

# Health and well-being

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## Coeliac disease

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People who have Coeliac disease have a bad reaction 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 and 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 that 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. 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)
- Weight loss
- Abdominal pain/discomfort
- 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, of course, be other reasons for these symptoms to occur rather than because someone has Coeliac disease. If someone who has Down's syndrome is showing some of these symptoms, make an appointment for a check-up with their doctor.

The process of diagnosing Coeliac disease starts with an assessment by a doctor of a person's symptoms and a physical examination. If the evidence suggests the person may have Coeliac's disease, the doctor will arrange for a blood sample to be taken. The blood sample will be tested for the antibodies that are usually present in people who have Coeliac disease. The doctor may also suggest a short trial of cutting out certain foods from the person's diet to see if this helps.

If the antibodies are present, the doctor will make a referral for a biopsy of the gut. This will usually be performed by a Gastroenterologist and 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 tissue 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 for a biopsy 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 because 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. It may also be a good idea to avoid oats for a while; seek advice about this.

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

### **How will my son/daughter cope with their new diet?**

We know a number of adults who, with support, cope very well with sticking to a gluten-free diet. In fact the tendency of people with Down's syndrome towards sameness and repetition can be usefully employed in some individuals to make sure they stay on track with their new 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)

## Further information and advice

If you have any questions about health issues, you can call DSA's Helpline (Tel: 0333 1212 300) or email using [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk) . If an information officer is unable to answer your question, they can make a referral to the medical adviser at the UK Down Syndrome Medical Interest Group (DSMIG). Please note DSMIG can provide general advice about health issues but they are not able to comment on individual test results. DSMIG are happy to take enquiries from health professionals but they will not take direct from enquiries from families or supporters.

## Resources and useful information

### DSA

[Gastrointestinal – Children \(Health Series\)](#)

[Gastrointestinal – Adults \(Health Series\)](#)

[Tips for supporting a person to have a blood test](#)

### Other

Coeliac UK – information about living gluten free  
[coeliac.org.uk/home/](http://coeliac.org.uk/home/)

Books Beyond Words - A resource for people who have learning disabilities about constipation called 'The Trouble With Poo'

### Contact us

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