

FACTSHEET

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Coeliac disease

What is Coeliac disease?

Coeliac Disease is a condition where the lining of the small bowel is damaged due to a protein in food called gluten. Gluten is found in grains such as wheat, barley, triticale and rye. Proteins very similar to gluten are found in oats and may also cause coeliac disease.

When gluten is included as part of the diet, this can lead to damage of the tiny finger-like projections (called 'villi') in the small bowel. The villi are responsible for absorbing food. The inflammation caused by gluten makes the villi flat, which can lead to poor absorption of the nutrients found in food.

How common is it?

There is now more awareness about coeliac disease in the community, but the incidence of coeliac disease is also increasing. It is estimated that coeliac disease affects around 1 in every 100 people. It is more common in people of European descent, but can affect anybody. It rarely occurs before 12 months of age. It can affect children of any age after they start eating foods containing gluten.

The development of coeliac disease is related to both genetic and environmental factors. Close relatives of someone with coeliac disease have an increased risk of developing the disease (estimated at up to 10%).

Coeliac disease can also develop with other autoimmune conditions such as type 1 diabetes and thyroid disease. It is also more common in people with chromosomal conditions such as Down syndrome (trisomy 21).

What are the symptoms?

Coeliac disease can lead to a number of symptoms, however some children have few symptoms or even none at all. The symptoms usually relate to the changes in the surface of the gut and the poor absorption of energy, vitamins and minerals. Symptoms can include:

- Abdominal pain
- Bloating
- Diarrhoea
- Vomiting
- Constipation
- Irritability
- Poor weight gain or even weight loss and slow growth.
- Deficiencies of vitamins and minerals, especially iron, can lead to anaemia (looking pale and feeling tired)
- Osteoporosis (brittle bones from low calcium and vitamin D)
- Mouth ulcers
- Unexplained fever.

Some children may not have any symptoms but blood tests can be done to check if there is a concern about their growth, or they have a close family history (usually a parent or sibling) or another medical problem known to be associated with coeliac disease (e.g. diabetes, Down syndrome).

How is it diagnosed?

Screening for coeliac disease is initially done with blood tests, but confirmation of the diagnosis requires a biopsy from the surface of the small bowel. As coeliac disease is a life-long condition, it is important that the diagnosis is

confirmed with the biopsy as blood tests alone can overcall the diagnosis (5-15% false positive screening tests when compared to biopsy). Gene testing for coeliac disease is generally not recommended as a positive gene test result is not diagnostic of coeliac disease.

The blood tests include looking for increased levels of antibodies (such as anti-gliadin, deamidated gliadin, anti-endomysial and anti-tissue transglutaminase antibodies). These antibodies have to be performed in conjunction with the blood test 'Total IgA' to help interpret the antibody results. When these antibodies are raised, the diagnosis of coeliac disease becomes more likely and a referral to a paediatric gastroenterologist is required for further assessment and a biopsy.

This may take time but it is essential for your child to remain on their regular diet containing gluten until the biopsy is done.

The biopsy is done under general anaesthetic. Biopsies (superficial pieces of the small bowel lining) are taken using an endoscope (a flexible tube with a camera attached to its end) that is passed via the child's mouth into the stomach and then the small bowel.

What is the treatment?

Once coeliac disease is confirmed, it is important to fully exclude gluten from your child's diet for life (gluten-free diet (GFD)). The GFD needs to exclude all sources of gluten, as eating small amounts of gluten can cause further damage to the gut and affect growth even though it may not lead to symptoms. It is important to meet with a dietitian to learn about the GFD to make sure that you are given the right advice about your child's diet.

Many common foods need to be replaced with gluten-free alternatives. These include:

- Breads
- Biscuits
- Cereals
- Pasta

Also you will need to learn to identify hidden sources of gluten, particularly in commercially packaged food. It is important that even small amounts of gluten-containing foods are not given to your child, even if your child does not seem to get symptoms from these foods.

Once your child is on a GFD, the inflammation in their small bowel settles without any other medications and their gut will heal. As there may be low levels of some vitamins and minerals, sometimes your doctor may suggest that your child has extra supplements initially. Your doctor may also suggest that your child has a low lactose diet for a short period. This is because the

changes of coeliac disease can lead to a lack of sugar-splitting enzymes, which are located on the villi. These enzymes return to normal levels once your child's bowel recovers with the GFD.

It is important for your child to have follow-up with their dietitian and their doctor to make sure that they recover as expected and remain well with normal growth. Your doctor will monitor your child's growth and do regular blood tests to ensure that the coeliac antibody levels have returned to normal. It may take time (sometimes over a year) for the antibody levels to return to normal. Monitoring the antibody levels also helps the doctor make sure that your child is adhering to the GFD.

The future

The Coeliac Society offers support to people affected by coeliac disease and their families. Your doctor can help complete a membership application after the diagnosis is established if you wish to join (website details below).

Currently researchers are working to develop genetically modified grains that will be safe for people with Coeliac disease. Other research is focusing on whether some oats can safely be included in a gluten free diet. In Australia at the moment, it is recommended to exclude all oats from the diet. You should discuss these issues further with your doctor.

For more information

Coeliac Society of Australia

www.coeliac.org.au

Remember

- Coeliac disease has many symptoms ranging from none to severe.
- Make sure your child stays on a normal diet containing gluten until the diagnosis is confirmed with a biopsy.
- A life-long gluten-free diet is the treatment for coeliac disease.
- A dietitian is essential in the care of your child, to make sure that your child's diet is right.