

Family Testing for Coeliac Disease

This leaflet is for families where someone has a confirmed diagnosis of coeliac disease

Who else in the family should be offered testing for coeliac disease?

It is advised that 'first degree relatives' of someone with coeliac disease should be offered testing. This means offering testing to parents, brothers and sisters and children of the person with coeliac disease. Even those without symptoms can be at increased risk of complications such as iron deficiency or fragile bones if coeliac disease is untreated for a long time.

It is definitely not compulsory that anyone gets tested but something to think about. Coeliac UK can be a useful source of information to help this decision (www.coeliac.org.uk). Testing should be arranged by contacting the GP surgery to discuss. We suggest bringing a copy of this leaflet to the GP to assist them being sure which tests are required.

What tests should be done?

Testing should be with blood tests for 'TTG' (tissue transglutaminase IgA), plus ideally blood HLA-typing for DQ2/8

HLA DQ2/8 and TTG can be ordered via the standard GP lab order system. TTG tests are only useful if the person is on a gluten-containing diet (at least one portion gluten e.g. slice bread, bowl of pasta, most days for 6 weeks before the test)

What is HLA-typing DQ2/8?

Virtually all coeliac disease occurs in people with specific genetic types called HLA DQ2 or DQ8. However it is very common to be in these groups so it does not confirm coeliac disease (about 40% of UK population are DQ2/8 positive). People

who are **not** in these genetic groups are extremely unlikely to develop coeliac disease. This test result is not affected by the diet and does not alter over time.

What do the results mean?

- **TTG High:** Possible current coeliac disease, will need further investigation
- **TTG Normal:** No current coeliac disease (if on a gluten-containing diet)
- **Negative for both DQ2 and 8:** Risk of developing coeliac disease in the future virtually zero so no further tests needed.
- **Positive for DQ2 and/or 8:** There is an increased chance of developing coeliac disease during the person's lifetime so considered 'at risk' (probably around 1 in 10-20 will develop coeliac at some point, but most will not).
 - If someone is positive for DQ2/8 but has a normal TTG there is no need make any changes to the diet. Currently there doesn't seem to be anything that will reduce the chance of getting coeliac disease.
 - The person should know that they should ask about **a further TTG test in future** if they develop gastrointestinal symptoms or other symptoms that could be due to coeliac disease. (see Coeliac UK website for details of other symptoms).
 - HLA DQ2/8 only needs doing once, there is no need to repeat it as it does not change over time and it not altered by diet etc.

Further information:

Coeliac UK has lots more information about screening for coeliac and HLA DQ2/8 testing:

<https://www.coeliac.org.uk/information-and-support/coeliac-disease/about-coeliac-disease/causes/genetics/>

<https://www.coeliac.org.uk/information-and-support/coeliac-disease/getting-diagnosed/screening-for-coeliac-disease/>

NICE National Institute for Health Care excellence: Coeliac disease: recognition, assessment and management

<https://www.nice.org.uk/guidance/ng20>

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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 / 826319