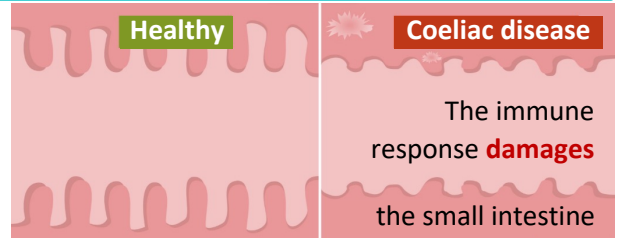


# Coeliac disease

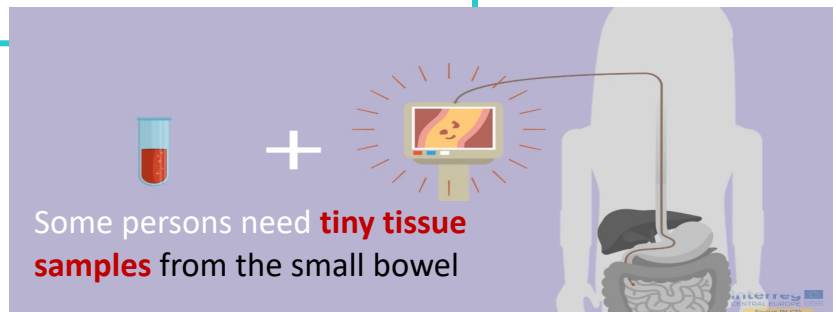
## What is coeliac disease?

- Persons with coeliac disease show an abnormal reaction to gluten.
- The abnormal reaction leads to damage of the own body-tissue, particular in the mucosa (lining) of the small bowel. The body produces substances (**antibodies**) against own tissue (**tissue-transglutaminase and endomysium**). Therefore, coeliac disease is an **auto-immune-disease**.



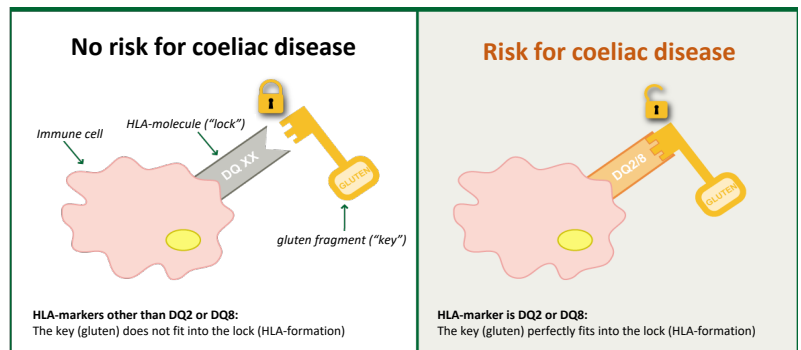
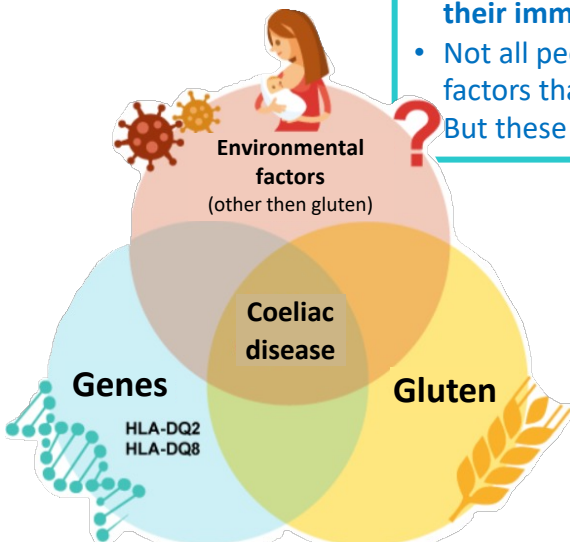
## How is it diagnosed?

- These abnormal **antibodies** can be measured in blood and help to diagnose coeliac disease.
- In some children the **diagnosis** is made by **blood tests** only. In others, tissue samples (**biopsies**) from the small bowel are additional needed to prove the damage in the mucosa.
- The mucosa heals and antibodies become normal when the person keeps a strict **gluten free diet**.

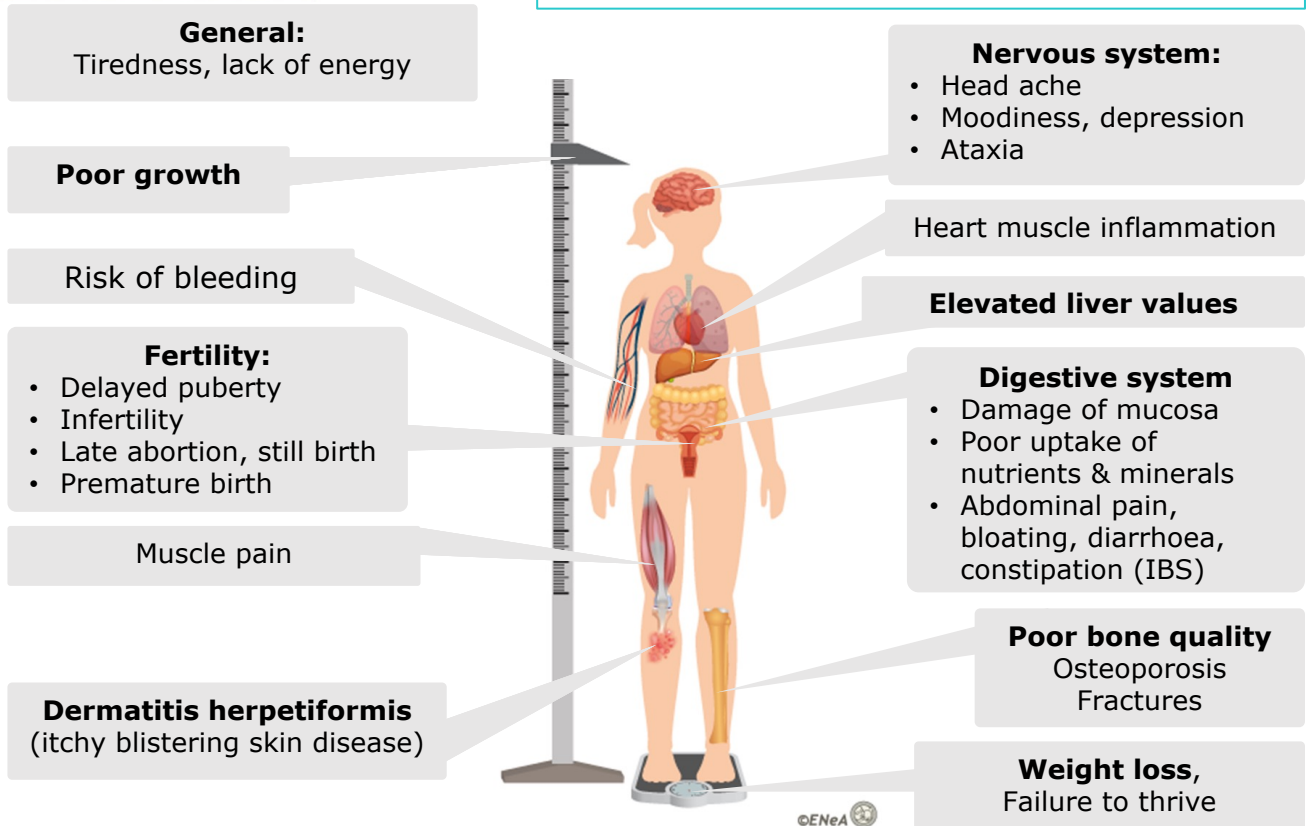


## Who is at risk for coeliac disease?

- The abnormal response occurs only in persons with **certain markers on their immune cells**, called **HLA DQ2 / DQ8**.
- Not all people having HLA DQ2 or DQ8 develop coeliac disease. Other factors than gluten play a role, e.g., from our environment or lifestyle. But these factors are still unknown. The disease cannot be prevented.



## Possible signs of coeliac disease



- Coeliac disease mostly starts in the first years of life. **Not all** persons with coeliac disease **have signs or symptoms** in spite of having a damaged mucosa. Symptoms are very variable, unspecific and can be outside the digestive tract. They may develop years or decades after the disease has started.
- Therefore, the **diagnosis of coeliac disease is commonly missed**. Only those with more severe symptoms are diagnosed (“the tip of the coeliac iceberg”).
- Coeliac disease occurs in about 1 of 100 persons. **First degree relatives** (siblings, parents & children) have the disease **8 times more likely**. Therefore, they should be tested. The **blood test for tissue-transglutaminase antibodies (tTG or TGA) finds cases with and without symptoms**.

### Classic coeliac disease: symptoms of malabsorption

- Positive antibodies
- Villous atrophy
- Symptoms from the digestive system

### Symptomatic coeliac disease: unspecific symptoms

- Positive antibodies
- Villous atrophy
- Symptoms outside the digestive system

### Subclinical / asymptomatic coeliac disease

- Positive antibodies
- Villous atrophy
- No symptoms

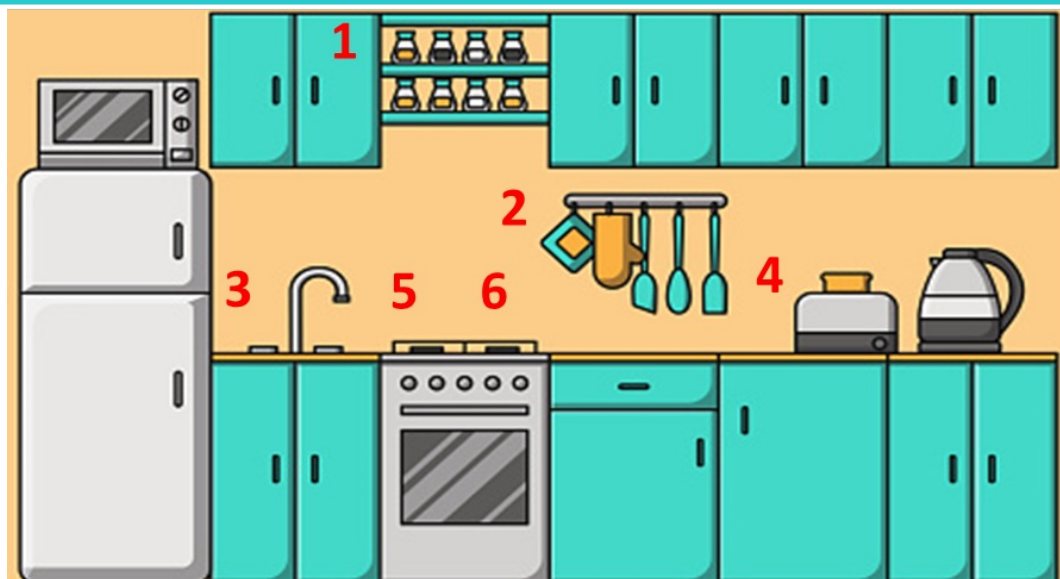
Gluten containing grains and their products	Gluten-free if fresh & not processed	Gluten-free cereals and legumes
<ul style="list-style-type: none"> <li>• Wheat</li> <li>• Barley</li> <li>• Rye</li> <li>• Spelt</li> <li>• Emmer</li> <li>• Dinkel</li> <li>• Bulgur</li> <li>• Triticale</li> <li>• Couscous</li> <li>• Oats (if <u>not</u> labelled as gluten free)</li> </ul>	<ul style="list-style-type: none"> <li>• Meat</li> <li>• Fish</li> <li>• Eggs</li> <li>• Fruits</li> <li>• Vegetables</li> <li>• Potatoes</li> <li>• Yuca</li> <li>• Tofu</li> <li>• Milk, cream</li> <li>• Cheese (with no added ingredients)</li> <li>• Nuts (natural, roasted)</li> </ul>	<ul style="list-style-type: none"> <li>• Rice</li> <li>• Sorghum</li> <li>• Maize/corn</li> <li>• Oats (if labelled as gluten free)</li> <li>• Millet</li> <li>• Chia</li> <li>• Buckwheat</li> <li>• Quinoa</li> <li>• Treff</li> <li>• Lentils</li> <li>• Chickpeas</li> </ul>

## Therapy

- The only effective therapy is a **life-long** diet strictly avoiding gluten (**gluten free diet**).
- Packed food products labelled with the **Crossed Grain Symbol** or “Gluten free” are safe. 
- With the diet, the mucosa heals, latest after 3 years.
- With a strict diet free of gluten the **prognosis is excellent without complications**.
- With dietary mistakes, the body remembers and responds: the damage starts again.
- Keeping the diet is not easy. But you and your family will “grow into it”.

## The most important measures when you get home to avoid cross contact with gluten

1. **Store gluten-free products in separate closed containers** and label them clearly.
2. **Use clean** kitchen utensils.
3. **Hands and surfaces** should be cleaned before preparing gluten free foods (water is sufficient)
4. **Toaster:** Shared for gluten free and gluten containing food is possible, but keep it crumb free
5. **Pasta:** Prepare gluten-free pasta in clean pot with fresh water. Drain first the gluten-free pasta, and second the gluten-containing pasta if sharing the colander.
6. **Fried foods:** Gluten-free foods should be fried first, thereafter gluten-containing foods.





## Get help

- **Dietary counselling** by a professional dietician experienced with gluten free diet.
- **Patient support organizations** (“coeliac society”) provide support and written material
- **Peer groups** for children, adolescents, adults and parents of affected children
- **Psychologist**, in case your child needs support to deal with the diagnosis or the diet
- **Doctors** for regular check up to control growth and development and perform blood testing for antibodies every 6 months until normalized. Thereafter, every 1 or 2 years. Earlier if symptoms occur.
- **Inform** family, friends, teachers in kindergarten & school. Ask to support your child to keep the diet
- **E-learning tool for patients and parents:** to learn more (available in English and 8 other languages)

## Important points

- **Keep the written report** with the results of your child confirming coeliac disease diagnosis on a safe place with other medical records
- **See dietician:** Name, Telephone number:
- **Next appointment with doctor:** Date, Time
- **Link to e-learning tool:** [www.celiacfacts.eu](http://www.celiacfacts.eu)
- **Contact to coeliac support organization:** Name, address, website

