DOWN'S SYNDROME ASSOCIATION

The Down Syndrome Medical Interest Group

Coeliac Disease

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A Down's Syndrome Association publication

What is Coeliac Disease



Coeliac disease is when the body reacts badly to gluten, which is a protein found in wheat, barley and rye. The wall of the small bowel (intestines) becomes inflamed, and its lining becomes flat. This makes it harder for the body to absorb vitamins, minerals and calories.

Coeliac disease is often diagnosed in childhood, but it can develop at any age, even if the person has not previously shown any signs of having the condition.

Coeliac disease is an autoimmune condition and it is more common in people who have Down's syndrome.

Autoimmune conditions are diseases where the immune system, the body's defence mechanism against infection, attacks parts of the body in the same way that it would attack a germ and damages it.

With coeliac disease, the immune system wrongly identifies certain substances found in gluten as a threat to the body and attacks them. This is what causes the damage to the small bowel.

Here are some of the more common symptoms of coeliac disease:

- Diarrhoea (which may be quite smelly) or constipation
- Indigestion
- Weight loss
- Stomach aches
- Passing wind and bloating
- Feeling tired, lack of energy or motivation (because the body is having difficulty taking in nutrients from food)
- In children, not growing at the expected rate
- There can be other reasons for these symptoms to occur rather than coeliac disease. If someone who has Down's syndrome is showing some of these symptoms, they should see their doctor.



How is it Diagnosed?

The process of diagnosing coeliac disease starts with an assessment of a person's symptoms and a physical examination. If coeliac disease is suspected, the doctor will arrange for a blood sample to be taken. The blood sample will test for the antibodies that are usually present in coeliac disease. The doctor may also suggest a short trial of cutting out certain gluten-containing foods from the person's diet to see if this helps.

If antibodies are present, the doctor will make a referral for further testing. This will usually be to a gastroenterologist. They may arrange more blood tests or perform an endoscopy. An endoscopy involves a flexible tube with a small video camera (endoscope) being fed through the mouth and down into the small bowel where a sample of bowel wall will be taken for analysis. A local anaesthetic or sedative is often used to help the patient relax. A biopsy is the only way to be certain that a person has coeliac disease.



It is possible to have coeliac disease and not have the antibodies in your blood. If symptoms continue, the doctor may still make a referral anyway.

There is no formal coeliac disease screening programme in the UK for people who have Down's syndrome. If there is any evidence (even if it appears relatively minor) to suggest that a person may have the condition, their doctor should be asked to carry out tests.

Coeliac disease should be discussed as part of an Annual Health Check. Everyone who has Down's syndrome over the age of 14 years is entitled to a free Annual Health Check with their GP.

How is Coeliac Disease Treated?

Once the diagnosis has been made, the person with Down's syndrome will need a gluten-free diet. Even a small amount of gluten can cause the symptoms already discussed. This means wheat, barley and rye should be avoided. It is important that a gluten-free diet is balanced and healthy. Your GP can give help and advice about managing with a new gluten free diet. You may be referred to a dietician for support and advice.



Some people may need to take vitamins and minerals while the body repairs itself.

How will my Son/Daughter Manage With Their new Diet?

We know a number of adults who, with support, manage very well with sticking to a gluten-free diet. To stick to the diet, the person needs to learn about the foods and other non-food substances (e.g. some medications, lipsticks, stamps), that may contain gluten. Most people will need help and support with this to varying degrees.



Visual supports can be useful to help teach about the new diet. These could include a resource around recognising gluten-free foods and packaging labels. There is an internationally recognised 'Crossed Grain' Symbol that is found on packaging for gluten-free foods.

It may be useful to think about how to give your son/daughter the means of explaining that they have Coeliac Disease. This may be through teaching them the words they need to know and/or giving them a way to let strangers know about their Coeliac Disease (e.g. a laminated card with gluten free written on it to present to a waiter or shop assistant)

Sources of Support

Coeliac UK has lots of information about living with Coeliac Disease.

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