The House of Discovery: work out what matters

To the patient

Has the patient got troublesome symptoms (eg GI symptoms, weight loss, fatigue) and is hoping for an answer, or is coeliac going to be completely unexpected? Will a diagnosis be received as good news (they have an answer) or bad news (a life-changing diagnosis)?

Did they ask for a coeliac test, or is this coming from the doctor? This will have a big impact on how prepared they may be for the diagnosis.

Do they have any prior experience of coeliac disease? eg from a family member.

What is their prior knowledge of coeliac disease? Most people know it is something to do with wheat, but there is often confusion between wheat intolerance exacerbating IBS and true gluten enteropathy. It is important that they understand both the gravity of the condition, and also the positive news that it is entirely treatable.

To the doctor

When to suspect
Coeliac is common – about 1% of the population - and underdiagnosed. Symptoms are often vague so the key thing is to think of it often and consider a test – eg tiredness, IBS or other GI symptoms, weight loss, iron/vitamin deficiency, osteoporosis.

Part of the autoimmune cluster including type 1 diabetes, autoimmune thyroid and liver disease, pernicious anaemia, Addison's, vitiligo – consider testing with these.

Family Testing
Coeliac runs in families, so first degree relatives should be offered a test (incidence is at least 5%) – this might be why your patient has come for a test, but is also something to advise a patient when they are diagnosed so that they can inform their relatives.

Coeliac is more common in people of Irish descent – possibly because of greater historical consumption of oats and potatoes rather than wheat and barley.

What to look out for in the *House of Discovery*

Finding dry rot

A negative test may be perceived as bad news if someone is looking for an answer, but a positive test is a life-changing diagnosis with implications for the rest of their life. The patient may need time to take this on board.

Are there any other diagnoses to consider? Does coeliac explain all the symptoms, or do other tests need to be done eg for severe weight loss? Are other autoimmune conditions present? - could be more bad news!

Tools for the toolbox

"It's not likely, but one thing I think we should check for is coeliac disease, since we wouldn't want to miss that"

"The test has come back positive for coeliac disease," (pause) "We will need to do a further test to confirm it, but it does seem likely that this explains how you have been feeling."

Tending the garden

While coeliac is not linked to an unhealthy lifestyle, there are implications for chronic disease management and follow up:

- 30% of people with coeliac have functional asplenia so vaccinations are recommended (see Foundations).
- Annual follow up to review symptoms and consider blood tests (see Foundations).
- Coeliac UK can offer good advice and support

Foundations

Based on NICE CKS coeliac disease 2016

Diagnosis For test to be reliable, should have eaten gluten containing foods twice daily for 6 weeks.

Measure transglutaminase antibody. This is an IgA antibody so can get a false negative in IgA deficiency, otherwise a negative result excludes coeliac.

The diagnosis must be confirmed with an endoscopy and duodenal biopsy while remaining on a gluten containing diet.

Vaccinations Pneumococcal and influenza vaccination recommended for all with coeliac. Theoretical increased risk of other capsulated bacteria (Meningococcal, HIB), but Meningitis vaccine only recommended where known asplenia, and HIB not recommended as very rare incidence in UK now. Risk of asplenia is greater if coeliac undiagnosed for a long time.

Dietary treatment Always involve a dietician, as it is complicated. Wheat, barley and rye are the sources of gluten, but oats are often contaminated so have to be specifically gluten free oats if eaten at all. Malt, in most beers, is made from grains so contains gluten; Malt whiskey is ok though, as it has been distilled. Contamination is a problem – eg chip shop chips are cooked in oil also used to fry batter; need to use a separate chopping board/toaster to those used for gluten-containing products.

The House of Decision: decide together what to do

Rooms to look out for

Empty Rooms

Aside from testing for coeliac, there are no lab tests for wheat intolerance or other intolerances (there are some dynamic tests for lactose intolerance, but they are not simple). Exclusion and rechallenge is the only way to test for more general intolerances. This can be hard to accept.

Locked Rooms

Diagnosing coeliac disease in a patient already on a gluten-free diet is very difficult. Patients should ideally add gluten back for 6 weeks before a blood test or an endoscopy, but this may not be acceptable to them. There are genetic tests, but not for use in primary care.

Room 101

There are several areas within coeliac disease which might be very difficult for the patient to accept or want to face:

- Having to remain on gluten while being tested.
- Having to have an endoscopy (some patients have a very strong aversion to this as it does sound very unpleasant!)
- The severity of a strict gluten-free diet, especially if someone feels well, or if combined with another auto-immune condition affecting diet like type 1 diabetes.
- The restrictions on drinking beer. Wine and spirits are fine (spirits made with grain are distilled, so all trace of gluten is removed).

Key decisions in the *House of Decision*

Coeliac disease does not leave much room for options for the patient; there is only one way to properly diagnose it and only one way to treat it, while leaving it untreated is very unwise.

The management of coeliac disease is therefore less about considering options and more about helping the patient to understand the diagnosis, working through the management with them in a supportive way that is clear, but does not become too dictatorial.

Key actions to take with a positive blood test:

- Stay on a gluten-containing diet
- Refer to gastroenterology for OGD and biopsy

Key actions to take once diagnosis is confirmed:

- Refer to a dietician
- Recommend vaccinations – influenza and pneumococcal
- Consider if a dexascan is warranted (esp older women)
- Recommend testing of first degree relatives
- Arrange annual follow-up

The High Tech Room

There is a lot to explain about coeliac – make sure you give yourself time!

It is important to get across how it is different to wheat intolerance. Some people may think that going gluten-free is a bit trendy these days. We need to explain to them that this is different - it is not just a matter of cutting down on gluten a bit but gluten must be excluded entirely.

Tools for the toolbox

"How much do you know about coeliac disease?" (don't ask "what do you know" – it sounds like a quiz!)

"Coeliac disease is common, and although it will have a big impact on what you can eat, the good news is that it is completely curable with the right diet"

Explaining about villous atrophy in the small intestine is probably too much detail for most patients, but to explain that gluten 'changes the lining of the gut so that it can't absorb nutrients properly' would get across the essence of what happens – and also explain the reason why it can take a while for symptoms to resolve and why you need to be on gluten for 6w before testing (since the changes take a while to develop and resolve).

Foundations

Lactose intolerance coeliac is a cause of secondary lactose intolerance and so it is often present at diagnosis and can take up to 2 years for the bowel to recover from this and produce normal levels of lactase.

Annual Follow-up to review symptoms, adherence to diet and weight.

Also consider blood tests to check for malabsorption and development of any other autoimmune conditions (thyroiditis, hepatitis, Addison's); hence FBC, Ferritin, B12/folate, U&E, LFT, TSH, Vit D, Calcium. Also check transglutaminase antibody for confirmation of adherence to diet (should be negative) although correlation with dietary adherence is not always reliable.

Cancer risk There is a very small increased risk of GI non-Hodgkin's lymphoma, but this seems to be linked to undiagnosed or poorly managed coeliac. After 10 years of a gluten-free diet this increased risk disappears. NO requirement for any cancer surveillance, but should be aware of the risk, especially when undiagnosed for some time.