

Testing for Coeliac Disease in Children and Young People

Coeliac disease is usually diagnosed with blood tests, but sometimes a procedure called an 'upper GI endoscopy with biopsy' is also required. This leaflet gives you more information about those tests.

There are slightly different testing regimes used in older adults who are more likely to need a biopsy.

Why is accurate testing for coeliac disease important?

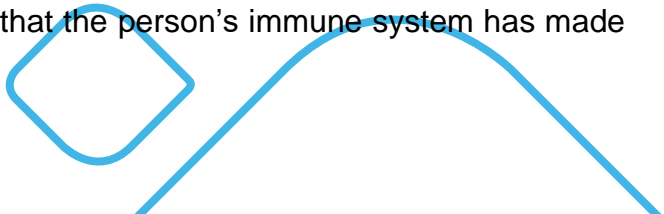
Coeliac disease is condition triggered by gluten in food. It can cause a wide range of symptoms and long term complications such as anaemia, osteoporosis and reduced fertility. The treatment is a lifelong strict gluten-free diet which can reverse all the symptoms and complications. People with a close family member with coeliac disease are at increased risk of developing coeliac disease, even without obvious symptoms, so may also be offered testing.

It is important that coeliac disease is accurately diagnosed so that a strict diet can be started if needed and long term follow-up arranged. It is also important to have a clear diagnosis to prevent unnecessary dietary exclusions. There are some people who do not have coeliac disease but just do not tolerate gluten very well, these people can have small amounts of gluten and do not have the risks of complications.

It is vital that gluten is eaten regularly for at least 6 weeks before testing and continued until testing is completed. Gluten is found in wheat, barley and rye. A meal containing gluten such as bread, Weetabix or pasta should be eaten at least once each day. A low gluten or gluten-free diet will make the tests inaccurate. If symptoms make this impossible please discuss the next step with your health care team.

Which blood tests are used?

The main test for coeliac disease is 'IgA Tissue transglutaminase antibody', usually shortened to TTG (or tTG). This measures one of the antibodies that the person's immune system has made



against gluten. If the lab finds increased levels of 'TTG' then another antibody, called endomysial antibody, (EMA) is also tested.

What do the blood test results mean?

Normal results: A normal level of TTG means coeliac disease is very unlikely (so long as a good amount of gluten was in the diet for the 4-6 weeks prior to the test).

Results which confirm coeliac disease: The combination of a high TTG level, over ten times the normal upper level, plus a positive EMA test, is sufficient to make an accurate coeliac diagnosis. At the RUH the normal TTG is between 0.1 and 3.9u/ml so a diagnostic level is over 40, but other labs may have different values.

It is always suggested that the test is repeated to be absolutely sure of the result.

About 60-70% of all coeliac disease in children is diagnosed this way, without needing a biopsy.

Inconclusive results: If the TTG is raised above normal levels, but not very high, or if the EMA is negative, then coeliac is possible but not confirmed. Further testing is then needed to confirm or exclude coeliac disease. This usually involves a biopsy test/upper GI endoscopy. In some situations repeating the blood tests after a few months, while continuing a gluten-containing diet, is advised.

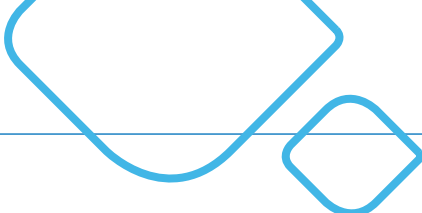
What is a 'biopsy' and 'upper GI endoscopy'?

A biopsy is when a tiny sample of tissue is taken to look at under a microscope. A flexible telescope is used to get the biopsy sample during a procedure called an endoscopy.

Coeliac diagnosis needs biopsy samples from the duodenum, which is just beyond the stomach, so the endoscopy is done via the mouth. This procedure gets called different names such as 'gastroscopy', 'oesophago-gastro-duodenoscopy' (OGD) or 'upper GI endoscopy'.

What does the coeliac endoscopy and biopsy involve?

- The endoscopy is done in hospital by a specialist in stomach and bowel conditions (a gastroenterologist).
- Children under 16 years will have the procedure at Bristol Children's Hospital. It is done under a short general anaesthetic so they will be fully asleep.
- Older teenagers and adults will be referred to the RUH adult endoscopy team. In older teenagers/adults the procedure is done with numbing spray in the throat plus sedation, so they are very drowsy but not fully asleep.
- A thin flexible telescope, with a tiny camera at one end, is inserted into the mouth and passed down into the stomach and upper small intestine (duodenum). The specialist will look at the inside of the gut and take tiny biopsy samples to send to the lab.
- An upper GI endoscopy does not need any special laxatives or 'bowel clearance'. Advice will be given about how many hours before the test to stop eating/drinking.
- The actual procedure takes about 15-20 minutes. Once recovered from the anaesthetic or sedation you go home the same day.

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- In children and young people this is a very safe test, but as with all procedures and anaesthetics there are some rare complications such as bleeding or a reaction to the medications.

Getting the biopsy test results:

You will be informed of the biopsy result, and what to do next, by letter or telephone a few weeks after the test. The biopsy results will show if coeliac disease or any other problem is present. Straight after the test you will be told if there was anything obviously abnormal on the telescope test, but with coeliac the changes can usually only be seen under the microscope when the biopsy is looked at in the laboratory.

What if I am worried about having an endoscopy?

An endoscopy is only advised if the blood tests cannot give a definite diagnosis. It can be quite a scary prospect, but we generally find that after the procedure families and young people feel was much less of an issue than they thought it was going to be. There are further links for information at the end of this leaflet.

If after looking at all the information, you decide not to go ahead you can discuss the alternatives with your health care team. Options may sometimes include starting a strict gluten-free diet as if coeliac had been confirmed. The diagnosis will then be revisited in the future with reintroduction of gluten and repeat testing. Sometimes the advice is to continue a normal diet and repeat blood tests after a few months. HLA DQ2/8 blood tests sometimes give some additional information (see below).

The RUH paediatric team or your GP will sometimes refer you to the team at Bristol Children's hospital, or for older teenagers to the RUH adult gastroenterology team, to discuss the options in more detail.

Other tests used in coeliac disease:

HLA DQ2/8: This is a type of genetic or tissue-type test. It shows if someone is in the group that may potentially develop coeliac disease at some point in their life.

It cannot be used to diagnose coeliac disease by itself as more than 40% of all people are HLA DQ2/8 positive.

DQ2/8 is used in testing family members to see who is at risk. A negative DQ2/8 test is sometimes used to rule out coeliac disease if someone is unable to get enough gluten into their diet for accurate coeliac testing. It may help add to the information if someone does not want a biopsy.

Other tests: There are some other blood tests such as IgG tests used in specific circumstances. Dermatologists sometimes do skin biopsy test for specific gluten related skin conditions (dermatitis herpetiformis)

Further Information:

CoeliacUK: Lots of information about coeliac disease including diagnosis www.coeliac.org.uk

RUH leaflets about a wide range of conditions are on the RUH website. This includes further information about coeliac disease and testing for family members

www.ruh.nhs.uk/ChildrensLeaflets - or scan QR code



Having an endoscopy and biopsy:

Bristol Royal Hospital for Children Website: www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bristol-royal-hospital-for-children/

Webpages for 8-12 year olds: www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bristol-royal-hospital-for-children/childrens-website/ The section on 'going to theatre' talks about surgery, but the general information about anaesthetics and day cases in the video is the same for an endoscopy.

On the RUH webpage there are also **Short films for children about having an anaesthetic** (this mentions operations/surgery but the general information is the same for an endoscopy).

Information for teenagers over 16 years & adults having an endoscopy at the RUH:

www.ruh.nhs.uk/patients/services/gastroenterology/endoscopy.asp

The information in the leaflet is based on professional guidelines including those of The European Society for Paediatric Gastroenterology: www.espgan.org/home

This leaflet is intended to be used together with specific advice from a health professional. Please contact your GP or medical team if you have any further questions or if you are concerned.

If you or your child has been seen by the paediatric coeliac team at the RUH they can be contacted by email on ruh-tr.paediatriccoeliacteam@nhs.net.

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Please contact the Patient Advice and Liaison Service (PALS) if you require this leaflet in a different format, or would like to feedback your experience of the hospital.

Email ruh-tr.pals@nhs.net or telephone 01225 825656.

