attack!
- This can make you and your oesophagus feel very sick.
- It can cause inflammation, irritation, nausea, food impactions, vomiting, stomach pains and a general feeling of being unwell.
- Sometimes it can make you not want to eat anything at all.

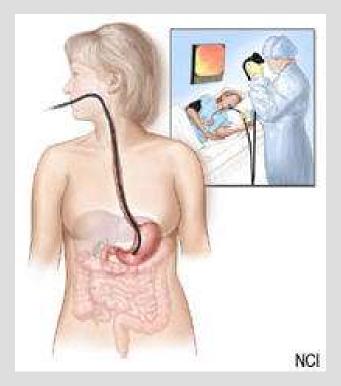


*EoE can also be triggered by aero-allergens such as grass, dust or pollen.



How do I know if I have EoE?

• The only way to check whether eosinophils are present in the oesophagus is to perform an endoscopy and take multiple biopsies of the oesophagus.



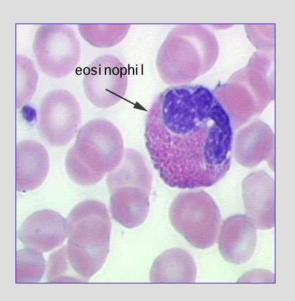
- o An endoscopy is when a gastroenterologist places a narrow tube with a camera down the patient's oesophagus. A biopsy is when a very small sample of tissue is taken.
- The gastroenterologist will note how the oesophagus looks, as there may be furrowing (lines or ridges from damage).
- Most of the time, an endoscopy is performed as day surgery. The invasiveness of an endoscopy is especially challenging for children.



The diagnosis

• Once the biopsies are taken, a pathologist reviews them under a microscope to see whether there are any eosinophils. Generally, if more than 15 per highpower field are found, active EoE is diagnosed.







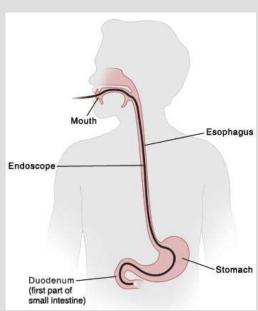
Eosinophilic gastrointestinal disorders (EGIDs)

- Although EoE is the most diagnosed EGID, other parts of the body can also be affected:
 - Eosinophilic gastritis: high numbers of eosinophils in the stomach
 - Eosinophilic duodenitis: high numbers of eosinophils in the duodenum
 - Eosinophilic enteritis: high numbers of eosinophils in the small intestine
 - Eosinophilic colitis: high numbers of eosinophils in the large intestine
 - Eosinophilic gastroenteritis: affects the stomach and small intestine.



PPI-REE diagnosis

- Proton-pump inhibitor-responsive oesophageal eosinophilia (PPI-REE or PPI-ROE) is a newly recognized entity that must be differentiated from EoE.
- PPI-REE refers to patients with esophageal eosinophilia on biopsy who respond to a course of PPI therapy.





I've been diagnosed with an EGID. What now?

- Being diagnosed can be the end of a very long journey and the beginning of a new one.
- It is very important that you work with your gastroenterologist, allergist and/or dietitian to find the best treatment plan for you or your child.

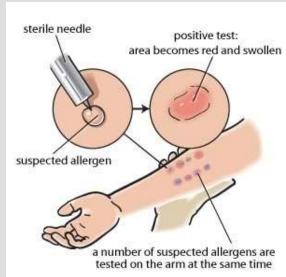


- No two cases are the same and there may be a time of trial and error before you find what works best for you or your child to relieve symptoms.
- There will probably be some tests to determine if there is an allergic component.
- Once a treatment plan is in place, ongoing review is essential.
- It is just as important to receive adequate support through groups such as ausEE and your family and friends.

Allergy Testing

 Some physicians may decide to send you or your child to an allergist.

- They may perform tests such as:
 - Skin Prick Testing (SPT)
 - Atopy patch testing
 - RAST blood testing
- These tests may indicate if there is an immediate or delayed allergy.
- In EGID patients it is not uncommon for allergy test results to be negative.

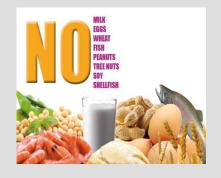


Skin Prick Testing



What are some common treatment plans?

- An elimination diet* is one treatment:
 - This may mean excluding the eight most allergenic foods, which are dairy, eggs, wheat, fish, peanuts, tree nuts, soy and shellfish.
 - Some treatment plans may eliminate less, some more. Each case is unique.
 - o If you are not eating enough or not receiving enough nutrition from your food, you may be placed on an elemental formula. This is a safe and effective way to maintain nutrition in those who have difficulty tolerating many foods.
 - o If a patient cannot tolerate any foods, an elemental diet may be required, which means eliminating all foods except for an elemental formula.





*It is very important that you work with a qualified dietitian before beginning any kind of elimination diet.



Other treatment options

- Some patients may be prescribed a corticosteroid medication. These are either sprays that are swallowed, or a liquid preparation typically mixed with an artificial sweetener to make a slurry that is swallowed.
 - Swallowing the medication 'coats' the oesophagus to help reduce the eosinophil count.
 - Unfortunately, this treatment does not work for everyone.
- Other drugs (such as reflux medication) may also be prescribed.



Nutrition and tube feeding

- It is crucial to have a qualified nutritionist or dietitian to monitor adequate nutrition levels.
- If those levels are not met, tube feeding, also called enteral nutrition, may be necessary. This is where food in liquid form is given through a tube into the stomach or small intestine.
- The most common tubes are:
 - a nasogastric tube (NG), which is put up the nose and down into the stomach
 - o a **gastrostomy**, sometimes called a PEG (percutaneous endoscopic gastrostomy), which is placed in the stomach during a surgical procedure. Some PEGs have a tube always hanging out and some replacement PEGs are flat ('profile' or 'buttons').





Living with an EGID

- It is important to remember that no two cases are the same. Each case will be treated differently.
- EGIDs are generally not life threatening; rather, they are life limiting and can create social challenges.
- This can affect many aspects of a family's life, so it is important to get support or give support where you can.
- Ongoing review with your medical team is important.





Online Support is Available

- We offer an online Facebook support forum that you can join here: www.facebook.com/groups/ausee
- We also have a group specifically for Adults diagnosed with an EGID and it can be joined at: www.facebook.com/groups/auseeadults
- The Official ausEE Group on Livewire can be joined by anyone aged between 10 to 20 who is living with an EGID: www.livewire.org.au





a charity dedicated to improving lives affected by eosinophilic disorders

To find out more, please visit our website at www.ausee.org



ausEE Inc. ABN 30 563 569 016 Australia ©2016 The information provided in this publication is for general information and support purposes only and is not intended as a substitute for professional medical advice from your doctor or other health care professional.