Eosinophilic diseases of the digestive system

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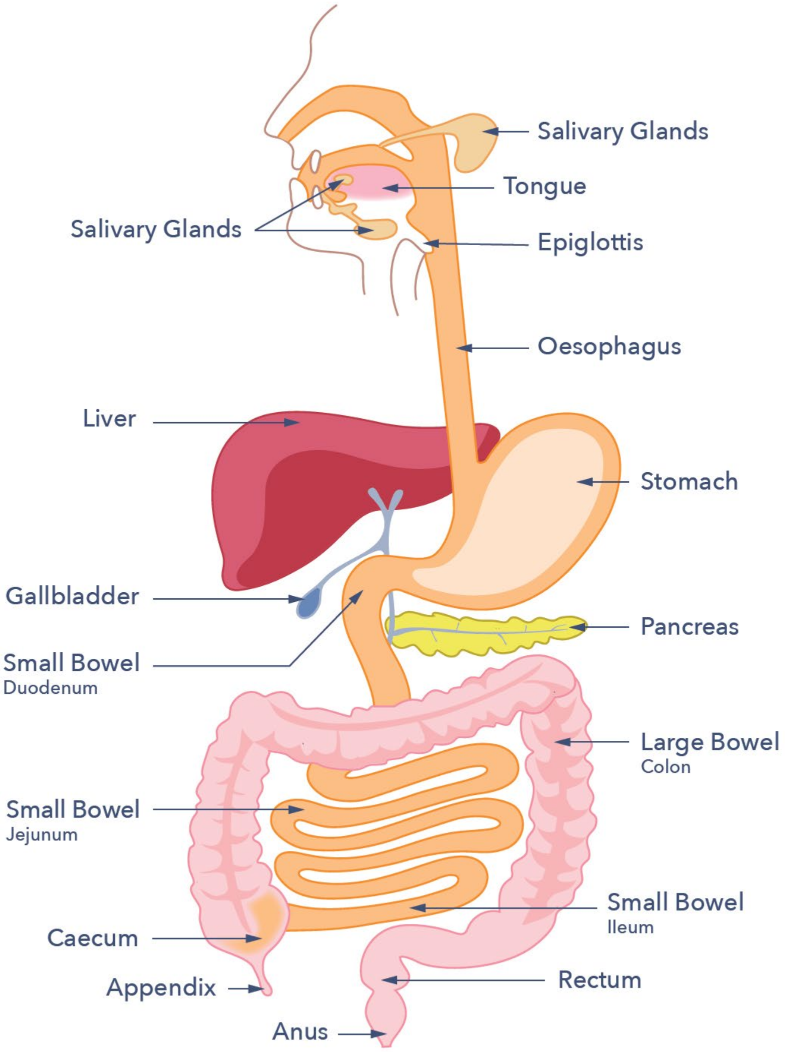
THE DIGESTIVE SYSTEM



OVERVIEW

This factsheet is about eosinophilic diseases.

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Eosinophilic Diseases (pronounced ee-oh-sin-oh-fil-ik) affect the gut. In eosinophilic disease, a type of white blood cell, known as an eosinophil, is present in the gut in higher amounts than expected. Eosinophilic disease has several types. They are classified by where the eosinophils are found.

Eosinophilic disease can be divided into two types:

1. Eosinophilic oesophagitis. This is also referred to as EoE (esophagitis - American spelling): which affects the oesophagus (food pipe or gullet).

2. Eosinophilic gastrointestinal disease (also referred to as EGID) can affect the stomach, small bowel or larger bowel or a combination of all.

There are other eosinophilic diseases that affect other areas of the body for example the blood and joints. These diseases are not associated with eosinophilic diseases of the gut.

What are eosinophils?

Eosinophils are a type of white blood cell (WBC). White blood cells are a part of our immune system that fights infection.

Eosinophils evolved in our immune system to fight parasites, allergens, harmful bacteria and other outside organisms. They release proteins. The proteins destroy the threat and remove harmful substances. It is normal for everyone to have eosinophils. Higher levels are found in people with atopy. Atopy includes allergies, asthma, and eczema. In eosinophilic disease, eosinophils are more numerous in the oesophagus or gut.

It is a rare condition. The estimated number of people living with EoE is 34 per 100,000 people. That's almost 1 in 3,000. But data suggests more cases are diagnosed each year. It is likely due to new guidelines and methods to diagnose it. EGID is thought to affect about 1 in 100,000 people. Exact numbers are hard to get due to a lack of knowledge among professionals. Only recently was there a global consensus on how to diagnose it and interpret its symptoms.

Unfortunately, it can take a long time to diagnose eosinophilic diseases. Many people are initially misdiagnosed. Due to the rarity of this condition, finding an expert can be difficult.

EOSINOPHILIC OESOPHAGITIS

Eosinophilic oesophagitis is the most common eosinophilic gut disorder. Eosinophils are normally absent from the oesophagus. In EoE, they are there and cause inflammation and disrupt swallowing.

WHAT ARE THE SYMPTOMS OF EOSINOPHILIC OESOPHAGITIS?

Symptoms can vary by person and age. They are often "non-specific," which delays diagnosis.

Symptoms are usually related to difficulty swallowing (dysphagia). This might feel like the food is moving slowly or sticking in the chest. It can happen on and off, but sometimes with every swallow. Food sticking can feel mild but can also be severe and very distressing. It can occur without pain or with significant pain.

Children may struggle to get enough nutrition. This can impact their growth. Children may also suffer "reflux" symptoms, like vomiting, regurgitation, or tummy and chest pain. Regurgitation is when food comes back up the food pipe. It is non-forceful. Sometimes people describe this symptom as “being sick in their mouth”. Symptoms can be uncomfortable. So, children may become fussy with food. They may prefer easier-to-swallow or "safe" options.

In older children, adolescents, and adults, food can occasionally stick severely. This doesn't allow any food or swallowed material to pass down the gullet. This is called a “food bolus obstruction” or FBO. If this occurs, urgent medical attention is needed.

Those with delayed diagnosis of EoE often develop coping strategies. For example:

- Excessive chewing and slow eating, being last to finish a meal.
- They avoid meat and bread. They prefer softer and/or wetter foods.
- Drinking a lot during meals.

EoE symptoms can become severe. They may stop people with EoE from eating socially, causing anxiety. This is especially true when eating out.

WHAT IS THE CAUSE OF EOSINOPHILIC OESOPHAGITIS?

The cause of EoE is not yet completely understood. But it is understood to be a delayed allergic condition. It can be triggered by eating certain foods. Most commonly (but not exclusively):

- Milk
- Wheat
- Nuts
- Soya
- Fish/shellfish
- Eggs

It may also be triggered by breathing in allergens, such as pollen.

However, it is important not to remove any of these foods before speaking with your gastroenterologist and having investigations.

HOW IS EOSINOPHILIC OESOPHAGITIS DIAGNOSED?

If you have EoE symptoms, you need a referral to a gastroenterologist. They specialise in digestion and gut problems. They are the only ones who can diagnose you. They will use an endoscope, a flexible tube with a camera, to look at the food pipe and take biopsies. Biopsies are small tissue samples taken from the wall of the food pipe. To ensure an accurate diagnosis, it is standard to take six biopsies in one endoscopy. They will be taken from the top, middle, and bottom of the food pipe.

Usually, the oesophagus has few or no eosinophils in biopsy samples. In patients with EoE, there are higher levels. The diagnosis can be made by counting the number of eosinophils. If the count is more than 15 per 0.3 mm^2 (previously called "high power field"), EoE is confirmed.

Unfortunately, there are no non-invasive tests to diagnose EoE in the UK. So, blood tests and x-rays are not helpful. Symptoms alone cannot diagnose this condition. The only test is the camera test.

Allergy testing does not help to either diagnose the cause or help with identifying the triggers. This is because eosinophilic disease affects a different part of the immune system.

WHAT ARE THE TREATMENT OPTIONS FOR EOSINOPHILIC OESOPHAGITIS?

EoE is a chronic (long term) disorder that can wax and wane. There is no known cure. But there are options to treat the inflammation and manage symptoms. Your gastroenterologist will discuss options with you. They include medical or dietary management. In severe cases, for example a food bolus obstruction, endoscopic dilatation may be needed. See page 8 for more details.

All treatments for all conditions have pros and cons. They also have a varying chance of success. Some will respond to one treatment. Others will need a mix of treatments to manage their EoE.

Dietary treatment

Always work with a dietitian who has expertise in EoE if you choose dietary management.

Dietary treatment involves removing suspected trigger foods. They may be causing the inflammation. As stated above, the most common triggers for EoE are milk, egg, wheat, soya, fish, and nuts. However, it does not mean you should avoid all six foods.

Experts recommend using a "step up" approach This involves removing the minimum number of foods. Then the repeating a camera test and biopsies after around 8 – 12 weeks to see if the eosinophil count has improved. If the EoE remains active, more foods would be removed. A repeat camera test would be done in 8-12 weeks. You may need multiple endoscopies to figure out the trigger food / foods or until the EoE is controlled. Then, the dietitian can make a long-term plan.

The usual "step up" approach for dietary treatment of EoE is as follows:

1. Milk/dairy (1 food exclusion diet)

2. Milk/dairy + wheat or egg (2 food exclusion diet)

3. Milk, egg, wheat and soya free – MEWS free (4 food exclusion diet)

4. Milk, egg, wheat, soya, fish/shellfish and nut free (6 food exclusion diet)

This approach removes the most common problem foods first. So, it will mean fewer endoscopy procedures for most people than removing all 6 at once. Always work with a dietitian who has expertise in EoE if you choose dietary management. Removing foods without expert help can lead to malnutrition.

Elemental formula diet (liquid diet)

The elemental formula diet has limited use in EoE. It is only for when all other treatments have failed. If an elemental diet is required, you will not be able to eat any food for the whole time. This can be tricky to do due to the taste of the diet and the impacts on the social aspects of eating. It can also have significant healthcare costs.

If this treatment is needed, it may be hard to take enough formula to meet nutritional needs. Therefore, some patients may require a naso-gastric tube. This is a tube passed down the nose, through the throat, and into the stomach.

Topical steroids (budesonide or fluticasone)

Topical steroids are a localised treatment. They are not absorbed in other parts of the body. You can think of them like a steroid cream for eczema, that only work on that specific area. These medications are a treatment rather than a cure. Some people may need this treatment long term.

The most common form of swallowed topical steroid used for EoE is oral viscous budesonide, or OVB. This medication is made up into a slurry by mixing it with sucralose sweetener. It is then swallowed to create a coat on the food pipe and treat the inflammation. Your medical team will advise you on making this slurry. Aim for a runny honey texture.

Steroids can quickly reduce symptoms. They help most people with EoE. They work for up to 85 in 100 people with EoE. Their symptoms improve. This happens within 12 weeks of starting therapy. Steroids treat the inflammation. So, they may prevent or treat the fibrous narrowing called strictures. Strictures can occur in some people with EoE.

A newer treatment is an oro-dispersible form of budesonide, called "Jorveza." This is a little tablet. It is placed on the tongue or the roof of the mouth. It mixes with saliva and dissolves in the mouth. It creates the right texture to coat the food pipe and treat the inflammation.

At present these are only licenced in the UK and Europe for use in adults to induce remission. They are not licensed for use in children. But some specialist paediatric centres have experience with this medicine and they might offer it.

As with the budesonide slurry, this medicine should be taken twice daily:

- After breakfast followed by cleaning the teeth.
- At bedtime, after cleaning the teeth.

Swallowing this medication after it dissolves, leaves a coating. It treats the inflammation. Avoid eating or drinking for 30 minutes after taking the oro-dispersible tablet.

Other preparations include an asthma pump (fluticasone inhaler spray). Rather than breathing in the “puff” created by the pump, this is sprayed in the mouth into the cheek and then swallowed. Like with other treatments, do not eat or drink for at least 30 minutes after taking this medication.

It is important to follow the instructions on how to take the medicine to improve how well it works and limit any side effects. For example, a side effect is a fungal infection called thrush in the mouth or throat.

For more information on taking these medicines contact the EOS Network (see support section).

Usually, systemic steroids are not used to treat EoE. They are only for people with a gullet narrowed by inflammation (an inflammatory stricture). This is done in specialist centres and for a limited time only.

Proton pump inhibitors (PPI) (examples omeprazole and lansoprazole.)

Doctors often use these drugs for acid reflux diseases. They reduce inflammation in up to half of people with EoE, as shown by biopsy. But no one has compared the improvement to other methods. No trials with a placebo and PPI have been done. This is the best method of testing whether a treatment is effective. In some patients with milder disease, PPI medicines can help. Common PPIs are omeprazole and lansoprazole, but others also exist. High doses can lead to remission of EoE.

It is very important that people on PPI medicines should be off the medicine for three weeks before their first endoscopy to check for EoE. This is because PPIs may reduce eosinophils below the threshold to make the diagnosis. Please discuss this with your gastroenterologist before coming for an endoscopy.

In severe cases, a stricture may have narrowed the food pipe. A dilation might be needed. This is an endoscopic procedure usually done under sedation. The stricture is stretched to widen the oesophagus. This allows food to pass through more comfortably. Dilatation also needs to be used with diet or drugs, as described above. More than one dilatation procedure may be needed.

Interventional treatment for example dilatation in children in UK is often performed by surgeons.

Guidelines

British Society of Gastroenterology (BSG) and British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN) joint consensus guidelines on the diagnosis and management of eosinophilic oesophagitis in children and adults | Gut (bmj.com) BSG/BSPGHAN Guidelines on Eosinophilic Oesophagitis.

EOSINOPHILIC GASTROINTESTINAL DISORDERS (EGID)

EGID cases are rare and can appear in both children and adults. People with EGID usually have long-term gut problems. These problems can be non-specific. These include:

- abdominal pain
- diarrhoea
- blood or mucus in the poo
- constipation
- nausea
- vomiting
- regurgitation
- weight loss or failure to thrive
- fatigue

Many people have symptoms for years. Getting a diagnosis is often challenging and delayed.

The EGID's pattern depends on which part of the gut the eosinophil inflammation affects.

- Stomach: eosinophilic gastritis (EG).
- Small intestine: eosinophilic enteritis (EoN). Depending on localisation eosinophilic duodenitis (EoD), eosinophilic jejunitis (EoJ) or eosinophilic ileitis (EoI).
- Large intestine: eosinophilic colitis (EC).

HOW ARE EOSINOPHILIC GASTROINTESTINAL DISORDERS DIAGNOSED?

The diagnosis of EGID requires careful exclusion of relevant parasites and other gut inflammation by a gastroenterologist. A healthy gut has some eosinophils. Until recently, there was no standard for diagnosing elevated eosinophils. This made diagnosis difficult. Studies in this area have not agreed on a figure for raised levels of eosinophils. This figure is used to diagnose EGIDs. In the USA, various centres have agreed on thresholds. The thresholds vary by where the inflammation is found.

Currently, an expert gastroenterologist must diagnose these conditions. They do a colonoscopy and an upper gut endoscopy. They take many biopsies. The biopsies show if there are many eosinophils in the gut lining. This is done with a full assessment of the symptoms. The symptoms are not enough for a diagnosis. But the symptoms get worse with certain foods. This can give clues to the condition. This is because food intolerance seems to cause EGID.

WHAT ARE THE TREATMENT OPTIONS FOR EOSINOPHILIC GASTROINTESTINAL DISORDERS?

Finding the foods that cause EGID is hard. There are often many causes. So, therapy often involves avoiding several food types. It also involves taking anti-inflammatory drugs. When the condition only affects the colon, you could be given a steroid (budesonide) by modified release capsule (rarely by enema). If the stomach or small bowel are affected, modified-release capsules of budesonide from your hospital's pharmacy may help.

In some people with complex eosinophilic gastrointestinal disease (EGID) these approaches are not enough to control it. They can cause serious ill health. In this situation doctors may use strong drugs. These include systemic steroids, such as prednisolone. They also include other anti-inflammatory drugs. These can have significant side effects. An expert in these diseases must carefully weigh the treatment's risks and benefits. Recently, global experts, including from the UK, agreed on the best approach. It is based on published evidence and shared experience. Unfortunately, there are no licensed therapies in the UK. However, doctors can prescribe some medicines for 'off-label' use. These include topical steroids and, for some patients with severe disease, biologic treatments. Off-label means the doctor wants to use the medicine in a way not allowed by its license. This could mean using the medicine for a different problem. Or, for a different group of people. Or it could mean a change in the dose or how the medicine is taken. The doctor should tell you the risks and benefits of the medicine and if funding is available. This will help you decide what treatment to take. Funding from a hospital, the NHS, a company, or a charity may take time.

Eating a healthy diet with EGIDs is hard. So, people need expert dietetic help. Ask your doctor for a referral to a gastroenterology or allergy dietitian.

WHAT ABOUT THE LONGER TERM

As you will have read, treatments can reduce the symptoms of eosinophilic gut disease. But they do not cure the condition. The person will need to be followed up. Treatment may need to be repeated, extended, or changed.

SUPPORT

The EOS Network helps people with eosinophilic diseases. They provide information and support to people with a diagnosis and their families.

Eosinophilic-Associated Diseases Charity EOS Network

RESEARCH

Current research supported by Guts UK includes work led by Dr Marcus Auth. Dr. Auth and his team are investigating metabolic and biological markers in poo samples. The markers could help diagnose and check eosinophilic disease. They could also reduce the need for repeat endoscopies.

Other research is looking at biological treatments. These include monoclonal antibodies as possible treatment for EOS.

REFERENCES

References available on request

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