Royal United Hospitals Bath
NHS Foundation Trust

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.

Slightly different testing regimes used in older adults, and they 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, and so may also be offered testing.

It is important to diagnose coeliac disease accurately so that anyone who needs a gluten-free diet can start it promptly and receive appropriate long-term follow-up. A clear diagnosis also helps avoid unnecessary dietary restrictions when coeliac disease is ruled out. Some people do not have coeliac disease but are just sensitive to gluten; they may tolerate small amounts without the risk of long-term 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 produced, triggered by gluten.

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: A high TTG level, over ten times the normal upper level is very suggestive of coeliac disease. At the RUH the normal TTG is less than 8.0u/ml so a diagnostic level is over 80u/ml, but other labs may have different values.
To confirm the diagnosis a second separate blood sample is needed to test for endomysial antibodies (EMA) or a repeat TTG test. There does not need to be any specific time period between these tests. 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, 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 whilst on a gluten containing diet.
In some situations, we advise repeating the blood tests after a few months, while continuing a gluten-containing diet and occasionally an HLA dq2/8 blood test can be useful.

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. 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 or endoscopist).
- 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.
- 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 gastroenterology team. In older teenagers/adults the procedure is usually done with numbing spray in the throat plus sedation, so they are very drowsy but not fully asleep. Sometimes there is an option to have the procedure via the nose rather than mouth using a very fine telescope with just the numbing spray (trans-nasal endoscopy) without sedation.
- 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.

- 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:

Straight after the test you will be told if there was anything obviously abnormal noticed on the telescope test. However, with coeliac there is not usually anything abnormal to see and the changes are only seen under the microscope when the biopsy is looked at in the laboratory.

You will be informed of the biopsy laboratory ('histology') result by letter or telephone a few weeks after the test. The biopsy results will show if coeliac disease or any other problem is present and what the next step is.

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 ned of this leaflet.

If after looking at all the information, you decide you do not want to go ahead with an endoscopy you can discuss the options with your health care team. Sometimes the advice will be to start a strict gluten-free diet as if coeliac had been confirmed, the diagnosis should then be revisited in the future with reintroduction of gluten and repeat testing. Alternatively, the advice may be to continue a normal diet and repeat blood tests after a few months. HLA DQ2/8 blood tests may 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 these 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 can be 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 used in specific circumstances such as IgG tests. Dermatologists may do skin biopsy test for specific gluten related skin conditions (dermatitis herpetiformis)

Further Information:

Coeliac UK: 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. There is also information on the RUH paediatric dietetic webpage.
www.ruh.nhs.uk/ChildrensLeaflets - or scan QR code
https://www.ruh.nhs.uk/patients/services/clinical_depts/dietetics/paediatrics.asp

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: There as some good videos about anaesthetics etc. 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.

Information for teenagers over 16 years & adults having an endoscopy at the RUH:
www.ruh.nhs.uk/patients/services/gastroenterology/endoscopy.asp

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. The information in this leaflet is based on professional guidelines including those of The European Society for Paediatric Gastroenterology: www.espghan.org/home
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 Support and Complaints Team (PSCT) if you require this leaflet in a different format or would like to feedback your experience of the hospital.

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

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