

## Department of Gastroenterology

# Refractory Coeliac Disease

### Information for patients the Addenbrooke's Coeliac Disease Clinic

In most patients with coeliac disease, the inflammation in the intestine gets better when gluten is removed from the diet. However, in some cases it does not. It is for this reason that we routinely perform a repeat biopsy after a few months of a gluten free diet. We do not expect the changes to resolve entirely. However, if there is no improvement then one of three things could be happening:

- It could be that some gluten is still finding its way into your diet. Whilst a blood test can often help us with this, it is not always useful. Inadvertent dietary gluten is the most common cause when inflammation in the intestine persists on a gluten free diet.
- Some people are very sensitive to gluten and may react to even the small amounts of gluten that are present in the gluten free products. These patients may need to try a diet in which even these foods have been removed (a 'sensitive' or wheat-free diet).
- It may be a condition known as 'Refractory Coeliac Disease' or RCD.

### What is refractory coeliac disease (RCD)?

This condition occurs when we are confident that the gluten has been removed entirely from the diet, and yet the intestine remains inflamed.

RCD can occur in patients who have been on a good gluten free diet for years, but suddenly start to experience the symptoms of coeliac disease again.

We do not yet know entirely why coeliac disease can become 'refractory' in this way. It is mostly found in patients whose coeliac disease is diagnosed later in life, and in those who have not managed to keep well to a gluten free diet over some years.

RCD is very rare.

## What are the risks of refractory coeliac disease?

- In some patients, RCD may be an early stage of a complication of coeliac disease known as 'Lymphoma'. This is a very rare type of tumour affecting the immune tissue of the intestine. By carrying out a special molecular test on previous biopsies, we can tell whether you are at risk of developing this condition.
- Even if we find that you are at risk of developing a lymphoma, we still do not know how great this risk is. However, we do know that this lymphoma is extremely uncommon, and that people can have RCD for many years without developing lymphoma.
- If we find that you are in the group of patients with RCD who are at risk, we will keep a close eye on your intestine. We can then pick up any problems at an early stage.

## What further tests will I need if I have refractory coeliac disease?

We may need to carry out a scan of your abdomen and an X-ray test of the small intestine.

Every year, we will then carry out the following tests to keep a close eye on the intestine:

- An endoscopy to take further biopsies. The endoscope that is used is slightly longer than the usual one so that we can look further into the small intestine. It is called an 'enteroscope' but the test is in every other detail the same as an endoscopy.
- A 'video capsule enteroscopy'. This is a small pill that you swallow that contains a camera and enables us to look further into the small intestine.

## Are there any treatments available for refractory coeliac disease?

- In many cases no treatment is required beyond occasional checks and additional endoscopies as described above.
- In some cases, the damage to the intestine may require additional help to replace nutrients that cannot be absorbed. Sometimes these may need to be replaced by injection.
- As there is no easy way of telling whether patients are very sensitive to tiny amounts of gluten, we may ask you to try a period of a 'wheat free' rather than 'gluten-free' diet. This 'sensitive' coeliac diet is more difficult to manage than the usual gluten free diet. We would only ask you to continue this if there is evidence that it is helping you.
- Some patients may be helped by the use of medications to reduce the activity of the intestinal immune system – these are routinely used for other inflammatory

conditions of the gut but can have side effects and are therefore not used unless absolutely necessary.

## Where can I find further information on refractory coeliac disease?

Please feel free to contact the consultant gastroenterologist – Dr Jeremy Woodward – via his secretary on 01223 596231 if you have any concerns or queries regarding this matter.

Please ask if you require this information in other languages, large print or audio format: 01223 216032 or [patient.information@addenbrookes.nhs.uk](mailto:patient.information@addenbrookes.nhs.uk)

Potete chiedere di ottenere queste informazioni in altre lingue, in stampato grande o in audiocassetta.

### Italian

若你需要本信息的繁體中文、大字體或音訊格式的版本，請要求索取。

### Cantonese

तमने आ माळिती बीछ भाषाओमां, मोटा अक्षरोमां अथवा सांभली शकाय जेवा माध्यम (ओडीओ डोमेन्ट)मां जेठती छोय तो कृपा करीने पूछो.

### Gujarati

تکایہ پرسیار بگہ نہ گہر نہ وزانیاریہت دہوی بہ زمانیکی تر ، بہ بیٹی گہورہ یانیش بہ شیوہی دہنگ

### Kurdish

آگر آپ کو یہ معلومات دوسری زبانوں میں، بڑے الفاظ کی اشاعت میں یا آڈیو ٹیپ پر درکار ہوں تو براۓ مہربانی اس کیلئے درخواست کریں۔

### Urdu



Addenbrooke's is smoke-free. Please do not smoke anywhere on the site.  
For advice on quitting, contact your GP or the NHS smoking helpline free, 0800 169 0 169

### Document history

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