

#### Deutsche Zöliakie Gesellschaft e.V.



## **Coeliac disease** Living with a gluten-free diet



### What is coeliac disease?

Coeliac disease is a chronic disorder of the small intestine, caused by a **life-long intolerance** toward a **protein** called **gluten**. Gluten is found in grains, mainly **wheat**, **spelt**, **rye**, **barley** and **commonly used oats**.

In the small intestine, foods are split into their components, which are then absorbed into the body by the small intestine's mucous membrane. To make sure that the body can be supplied with sufficient nutrients, the small intestine is equipped with many folds, the so-called villi. In sufferers of coeliac disease, **consumption of gluten** triggers an **auto-immune reaction of the mucous membrane in the small intestine**. The villi atrophy. This makes the surface area of the small intestine smaller and smaller, and the body can no longer absorb enough nutrients, which can cause deficiency symptoms.

#### What symptoms can occur?

The most common symptoms are:

- → Diarrhea
- → Vomiting
- → Growth disorders
- Poor concentration
- Lack of appetite
- → Deficiency symptoms
- Moodiness/ weepiness

### The diagnosis

Because of the many changes coeliac disease can bring to a person's life, a firm diagnosis is absolutely crucial. A blood test while the patient is on a glutencontaining diet to detect transglutaminase antibodies, endomysium antibodies and gliadin antibodies can provide initial important indications of coeliac disease. The final confirmation of the diagnosis requires a biopsy of the small intestine. The small **intestine biopsy** used today is harmless and takes no more than 10-15 minutes. A camera probe is inserted via the mouth, esophagus and stomach into the small intestine. Several tissue samples are taken and examined histologically.

The **antibody test** alone cannot replace the biopsy of the small intestine. Stool examinations, quick tests or IgG4 allergy tests also cannot provide a reliable and firm diagnosis of celiac disease.

### The treatment

The only way the smoothed mucous membrane of the small intestine will permanently regain its normal shape and function is with a **life-long**, **strictly gluten-free diet**. Even miniscule amounts of gluten can cause the damage to recur! As long as coeliac patients stick to the gluten-free diet, they generally experience no symptoms. Since there are no alternative treatments for coeliac disease, sufferers must completely change their diets and possibly their lifestyles! However, in most cases noticeable improvement is felt just a few days after switching to a gluten-free diet. The patient's general well-being improves and the symptoms abide. The time it takes to become completely free of symptoms can vary greatly, depending on, among other factors, the degree of damage to the small intestine, the patient's age, and sometimes initial (hidden) mistakes in terms of diet.

A subjectively perceived lack of symptoms after violating the diet does not mean that the gluten-free diet can be discontinued.

Often, perceptible symptoms caused by gluten in the diet do not return until much later, sometimes years later. Long-term effects after discontinuing the gluten-free diet can lead to severe illnesses, which then make the healing process much more difficult.



### A quick overview of foods

#### 😕 Contains gluten

→ Wheat, rye, spelt, barley, commonly used oats, green spelt, einkorn wheat, wild emmer, ancient wheat, Kamut<sup>®</sup> (Khorasan wheat), Triticum species and other wheat derivatives

and all products made from those grains, such as: flour, grits, pearl barley, flakes, bread crumbs, pasta, bread, buns, gnocchi, pizza, dumplings, couscous, bulgur

- breaded vegetables
- → breaded meat and fish products, surimi, fried herring, bread sausage, meat products with vegetable proteins (wheat)
- → dairy products with added grains
- → beer, malt beer, grain coffee, malt coffee

#### **Added gluten possible**

- → corn flakes, millet bread, buckwheat bread, soy pasta, "gluten-free" baked goods from regular bakeries ready-made meals, thickened soups and sauces
- → dried fruit, preserved vegetables and fruits with additives
- → meat products, seasoned and / or marinated fish and meats
- → Light products, cream cheese products, cooked cheese, cheese with added seasonings and herbs, imitation cheese, pudding, desserts
- → flavored teas, powdered drink mixes, isotonic drinks, liqueurs, whisk(e)y
- prepared seasonings, seasoned salt, soup seasoning, seasoning mixes, seasoning sauces, curry powder, French fry seasoning salt, soy sauce, ketchup, malt vinegar
- → oils with added seasonings and herbs
- → French fries, mashed potatoes, croquettes, potato pancakes, potato chips

#### Gluten-free

- amaranth, canihua, millet / teff, corn, quinoa, rice / wild rice, soy Caution: Buy buckwheat and oats only if specially labeled "glutenfree", because of high risk of contamination
- → all unprepared fruits and vegetables
- → Fresh, un-breaded, unseasoned fish and/or meats (pork, lamb, poultry...) eggs, tofu (natural)
- cheese (emmentaler, sheep's and goat cheese, gouda, mozzarella, parmesan...)
  milk, dairy products (yoghurt, cream, curd cheese, buttermilk...)
- → mineral water, coffee, tea, fruit and vegetable juices without additives, wine, sparkling wine
- pure spices (salt, pepper, paprika, nutmeg, caraway ...) all fresh and frozen herbs mustard, vinegar without additives
- → butter, margarine, vegetable oils potatoes "natural" sugar, jams, preserves, honey, maple syrup

**Oats** and oat products **not contaminated** with gluten-containing grains are permitted in a gluten-free diet provided they do not cause any symptoms.

Good to know: As little as 1/8 gram of wheat flour damages the small intestine and can cause symptoms.

### Avoid contamination – the safe gluten-free kitchen

Since even very small amounts of gluten can harm you, you should be especially meticulous and clean when working in your kitchen. Even small amounts of contamination, e.g. gluten-containing foods stuck to dishes or



cutlery or crumbs must be avoided. You should therefore be particularly careful if gluten-containing foods are prepared for other family members at the same time.

# How to create a safe gluten-free kitchen

- Clean your work surfaces thoroughly and wash any other surfaces and cupboards with a clean damp cloth, checking any crevices for crumbs.
- → If you will also be cooking normal meals in your kitchen, reserve a particular part of the clean work surface and the top sections of cupboards for gluten-free foods. No gluten-containing foods should be stored or prepared in these spaces.
- → Buy a new bread basket, toaster, and hand mixer. Use these exclusively for gluten-free foods.
- → Wash all kitchen tools, baking sheets, storage containers etc. in the dishwasher or thoroughly by hand before using them for gluten-free foods.
- → Wash all dishes in the dishwasher or thoroughly by hand with fresh warm water and a clean sponge or dishcloth.
- → Be sure that no gluten-containing crumbs get into your bread spreads (butter, jam, meat spread, cheese spread...)
- → Always use special pots and cooking utensils when cooking glutenfree meals.
- → If you touch gluten-containing foods, wash your hands thoroughly with fresh warm water.
- → If you prepare gluten-free and gluten-containing meals at the same time, use the gluten-free ingredients first. In the oven, bake glutenfree meals above the gluten-containing ones and do not use the fan.



### Membership

The annual membership fee of the Deutsche Zöliakie-Gesellschaft e.V. is EUR 45.00 per calendar year. There is also a one-time administrative fee of EUR 15.00 when you join.

For family members who are also members of the DZG, the annual membership fee is EUR 3.00.

Of course, persons with low incomes can request a reduction of their membership fees. Proof of income is required.

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I am interested in becoming a member. Please send me your joining documents:

- I suffer from coeliac disease myself
- I have a child with coeliac disease
- I have dermatitis herpetiformis Duhring
- I have diabetes mellitus combined with celiac disease
- I am not a sufferer, but would like to support your work with my membership

Name, first name
Sreet, treet number
Postcode, city
Telephone
Email

Datum, signature

### What does the DZG offer?

Our members receive a comprehensive information packet, which includes:

- → Detailed information material on coeliac disease
- → The current "List of gluten-free foods and medications"
- → The quarterly member magazine "DZG Aktuell"
- → An extensive recipe collection
- The "Request to the cook" in many languages in a convenient format
- The "Coeliac Disease Passport"
- The publication "DZG Medizin", a compendium of current medical information

### The DZG offers its members telephone consultations with doctors and nutritional advice by phone.

#### **Basic documentation**

Members receive the current list of gluten-free foods and medications every year. The lists are updated on a quarterly basis. You receive the updates together with your member magazine DZG Aktuell.

#### **Member** magazine

The member magazine DZG Aktuell regularly publishes current information on coeliac disease, medical articles and information on a gluten-free diet, vacation tips, new gluten-free products, travel and restaurant tips, as well as invitations and reports on events organized by the DZG.

#### **Conversation groups / contact persons**

The many members who volunteer their time to work as contact persons are an important initial source of support for all newly diagnosed sufferers in Germany.

#### **Baking courses**

The contact persons organize baking courses where members can practice working with gluten-free flour. The baking courses are very popular as a chance to meet other sufferers. The dates are published online in the schedule of events for each conversation group.

#### New diagnosis seminars

The new diagnosis seminars provide assistance for a successful start in gluten-free everyday life.



#### Leisure activities for children, adolescents and adults

Volunteer members of the DZG regularly organize leisure activities, city trips, or hiking weekends to foster contact and exchange among members. The current program is available at www.dzg-online.de.

### Tips for getting started

As a **member of the DZG** you receive comprehensive information material or you can browse the information online in the members' section. Read the "List of gluten-free foods" at your leisure, in particular the general information contained in the list. Browse the list of products attentively, a section at a time, to find out if the products you are accustomed to using are gluten-free, or what alternatives you might select instead.

Examine the contents of your kitchen cupboards and your pantry: Any stocks of foods that contain gluten must be sorted out. Foods that may contain gluten should be checked against the foods list. The list often contains an alternative from a different producer for these products!



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Also look for this symbol! It identifies foods that are gluten-free.

### Donations

The many activities of the DZG are financed primarily with membership dues. That way, the DZG can do its work in the interest of members independently of external influences. In addition, the DZG has been awarding the DZG Research Prize since 1997. It supports research projects on celiac disease, and has in the past funded a number of pioneering research projects on the development of celiac disease.

Your donation will allow us to continue to represent the interests of celiac sufferers and important research projects.

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