

WHAT IS NON RESPONSIVE AND REFRACTORY COELIAC DISEASE?

Non responsive or refractory coeliac disease is the name for when people with coeliac disease either do not feel better after starting a gluten free diet, or feel better to begin with but then start having symptoms again.

It's quite common to experience ongoing symptoms after starting a gluten free diet and this affects around 1 in 3 people. Most of the time, it's because gluten is still getting into the diet and some extra support around your gluten free diet might be all that is needed. However, if you are having ongoing symptoms, it's important not to guess about what the cause is and to visit your local healthcare team who are there to help.

Endoscopy and biopsy

If non responsive or refractory coeliac disease is suspected, the first step is usually to have an endoscopy with biopsy.

One reason for this might be to make sure that your diagnosis of coeliac disease is correct.

You might have had an endoscopy when you were first diagnosed, or it might be the first time you have one if you were diagnosed with blood tests. During endoscopy, a thin flexible tube is passed through the mouth and into the part of the gut that is affected in coeliac disease. Small samples are taken so that they can be looked at under a microscope.

The results of your endoscopy are important to see if your gut is damaged (this is also called villous atrophy).

If your gut looks normal then other causes of your symptoms will be considered like irritable bowel syndrome or lactose intolerance.

If you have ongoing gut damage, your diet will be reviewed to make sure you aren't accidentally eating gluten. Your healthcare team will also think about other possible causes of ongoing gut damage, like having a slow response to treatment with the gluten free diet. The possibility of refractory coeliac disease may also be considered.



Refractory coeliac disease

Refractory coeliac disease is a rare complication of coeliac disease, it is extremely rare in people under 30 years of age and most people with refractory coeliac disease are diagnosed over the age of 50.

Refractory coeliac disease affects between 4 in 100 to 3 in 1,000 people with coeliac disease. It is thought to be over diagnosed because it can be difficult to tell the differences between true refractory coeliac disease and coeliac disease where gluten is still getting into the diet. However, specific tests are now available in specialist centres which make it easier to diagnose accurately.

How is refractory coeliac disease diagnosed?

The specific test for the diagnosis of refractory coeliac disease is only available through specialist centres in Sheffield and Cambridge. These centres are there to support you and your healthcare team and are an approved NHS Rare Disease Collaborative Network (RDCN). **If your healthcare team think that you might have refractory coeliac disease, you should make sure that they are in contact with the RDCN centres so that you have access to specialist advice.**

You might be referred to the RDCN centres, or your local healthcare team may see you while in contact with the specialists who can support by reviewing medical notes, offering advice over the phone and access to the specific tests required.

Download a leaflet about the RDCN centres to share with your healthcare team at www.coeliac.org.uk/nrcd



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Type 1 and Type 2 refractory coeliac disease

There are two types of refractory coeliac disease, Type 1 and Type 2. These types are different from each other in the way they are diagnosed, treated and the risk of complications.

Type 2 has high levels of certain cells called aberrant intraepithelial lymphocytes (IELs) but Type 1 doesn't have such a high number of these cells.

Type 2 refractory coeliac disease is associated with a higher risk of complications, including a type of cancer called enteropathy associated T cell lymphoma (EATL).

For both Type 1 and Type 2 refractory coeliac disease, the specialist centres in Sheffield and Cambridge are best placed to support an accurate diagnosis with specific tests only these centres can provide. Also to recommend and monitor treatment on an individual basis. The gluten free diet is also an important part of treatment. Support from a dietitian is required for help in sticking to a gluten free diet and to make sure that you are getting all the nutrients that you need.

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