EOSINOPHILIC OESOPHAGITIS:

WHAT YOU NEoED TO KNOW

This interactive guide aims to answer your questions about eosinophilic oesophagitis, which is usually shortened to just EoE.

Hopefully you'll find the information it contains helpful, but it isn't meant to take the place of your doctor or nurse.

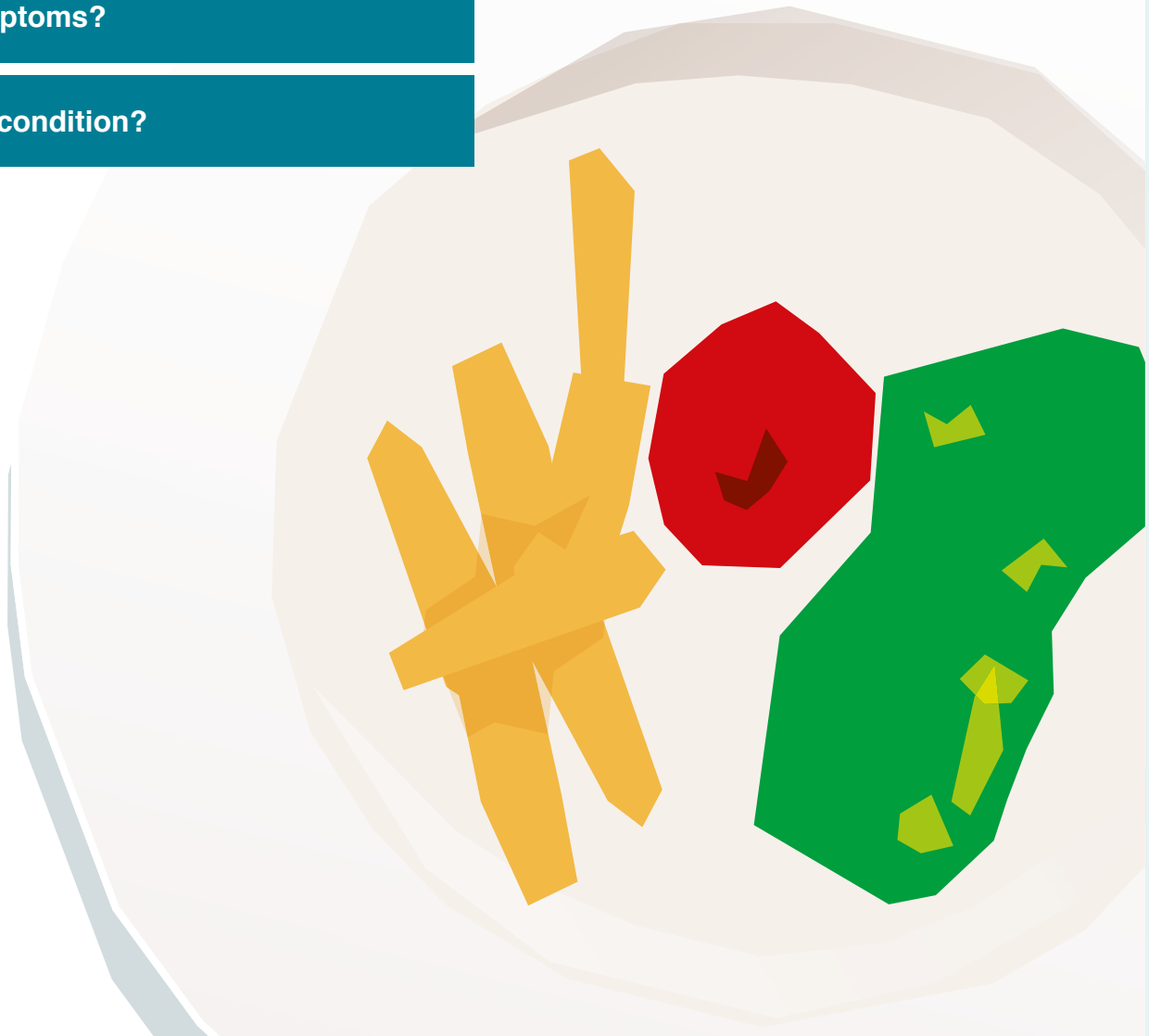
So, if you do have any worries about your EoE, or its treatment, do talk them through with a member of your healthcare team.

Please click on any of the sections below to find the menu screen for more information related to that topic

- What EoE is
- Who gets EoE
- How EoE is diagnosed
- How EoE is treated
- What to do in an emergency

What EoE is

- Why is it called “eosinophilic oesophagitis”?
- What are the symptoms?
- What causes the condition?



WHAT YOU NEED TO KNOW

What EoE is

Why is it called “eosinophilic oesophagitis”?

EoE is a disease of the oesophagus.

The oesophagus is part of your digestive system. It is the muscular tube that carries food from your mouth to your stomach.

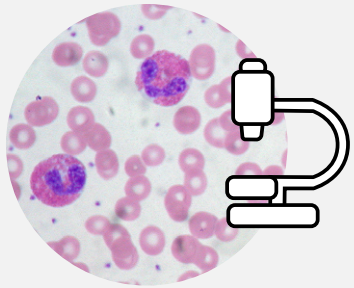
In EoE, certain white blood cells (called eosinophils) gather in the lining of your oesophagus.

While eosinophils play an important role in the body’s normal response to infection, you don’t normally find them in the oesophagus.

Too many eosinophils can cause inflammation.

When inflammation is present in the lining of the oesophagus, it is known as oesophagitis, hence the name, eosinophilic oesophagitis.

Eosinophils are a type of white blood cell



Eosinophils – which, under a microscope, can look a bit like ‘tomatoes wearing sunglasses’ – release certain chemicals that can promote inflammation

WHAT YOU NEED TO KNOW

What EoE is

What are the symptoms?

EoE can result in a range of symptoms.

The most common symptom is difficulty swallowing solid food.

Normally the oesophagus stretches to allow food to pass through. That's not so easy with EoE.

Because of the inflammation, the oesophagus swells making it narrower. Over time, fibrous tissue can also form making it stiffer.

While symptoms vary, typically food can feel like it is travelling slowly down the oesophagus. There may be a sensation of food sticking, usually in the chest.

Sometimes food can get completely stuck. When this happens, it is known as a food bolus obstruction.

The most common symptom of EoE

Food feels like it is sticking in the chest as it goes down

WHAT YOU NEED TO KNOW

What EoE is

What causes the condition?

We do not know exactly what causes EoE.

It does seem that eating certain foods may spark a reaction causing eosinophils to gather in the oesophagus.

The term allergy tends not to be used, because EoE only affects the oesophagus unlike some other types of food intolerance.

The food that sticks in the oesophagus isn't necessarily the same as the food that triggers the inflammation.

For example, cow's milk is the most common culprit behind the inflammation in EoE but, as a liquid, it wouldn't cause a blockage.

Instead, it's texture that determines how likely it is for a food to get stuck.

Meat is a common cause of food bolus obstruction because its tough, fibrous nature makes it prone to becoming lodged. Bread often gets stuck too because of its dense texture.

Foods that commonly trigger EoE


cow's milk


wheat


nuts


soya

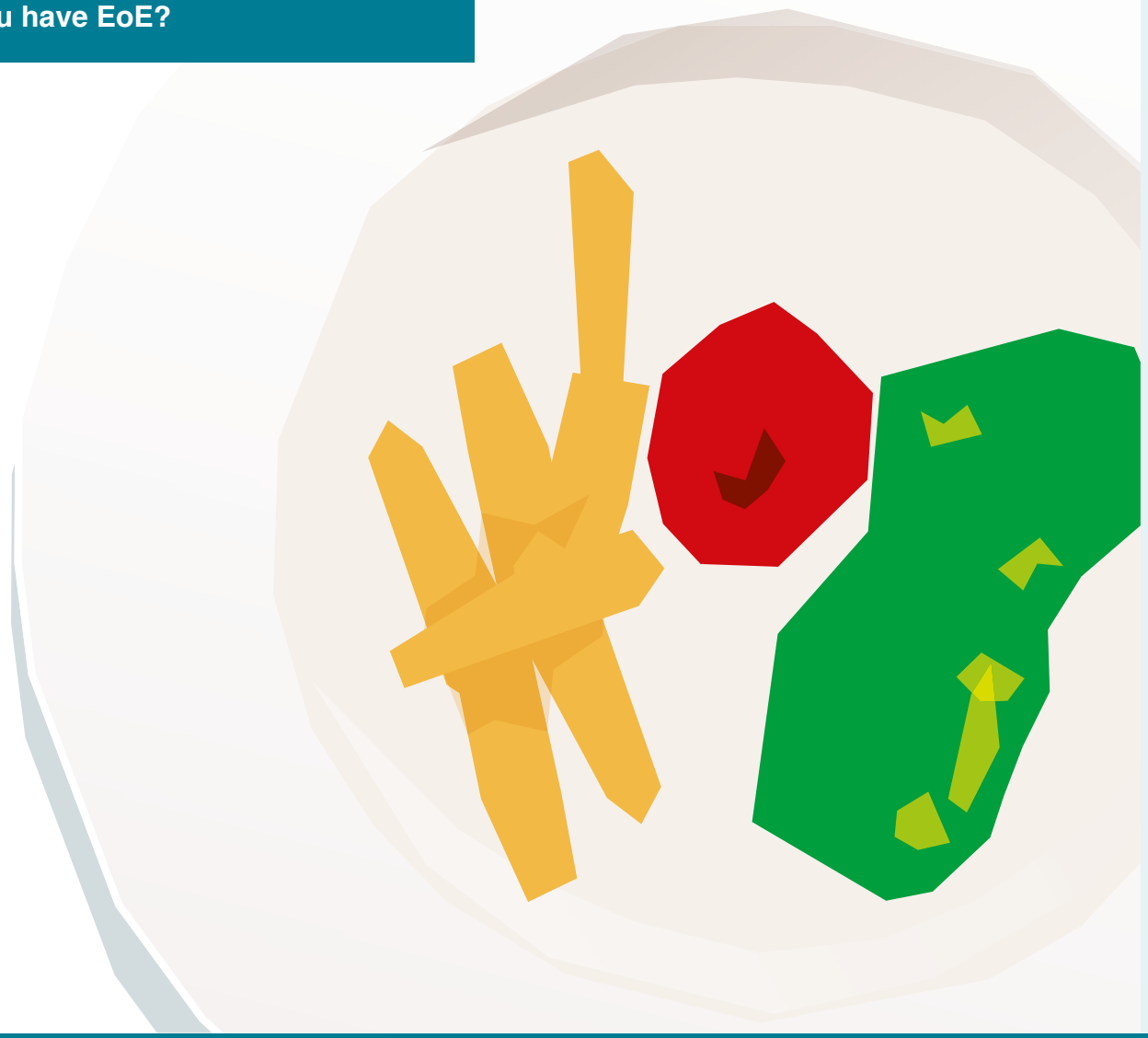

fish


eggs

WHAT YOU NEED TO KNOW

Who gets EoE

- Who does EoE usually affect?
- Can you tell if you have EoE?



WHAT YOU NEoED TO KNOW

Who gets EoE

Who does EoE usually affect?

EoE can affect people of any age, gender and ethnic group.

That said, it is more common among white people, and men are three times as likely as women to be affected.

People with allergies like asthma, eczema or hay fever seem to be more likely to get EoE. Having a parent or brother or sister with EoE can also increase the risk of having it.

Originally EoE was thought to be a childhood disease. But we now know EoE can affect people of any age, from babies to the elderly.

There is nothing people with EoE have done to cause the problem – rather, it seems to be a random change in the way their bodies react to food.

More people are being diagnosed with EoE, but it is still relatively uncommon. Recent figures suggest about 1 in 1000 people have EoE.

WHAT YOU NEoED TO KNOW

Who gets EoE

Can you tell if you have EoE?

People may adapt to living with EoE.

Sometimes, without really knowing that they are doing it, people who have EoE change the way they eat to help stop food from becoming stuck in the oesophagus.

For example, they may eat very slowly, chewing carefully. They often cut their food into small pieces and drink a lot of fluid at mealtimes to wash food down. They are often the last to finish eating and may avoid certain difficult-to-swallow foods, like meat and bread, preferring softer foods and soups.

Because they become used to the condition and adapt their way of eating, people with EoE may not remember precisely when the problem started.

Common eating behaviours for people with EoE

Taking small bites

Eating slowly

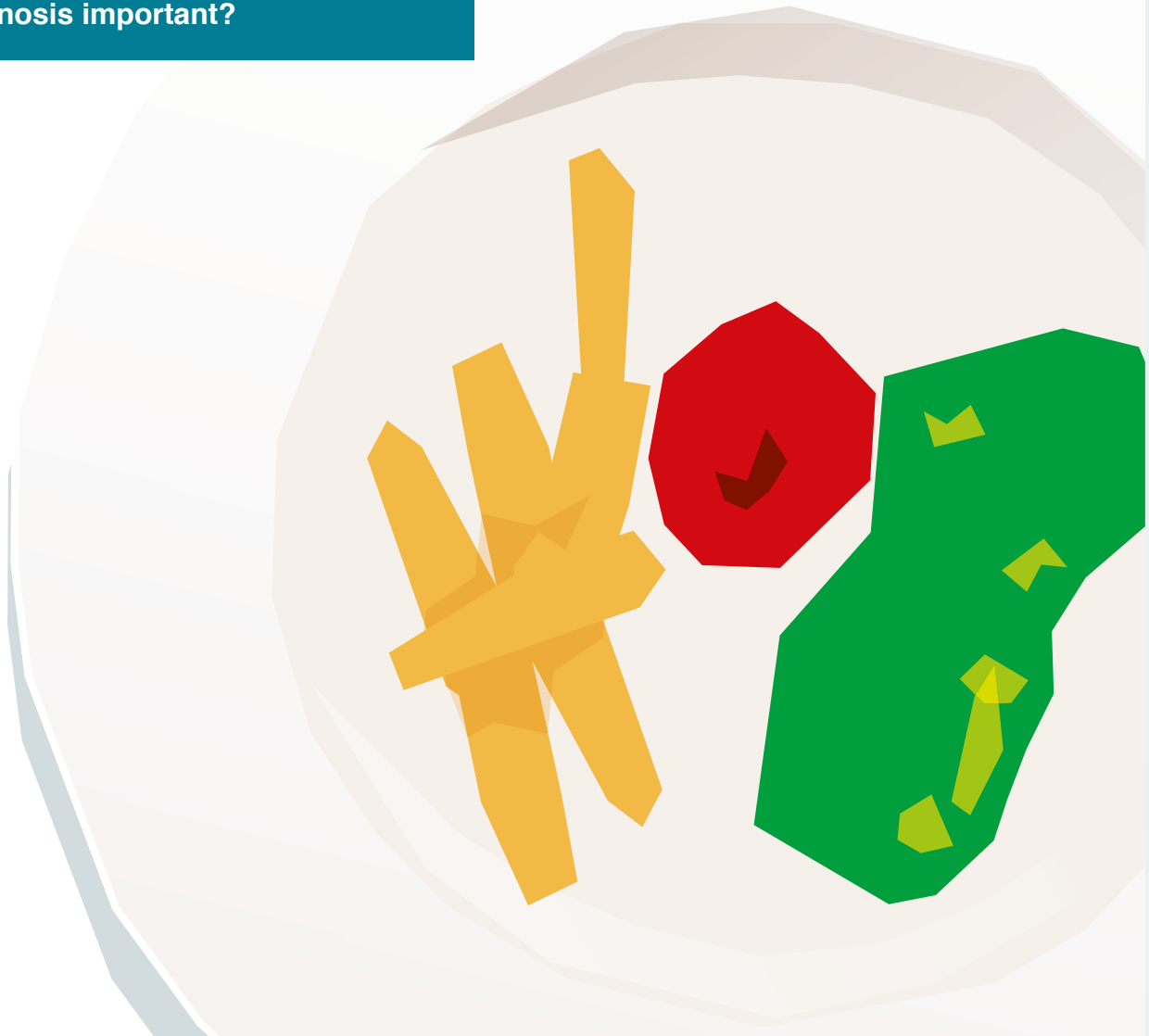
Drinking lots at mealtimes

Avoiding foods that stick

WHAT YOU NEoED TO KNOW

How EoE is diagnosed

- What are the tests for EoE?
- Why is early diagnosis important?



WHAT YOU NEoED TO KNOW

How EoE is diagnosed

What are the tests for EoE?

The only way to diagnose EoE is with an endoscopy.

Endoscopy of the oesophagus is normally carried out in a hospital. The procedure may be referred to as an OGD (which stands for oesophago-gastro duodenoscopy).

When a GP (or a doctor in A&E) suspects someone has EoE, they will refer them to a gastroenterologist - that's a doctor who specialises in the health of the digestive system.

The gastroenterologist will examine the oesophagus with a thin, flexible tube called an endoscope which has a tiny light and camera at the end.

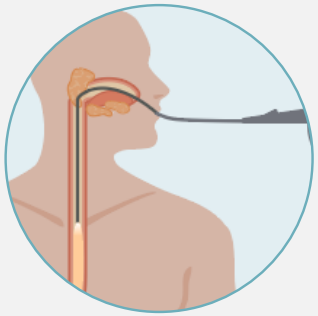
As well as looking for signs of EoE such as rings and furrows, tiny samples (called biopsies) of the tissue lining the oesophagus will be collected at the same time. These are then examined under a microscope to see if increased numbers of eosinophils are present.

Sometimes the oesophagus can look normal, but the number of eosinophils confirms someone has EoE.

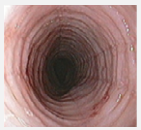
Because the inflammation in EoE can be patchy, tissue samples are obtained from different parts of the oesophagus. Guidelines recommend that 6 biopsies in total are taken.

A relatively new test which may be used to monitor inflammation is the oesophageal sponge. This test involves swallowing a capsule attached to a string. The capsule dissolves in the stomach releasing a small sponge. The sponge can then be pulled out by the string, collecting cells from the lining of the oesophagus along the way. This is not yet widely available.

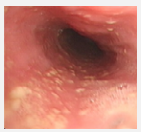
Signs of EoE may be seen with an endoscope



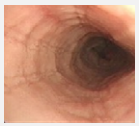
Rings



White spots



Furrows



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WHAT YOU NEoED TO KNOW

How EoE is diagnosed

Why is early diagnosis important?

Having EoE is no joke.

Symptoms can be unpleasant, embarrassing and also frightening if food gets completely stuck.

As well as social life challenges and restrictions, EoE may result in repeat visits to A&E for food blockages, impacting work and home commitments too.

If the inflammation in EoE is left unchecked, it is more likely to lead to severe narrowings of the oesophagus (called strictures). These bottlenecks in the oesophagus can make it very difficult for solid food to pass through.

Once it's diagnosed, however, EoE can be effectively managed to relieve symptoms and to prevent it from becoming worse.

X-ray showing severe narrowing of the oesophagus

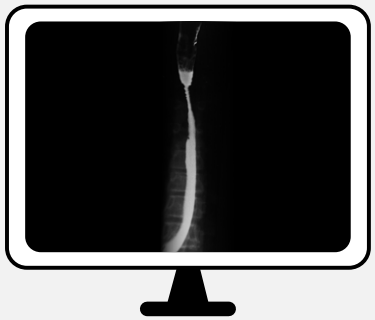


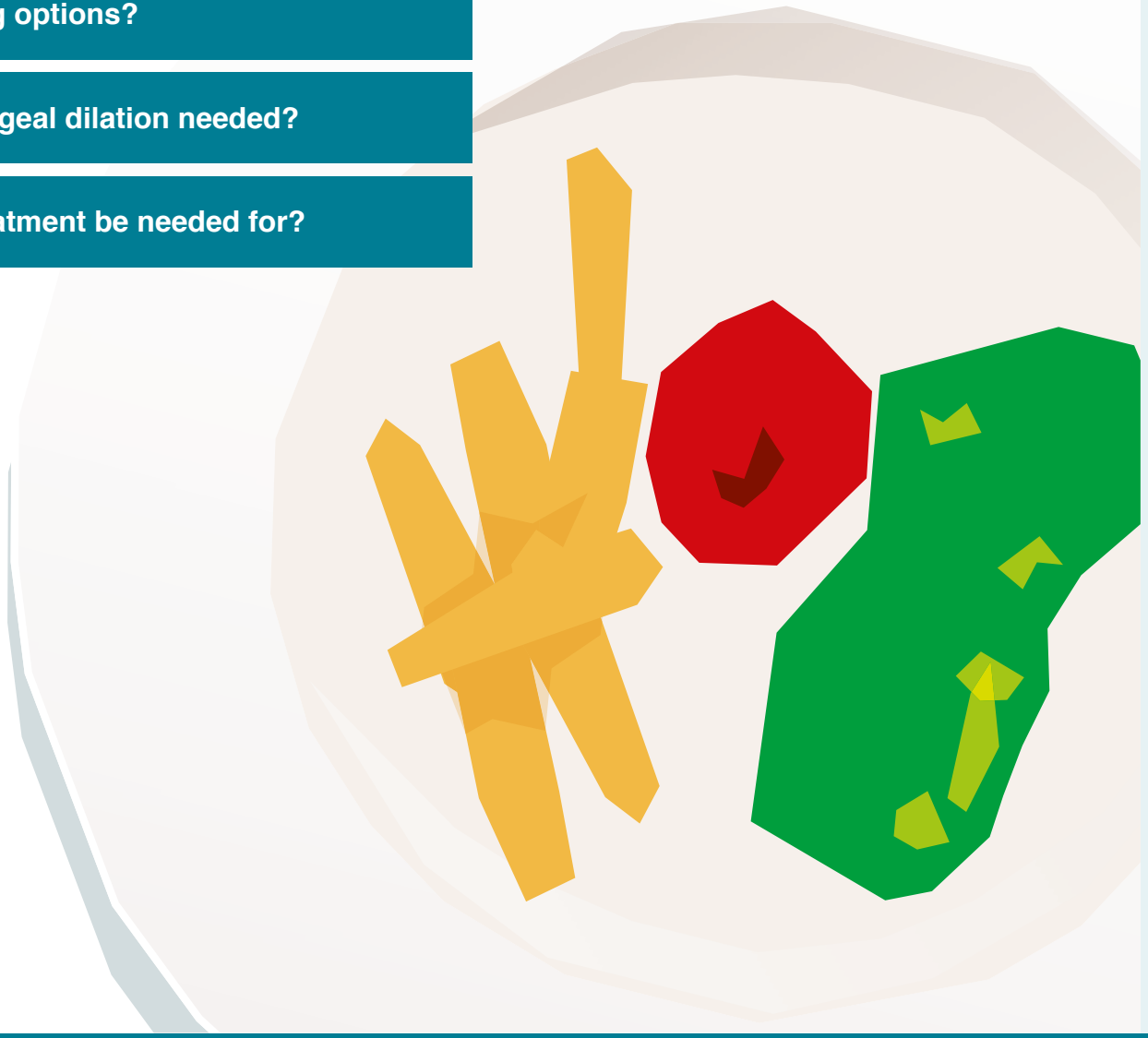
Image courtesy of Professor Stephen Attwood

This image is from a young man with untreated EoE who'd had symptoms for 10 years

WHAT YOU NEoED TO KNOW

How EoE is treated

- Can changing diet improve symptoms?
- What are the drug options?
- When is oesophageal dilation needed?
- How long will treatment be needed for?



WHAT YOU NEED TO KNOW

How EoE is treated

Can changing diet improve symptoms?

One way to improve symptoms is to take trigger foods off the menu.

For some people, just one food may be responsible, while in others many foods cause the condition.

Unfortunately, typical allergy tests, such as skin prick tests or blood tests, are not useful in finding the problem foods that may trigger inflammation in EoE.

So the gastroenterologist may suggest eliminating some of the top six food groups that are most likely to cause problems to see if symptoms get better. These foods are then reintroduced one by one to see which trigger EoE and so can be avoided in the future. During this time, the doctor may perform more endoscopies to see how the diet is working.

While elimination diets can be very helpful in treating EoE, they can be quite difficult to keep up in the long term. Specialist support from a dietician is important to help make sure the body's nutritional needs are still met when foods are excluded.

Sometimes, a stricter diet, called an elemental diet, is needed. With this diet, nutrition is provided by a special formula alone or sometimes with one to two simple foods that have a low likelihood to trigger EoE. All other foods are removed from the diet.

Elimination diets are used to help find culprit foods

Once identified, the problem food(s) can be avoided

WHAT YOU NEoED TO KNOW

How EoE is treated

What are the drug options?

There are medicines that can help manage symptoms of EoE.

The advantage of medication is that it is possible to have a relatively unrestricted diet; the disadvantage is that, as with any medicine, some people may have side effects.

Some people will have had a type of drug called a proton pump inhibitor before they see a specialist hospital doctor. While these acid blockers are easy to use, symptoms may not improve on these drugs.

Treatment with a steroid is something the specialist can discuss. Steroids are naturally produced in the body in response to injury. That's why they are commonly used in medicine for a variety of illnesses including inflammation in the lung (asthma), or in the skin (eczema).

In EoE, steroid therapy can reduce the activity of eosinophils in the oesophagus and ease the inflammation, with or without dietary changes. This type of steroid therapy is specially designed to avoid entering the bloodstream and so keep any side effects to a minimum.

The steroid approved for EoE comes in a tablet that slowly dissolves on the tongue so it can mix with saliva to coat the oesophagus. This type of tablet is called orodispersible.

EoE can be treated with a specially designed steroid

Steroids are very effective drugs for reducing inflammation

WHAT YOU NEoED TO KNOW

How EoE is treated

When is oesophageal dilation needed?

Dilation is used to treat strictures.

Some people with EoE can experience severe narrowings of the oesophagus called strictures. Where this happens, dilation (sometimes called dilatation) may be recommended to help make swallowing easier.

Dilation is a procedure performed by endoscopy to stretch the oesophagus. There is a very small risk of perforation (a serious tear in the wall of the oesophagus) during this procedure.

While dilation can provide symptom relief, it does not improve the underlying inflammation.

Dilation can be used to stretch the oesophagus if it is very narrow

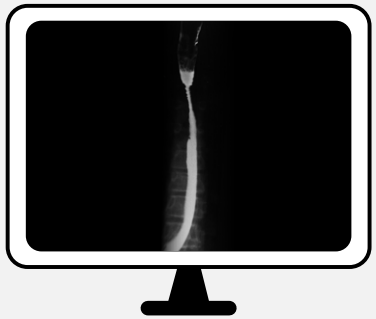


Image courtesy of Professor Stephen Attwood

Because dilation doesn't treat the inflammation, other treatments may still be needed despite having the procedure

WHAT YOU NEoED TO KNOW

How EoE is treated

How long will treatment be needed for?

EoE is typically chronic, meaning it can last for years.

While drug treatment is very effective at bringing symptoms under control (known as achieving remission), we do not yet have a cure for EoE.

Most, if not all, people with EoE will need treatment to control the inflammation in their oesophagus even when they feel well.

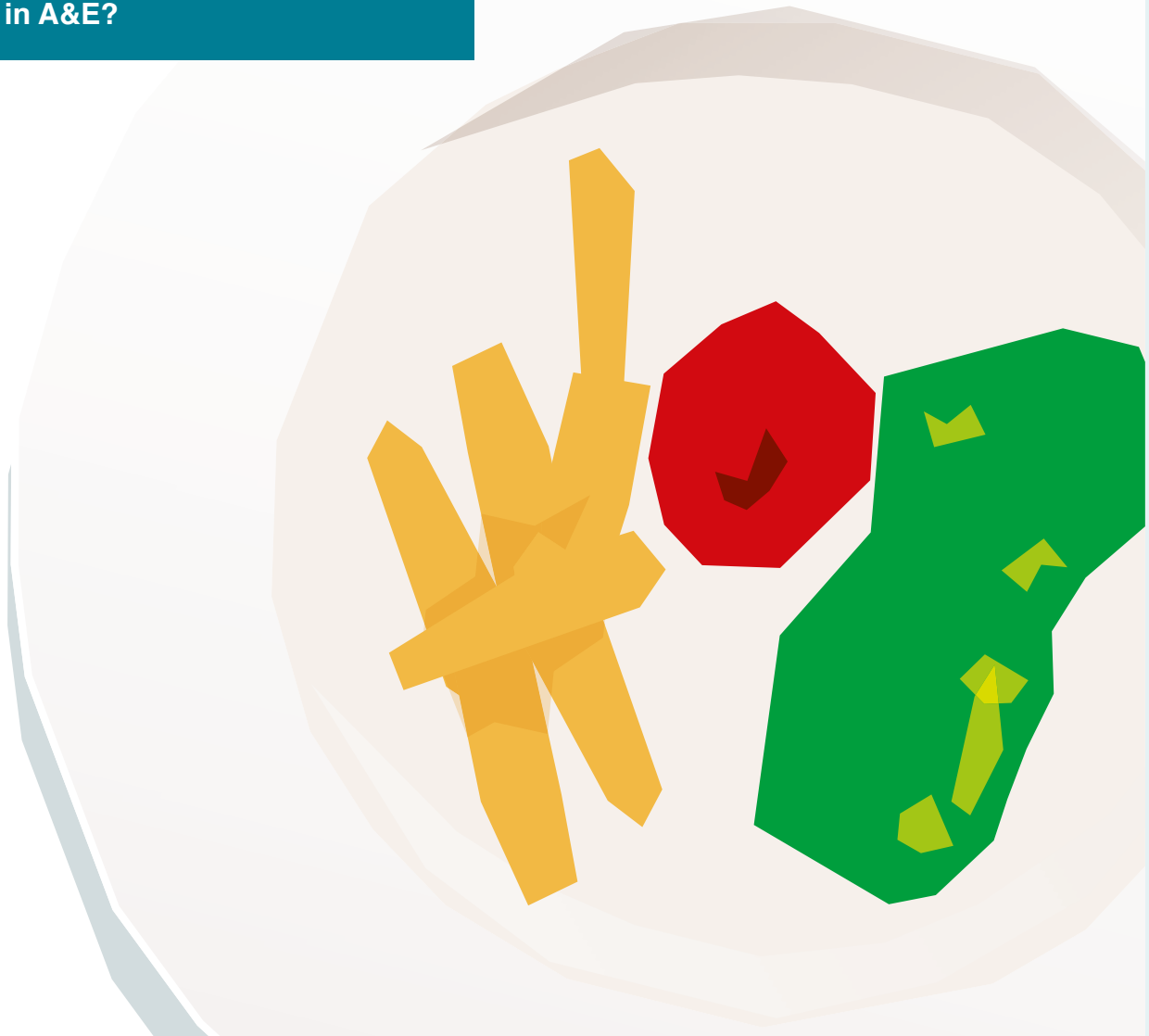
There is no cure for EoE

Without maintenance therapy, about 50% of people will likely relapse within 3 months of stopping treatment

WHAT YOU NEoED TO KNOW

What to do in an emergency

- What if food gets completely stuck?
- What will happen in A&E?



WHAT YOU NEED TO KNOW

What to do in an emergency

What if food gets completely stuck?

When food becomes lodged in the oesophagus it is called a food bolus obstruction, or FBO.

Immediately the food becomes stuck, there may be a sensation of squeezing in the chest that can be quite frightening. Sometimes there may be pain in the chest or oesophagus. Often people feel the need to spit out saliva, or they may start to drool because their saliva will not go down.

If chest pain is severe (for example, it is bad enough that the person struggles to talk), or they are finding it hard to breathe, or they feel very unwell/distressed, **seek emergency care straight away.**

If it feels more uncomfortable than painful, then trying to relax is recommended. That may be easier said than done, but food bolus obstructions can sometimes pass with time alone.

Some people find walking around and doing some gentle stretches can help shift the obstruction, as can sipping water or fizzy drinks (but be prepared, what is drunk may end up being regurgitated). If the food has not passed down within 2 hours, go to the emergency department.

Go straight to the emergency department if food has become stuck and any of the following symptoms are present:

- chest pain is severe, or
- it is hard to breathe, or
- you feel very unwell/distressed

WHAT YOU NEED TO KNOW

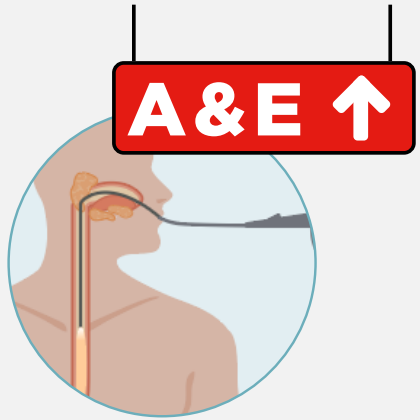
What to do in an emergency

What will happen in A&E?

Unfortunately, while a number of medicines have been tried for food bolus obstructions, there is very little evidence that any are effective in dislodging stuck food.

Instead, a gastroenterologist should remove the FBO with a special tool during an endoscopy. Ideally, 6 tiny tissue samples (biopsies) will be taken at the same time to check the number of eosinophils that are present in the lining of the oesophagus.

It is very important the gastroenterology team who normally manage care know about the FBO, even if it passes naturally without an endoscopy. It may be possible to bring forward the next routine appointment to discuss whether treatment changes are needed to help prevent another obstruction happening in the future.



A+E
↓
Gastroenterology
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Endoscopy
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Food removal

WHAT YOU NEED TO KNOW

Informed with care

Together we *know more.*
Together we *do more.*

For more information please visit

drfalk.co.uk

eosnetwork.org

or email

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