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CD SKILLS

A guide to living with celiac disease

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This e-brochure contains advice relating to gluten-free diet and gluten-free living, but it doesn't replace medical advice from your doctor, dietitian, or any other specialist. It is absolutely recommended to visit your physician and to follow his advice.

Living with coeliac disease

You have probably just been diagnosed with coeliac disease and you have to change to a gluten-free diet, which will enable you to control your health.

The first steps will not be easy and your head is probably overloaded with new information, but a coeliac diagnosis is not the worst thing, although it can feel like the end of your world.

This booklet/guide will provide you with information about coeliac disease, its symptoms, diagnostic methods and treatment, the importance of dietary adherence and regular follow-up as well as the recommended screening of family members. It will offer you guidance about living a gluten-free life, about changes in your lifestyle, where to find necessary information, patient support, and answers to your questions. Using this guide, you will find that eating, cooking and travelling gluten-free can be easy. Our tips will help you to transform your kitchen into a gluten-free zone or at least into a safe environment where the risk of gluten contamination is minimized. We recommend you to watch our "Gluten-free kitchen" video tutorial, available at our project website http://www.interreg-danube.eu/approved-projects/cd-skills.

You will find a detailed gluten-free bread recipe and some gluten-free shopping tips. You will also see that a gluten-free diet can be rich and varied. You will soon be able to leave your symptoms and suffering behind by following a diet, a treatment that involves no medications, no side effects, and no surgical procedures. All you have to do is cut "gluten"- a protein fraction from wheat, rye, barley, and in some cases oats or their crossbred varieties, and its derivatives out of your diet. By cutting out gluten, your body will begin to recover, however, it is crucial to assure that your diet is properly balanced. The fact is, a lot of foods are perfectly safe for you: meats, vegetables, fruits, fish, and most dairy products (natural and unprocessed). Rice, corn, potato, buckwheat, quinoa, and millet are all safe, as long as they are not contaminated with gluten. This booklet/guide will support you to make a smooth transition into your new lifestyle.

Make an effort to learn all you can about your condition. Read recently published books written by acknowledged experts and turn to websites run by national coeliac organizations, noted coeliac research centres, and trusted publications. The Internet can be a source of material but some of it might not be reliable.

We suggest you join a coeliac disease patient support group (coeliac society), which will give you plenty of information, food samples, tips for local restaurants, physician recommendations, recipes, and, of course, friendship and emotional support; they organize various meetings, parties, picnics, camps, trips, and much more. We wish you a balanced gluten-free everyday life at home, on the go, and when dining out. If you would like to learn more about coeliac disease, please refer to our website and join our e-learning course for patients, which is available at www.celiacfacts.eu.

Dear reader, we hope that you will find a lot of helpful information reading our booklet/guide. We sincerely hope that it will help you to better organize the very demanding gluten-free life you are about to live. We also wish that meeting your everyday challenges of coeliac disease will be less stressful with our help.

Asst. prof. Jernej Dolinšek, MD, PhD

About coeliac disease

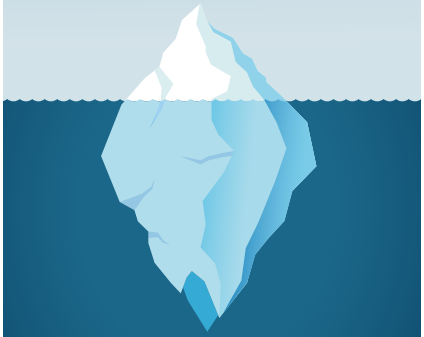
Coeliac disease is an autoimmune systemic disorder caused by ingestion of gluten and related proteins found in wheat, rye, barley, and in some cases also in oats in genetically predisposed individuals. It is one of the most common chronic diseases among children and adults and affects about 1% of the population in Europe. However, many patients remain undiagnosed.

Coeliac disease is a complex disorder strongly associated with HLA-DQ2 or DQ8 haplotypes and specific immunological and environmental factors. In coeliac disease patients, ingestion of gluten triggers chronic damage of the small intestine. The consequence of the morphological changes in the intestinal lining is its weakened function with symptoms of malabsorption. The characteristic clinical symptoms of the disease, such as diarrhoea and malabsorption syndrome, are not the most common forms of the disease anymore. Atypical symptoms and silent forms of the disease are becoming more and more frequent. Based on the clinical picture, coeliac patients can be divided into two groups: symptomatic and asymptomatic coeliac disease. The symptomatic coeliac disease usually presents with gastrointestinal or extra-intestinal symptoms and signs. The term asymptomatic or silent coeliac disease is used to refer to patients who were diagnosed with changes of intestinal mucosa characteristic for coeliac disease, although they seem to be clinically asymptomatic. Diagnosis of coeliac disease is primarily based on the clinical picture. However, the final diagnosis is always based on the presence of a specific reversible immune response and in the majority of patients also on detecting histological changes of the small intestine. In some cases, the diagnosis can be made without an intestinal biopsy. It is important, that patients do not start with a gluten-free diet before they receive the final diagnosis. The only possible way to treat coeliac disease is a very strict lifelong gluten-free diet, which improves the clinical picture, normalizes the level of antibodies, and restores the damaged intestinal lining. Following a strict diet is also the only way to prevent the development of serious long-term effects of the disease. The most significant risk factor for long-term complications is inadequate gluten-free diet compliance.

TEST
YOUR KNOWLEDGE ABOUT COELIAC DISEASE

If you want to test your knowledge, please contact the lead partner.

The coeliac iceberg is large, representing 1% of the total population. However, only a small proportion of these patients is detected, corresponding to the tip of the iceberg. Various data show that only 10% of patients are detected due to symptoms and signs, whereas 90% can remain undiagnosed for a longer period.



The size of the submerged part depends very much on patients' awareness, knowledge of healthcare professionals, and availability of reliable diagnostic tools.

Prevalence and symptoms of coeliac disease

Coeliac disease (CD) occurs in 1 of 100 people in Europe and it is more frequent in women. Family members of patients are more often affected than the general population.

Possible symptoms and signs of coeliac disease

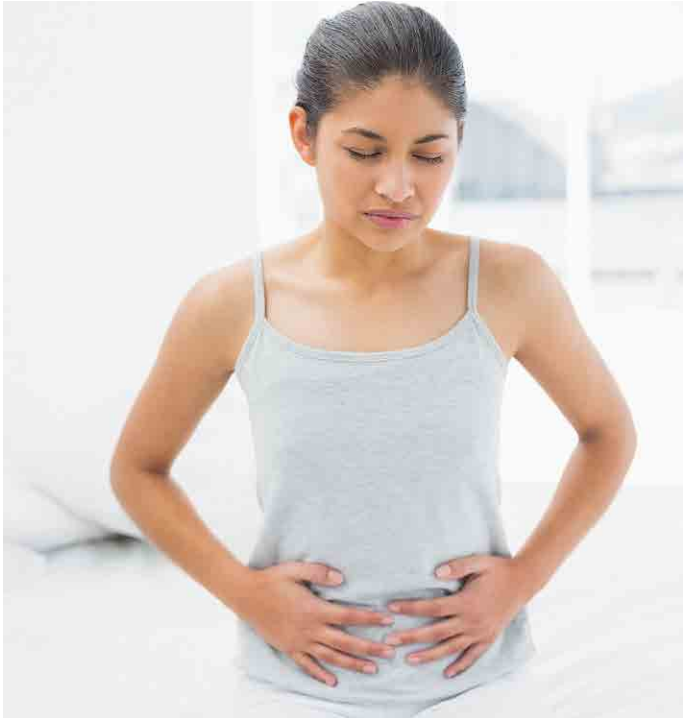
In coeliac disease, almost all organs can be affected, but the pattern of the damage is not unvarying and not all types of symptoms can be attributed to coeliac disease. Symptoms are usually a consequence of a combination of inflammation, nutrient deficiencies due to subnormal absorption, and autoimmunity to the enzyme transglutaminase (TG2). Antibodies against transglutaminase are produced early in the course of coeliac disease. Transglutaminase is present in the mesh-like architectural frame of tissues, called reticulin fibres, and is responsible for the integrity of connective tissue by making firm connections between molecules. The binding of coeliac antibodies to TG2 may disturb the normal interactions of TG2 with other proteins and may lead to structural alteration in different organs.

Coeliac disease can be present even in the absence of the actual symptoms. Many patients can be diagnosed by screening by means of demonstrating the coeliac-specific immune reaction from the blood, and in these cases, early diagnosis can prevent worsening of the clinical condition and development of complications.

Although coeliac disease causes impairment of intestinal absorption, gastrointestinal symptoms nowadays occur only in about half of the patients. There are vulnerable periods of life when high nutrient demands may lead to severe symptoms faster or more often. These are early childhood (1-4 years of age) and puberty, both characterized by a fast spurt in growth, and lactation period after giving birth in women. Most coeliac disease patients are, however, symptom-free during childhood or have non-specific or mild complaints for which no medical advice is sought. Some symptoms or signs, such as low bone mineral density or neurological problems may become apparent only after decades.

Stomach and gut

Diarrhoea, bloating and flatulence are common symptoms of coeliac disease. Reduction of the absorptive surface of the gut leads to decreased absorption of nutrients which partly remain in the gut and can cause diarrhoea, fatty, pale and bad-smelling stools, or an increase in the stool volume. Harmless bacteria normally present in the lower part of the gut may further degrade the gut content, which may lead to excessive production of gas and distension of the gut walls. This distension can be uncomfortable and can lead to some pain. Furthermore, changes in the gut content often cause changes in the composition of gut bacteria and those, which produce



more gas or acidic metabolites, may cause more symptoms. Many patients experience these symptoms only intermittently or only in the form of prolonged diarrhoea after infection with common viruses.

Lactose and other carbohydrate intolerances (secondary). Milk sugar (lactose) and table sugar (sucrose) are composed of two simple sugar molecules and need to be split by specific enzymes in the small bowel before they can be absorbed. These enzymes are found in the upper part of intestinal villi and are produced in decreased quantities when the villi are flattened by disease (such as coeliac disease). Thus, ingestion of large quantities of milk, dairy products, or sweets can lead to diarrhoea, excessive gas production, and cramping pain. Small amounts at a time can be better tolerated and tolerance slowly increases after a few months of proper treatment of coeliac disease. Contrary to the primary lactose intolerance caused by inherited low production of lactase (the lactose degrading enzyme), which is a permanent condition, the secondary lactose intolerance caused by the coeliac disease can improve after the gluten-free diet. However, patients who in addition to coeliac disease also have the genetic trait for primary lactose intolerance may continue to have symptoms.

Abdominal pain can be caused by distension and excessive gas in the bowel. It is usually a dull, diffuse sensation. Cramps are much less common. The pain may be relieved after passing stool, and in this way, symptoms of coeliac disease may be similar to a condition called irritable bowel syndrome. Epigastric pain or heartburn may accompany the coeliac disease, but it is more common in gastroesophageal reflux disease. Diarrhoea and cramps immediately following ingestion of gluten-containing food are not symptoms of coeliac disease. They are much more common in other disorders, such as non-coeliac gluten intolerance where the typical immune mechanism of coeliac disease is not present. Coeliac inflammation and infiltration with immune cells may be present not only in the small bowel but also in the stomach and the large bowel.

Recurrent vomiting may be a symptom of coeliac disease in children and may be caused by motility impairment. Antibodies to transglutaminase can bind to the muscular layers of the oesophagus, stomach, and small bowel and may cause incoordination and vomiting.

Constipation is as frequent as diarrhoea and it can be the only clinical complaint of coeliac disease. It is often resistant to household remedies. However, it usually resolves on a gluten-free diet. Transglutaminase-directed antibodies were shown to deposit in high amounts on the muscular sheets of the gut called endomysium and possibly disturb its contractile function and mechanical transport of gut content. Due to the high frequency of functional constipation in the normal population, the diagnosis of coeliac disease is often delayed, and some patients may continue to have constipation during treatment. The gluten-free diet contains less fibre in general and adopting a gluten-free diet is not recommended to people with constipation without coeliac disease.

The coeliac crisis has two forms; the first resembles an acute abdominal catastrophe with intense pain, distension, and poor general condition. These patients are usually referred to a surgical department and differential diagnosis of acute surgical condition should be considered. The second form of coeliac crisis is characterized by severe disbalance of body fluids as a consequence of intense diarrhoea, characterized not only by fluid loss, but also by the loss of potassium, sodium, chloride, calcium, and other minerals causing general weakness and cardiac problems. Such patients should always be treated in a hospital.

Ulcerative inflammation and strictures of the small bowel can be a complication of coeliac disease.

Mouth and teeth

Fissures and inflammation with redness of the oral mucosa or the tongue are often signs of vitamin B deficiency or loss of trace elements that can be seen in children with coeliac disease.

Mouth ulcers can be associated with coeliac disease. They might be caused by recurrent viral infections, compromised clearance in a nutritionally deficient host, or by an autoimmune mechanism.

Dental enamel defects. Only lesions occurring on permanent teeth are connected with coeliac disease as deciduous teeth are formed before birth and thus before any gluten effect could occur. The clinical relevance of these commonly seen spots is uncertain. However, impairment of enamel development during gluten intake is a typical feature of coeliac disease. It always appears symmetrically and follows the chronological order of the formation of teeth. In mild cases, enamel becomes weaker with horizontal streaks, but in severe cases, enamel may be completely missing at the top of some teeth, the affected tooth parts are smaller and decay very soon. Patients diagnosed as adults may have extensive caries and early loss of front teeth.

Haematological and bleeding disorders

Anaemia can be the leading and only clinical problem in coeliac disease patients and can occur even in the absence of any abdominal symptoms. Iron absorption occurs in the upper part of the small bowel, which is usually most severely affected in coeliac disease. Chronic iron deficiency can cause anaemia in the long run, which may be resistant to the oral iron replacement therapy or recurs when iron administration is stopped. However, after diagnosing and treating coeliac disease, iron absorption increases, and anaemia can be successfully corrected with oral iron therapy. Less often, folate or vitamin B12 deficiency can cause more severe forms of anaemia.

Bruising or prolonged bleeding time may be present in coeliac disease patients due to reduced fat absorption and deficiency of fat-soluble vitamins (including vitamin K, which is necessary for the production of several proteins involved in the blood coagulation process). Vitamin K deficiency can also cause prolonged hemorrhage during menstrual bleedings or after dental pro-

cedures. Doctors usually check vitamin K-related protein levels before they perform upper endoscopy and tissue sampling for the diagnosis of coeliac disease to avoid bleeding complications.

Malignant disorders of immune cells (lymphoma) can be a complication of coeliac disease.

Growth, development, and general health

Low body weight or slow weight gain is frequently seen in young children due to the impairment of absorption and lack of energy. Boys at school age with undetected coeliac disease are leaner than their peers during screening studies. Many adults with coeliac disease are skinny or are not able to gain weight as desired, but normal weight or even obesity can occur and do not exclude the presence of coeliac disease.

Weight loss is a severe sign of malabsorption and it is usually accompanied by fatigue, general weakness, lack of concentration, and signs of other nutrient deficiencies.

Growth retardation in children may accompany slow weight gain but can occur as an isolated sign of coeliac disease. Girls with undetected coeliac disease are shorter than their peers in population screening studies. Children seen with short stature in endocrinology departments are usually screened for coeliac disease, because coeliac disease may be present even without abdominal symptoms and in subjects with normal weight.

Short stature in adults is the result of growth failure during adolescence and can be avoided by the timely diagnosis of coeliac disease before growth process completion. When growth has been completed and the cartilaginous discs within bones with growing potential are closing, the final height will not be changed despite optimal treatment.

Delayed puberty is common when weight gain and growth are severely impaired. After treatment with a gluten-free diet, there is usually a catch-up.

General malaise and lack of energy are common signs of coeliac disease in adults. Patients are complaining of being constantly tired, may have frequent headaches, are often in a low mood, or may even be depressed. Moodiness is also frequent in young children who cannot properly explain their uncomfortable bodily feelings.

Skin disorders

Dermatitis herpetiformis, also known as Duhring's disease, is a cutaneous manifestation of coeliac disease characterized by itching and blistering rash typically localized on the elbows, knees, shoulders, back, and buttocks or other extensor surfaces, with extremities symmetrically affected. It is usually resistant to local ointments and because of itchiness and scratching leads to the formation of crusts, wounds, and depigmentation. Dermatitis herpetiformis usually occurs in adults and is slightly more common among males than females. Although only 15-20% of patients with dermatitis herpetiformis report gastrointestinal symptoms of celiac disease, the majority have villous atrophy. The gold standard for diagnosis is the detection of granular IgA deposits in the skin biopsies. Dermatitis herpetiformis is treated with a strict, life-long gluten-free diet, but sometimes disappearance of the rash may need a longer time, even up to 2 years. Patients with severe skin symptoms may need special medications in addition to their diet, however, these will not affect coeliac disease itself and a strict gluten-free diet should be followed.

Other skin disorders. Hair loss is mostly diffuse and only rarely patchy or complete. Hair shafts are thinner and more fragile. Although hair loss can be a presenting symptom, it is most frequently seen after a short period on a gluten-free diet when the general condition and absorption have already improved. Fast weight gain necessitates a lot of iron and zinc to be built-in into the newly synthesized proteins throughout the body and even improving the absorption of minerals may fail to cov-

er these requirements properly. This may lead to loss of rapidly renewing tissues, such as hair. Therefore, hair loss often necessitates long courses of iron and zinc replacement therapy.

Broken nails may occur in adults due to nutrient, iron, or trace mineral deficiency.

Dry skin can be a symptom of vitamin deficiency as well. Iron deficiency may aggravate atopic signs, but atopic eczema on its own is not connected to coeliac disease and will not disappear on a gluten-free diet.

Liver, spleen and pancreatic disorders

Elevated levels of liver enzymes are frequently found in laboratory tests at the diagnosis of coeliac disease and may improve after treatment with a gluten-free diet. Lack of energy and proteins due to impaired absorption can greatly influence liver function and may lead to fat accumulation and inflammation in the liver itself. Autoimmune hepatitis and autoimmune biliary disease can be associated with coeliac disease.

Severe liver failure due to coeliac disease has been detected in patients waiting for liver transplantation, and their condition improved after the diagnosis and treatment of coeliac disease. Antibodies against transglutaminase were present in the liver of such patients.

Spleen function disorder (hyposplenism) is a feature of a long-standing coeliac disease diagnosed in adults. Hyposplenism may compromise defense against certain bacteria, mainly those causing respiratory or neural infections. Therefore, an appropriate vaccination may be needed.

Pancreatic insufficiency is commonly found in all coeliac disease cases presenting with severe absorption problems because the pancreas is not getting proper stimulation from the gut. Normally, substances produced by gut villi induce the secretion of digestive enzymes. Furthermore, the pancreas can be damaged by the lack of proteins. Such insufficiency is reversible after treatment and pancreatic enzyme supplements may be beneficial in the first few months of treatment of coeliac disease. In adults who are diagnosed after long-standing malabsorption, permanent pancreatic failure can develop due to the damage of the secreting glands by antibodies against transglutaminase. Furthermore, antibodies can also damage the so-called pancreatic islets responsible for insulin secretion and may therefore cause diabetes mellitus.

Cardiovascular disorders

Dilatative heart disease and heart failure. Antibodies against transglutaminase can deposit in the heart muscle as well and can cause impairment of the pump function. Some patients develop a rapidly progressive life-threatening condition after stopping the gluten-free diet. Viral infections or deficiencies of trace minerals may contribute to these severe complications, which usually necessitate treatment with immunosuppressive drugs, or in some cases even heart transplantation.

Pulmonary disorders

Restrictive pulmonary disease (pneumonitis or alveolitis) can occur in coeliac disease patients, possibly due to an immune-mediated mechanism. Frequent airway infections may be present in children with severe anaemia and malabsorption due to their poor general health state.

Kidney disorders

Protein or blood in the urine may be a sign of the involvement of the kidneys in the immune reaction. Antibodies against transglutaminase may deposit in the kidney and cause inflammation. Coeliac disease is known to be more frequent among patients who have a special form of kidney disease called IgA nephropathy.

Musculoskeletal system

Swollen legs can be caused by low levels of proteins in the blood due to nutrient absorption deficiencies and impaired production (amino acids, trace metals).

Muscular cramps or pain (myalgia). Some patients may complain of muscular pain or cramps caused by low levels of potassium, calcium, or magnesium. This pain often occurs during the night or after a walk.

Muscular weakness and decreased muscular tone are common, especially in young children with coeliac disease. Vitamin E deficiency can be related to muscular weakness in elderly patients. In some patients, antibodies against neuromuscular proteins can cause weakness. Myalgia syndrome can occur in coeliac disease; however, it is more common in patients without coeliac disease.

Joint pain and inflammation can be a part of autoimmune features of coeliac disease and can resemble arthritis, however, they often resolve after the introduction of a gluten-free diet.

Osteoporosis and osteopenia. Reduced mineral density often occurs in adults with the clinical picture of malabsorption and patients with long-standing active disease. Osteopenia and osteoporosis require careful attention and investigations for coeliac disease, especially in men. In children, rickets due to low serum vitamin D levels can occur.

Changes in face proportions may occur if coeliac disease is developed but not recognized in childhood. The middle part of the face can be underdeveloped, but with a more prominent front. These changes in children can be prevented with a timely diagnosis of coeliac disease and appropriate treatment with a gluten-free diet.

Neurological problems

Headache occurs frequently and is often related to iron deficiency. However, classical migraine is not a common feature in coeliac disease patients.

Mood and behavioural disorders can be presenting symptoms of coeliac disease. Hyperactivity, concentration problems, tiredness, foggy mind, and depression can occur. Both adults and children can be irritable, and their social integration may be impaired. Patients are often referred to a psychologist or a psychiatrist before the coeliac disease is recognized. Lack of energy and anaemia can contribute to lower results in academic performance.

Sensorics or gait problems, i.e., neuropathy, can occur when a person is deficient in vitamins, especially B12, or other trace elements. An immune mechanism has been postulated.

Ataxia is a special form of impairment of movement, and it is considered to be a degenerative disease of the cerebellum due to a long-standing disease with consequent loss of a special type of nerve cells in the brain. Coordination of body balance, gait and voluntary movements are affected, and mental performance may deteriorate (dementia). When this complication is present usually no or only very little improvement can be achieved with the gluten-free diet. Antibodies against neural transglutaminase (type-6 and type-2) have been found in the brain of such patients.

Epilepsy can be associated with coeliac disease. Cases of patients with calcifications in certain brain areas have been described.

Reproductive system

Infertility and miscarriages are frequent presenting signs in women before the diagnosis of coeliac disease is made. Therefore, couples with fertility problems should be screened for

coeliac disease. Female patients may experience difficulties in getting pregnant and increased foetal loss is described. Treatment with a gluten-free diet may be beneficial if coeliac disease is confirmed. The birth weight of children born to untreated coeliac mothers can be lower. Functional impairment of the placenta has been reported and antibodies deposited in the placenta or transported through the umbilical cord from the mother's blood into the baby may be responsible for this.

Severe deterioration after giving birth is a typical manifestation of coeliac disease in young women with undetected or untreated coeliac disease. This occurs around the time when the baby is about 6 weeks old. In the context of nutrient malabsorption, pregnancy may already be a big challenge. During lactation, approximately 1 litre of breast milk needs to be produced daily and this represents an important amount of protein loss each day. Lactating mothers may soon develop low blood protein levels with circulatory problems and leg oedema as a result. Also, diarrhoea and weight loss are common, and such mothers may require treatment in an intensive care unit.

Associated disorders

Coeliac disease occurs more commonly in association with several other diseases, including type-1 diabetes mellitus, thyroid diseases, IgA deficiency, Down syndrome, Turner syndrome, Williams syndrome, and others. In these conditions, coeliac disease can be asymptomatic and needs to be detected by screening.

The most common nutrient deficiencies in coeliac patients

Common deficiencies in patients with coeliac disease (especially recently diagnosed or untreated) are deficits of calcium, vitamin D, vitamin B12, and iron.

Calcium is necessary for building and maintaining strong bones and teeth. In addition, the heart, muscles, and nerves need calcium to function properly, too. Among patients with lactose intolerance, calcium deficiency is present more frequently. Milk and dairy products are optimal calcium resources; a sufficient amount for adult person or adolescents is approximately 3-4 portions of milk/dairy products daily (1 portion is about the size of patient´s fist or palm). In patients with lactose intolerance, it is recommended to choose lactose-free products or plant-based products enriched with calcium. Nuts, legumes, seeds and sardines are also rich in calcium. If the patient can't consume enough calcium in diet supplementation is recommended.

Vitamin D helps in regulating the amount of calcium and phosphate in the body. These minerals are needed to keep bones, teeth and muscles healthy. Vitamin D is also important for the immune system. The risk of low vitamin D levels is higher from October until April when skin is insufficiently exposed to the sun. Especially during winter, it is recommended to consume more vitamin D in your diet. Optimal resources of vitamin D are sea fish, egg yolk, milk and other dairy products and liver.

For sufficient intake of vitamin B12, it is necessary to consume at least a small amount of food of animal origin (meat, fish, egg, milk). For vegans, supplementation of vitamin B12 seems to be essential.

Iron is an essential component of haemoglobin (red blood cell protein) that transfers oxygen in blood and tissues. Lack of iron manifests itself with sideropenic anaemia, weakness, shortness of breath and pale skin. Optimal sources of iron are meat (red meat contains more iron), liver, egg yolk, legumes, some nuts, dark green, yellow and orange vegetables and fruits. If you are a vegetarian on a gluten-free diet, consuming eggs and legumes is also recommended.

Diagnosing coeliac disease

Diagnosing the coeliac disease is like putting together pieces of a puzzle. When all pieces of the puzzle (clinical picture and different diagnostic tests) fit perfectly clinicians can easily diagnose coeliac disease. However, sometimes tests do not fit perfectly. In these circumstances diagnosing the disease becomes more challenging. It is very important that a person who is getting tested consumes normal amounts of gluten prior to testing. Any reduction of dietary gluten can have a major effect on the results of blood tests and intestinal biopsy.

Blood tests – serological tests

The initial step in diagnosing coeliac disease is a determination of the presence of specific antibodies in the blood. In coeliac disease, it is possible to detect antibodies against the enzyme tissue transglutaminase t-TG (TGA), found in many human tissues. These antibodies are produced only when gluten is consumed, and are very rarely found in individuals without the disease. They usually fall to normal levels within a couple of months after a patient with coeliac disease starts with a strict gluten-free diet. The same is also true for anti-endomysial antibodies (EMA), which are as reliable as TGA, however, the test is more difficult to perform and thus more expensive. Therefore, clinicians use it as a second-line test to confirm previously positive TGA test.

The current ESPGHAN (European Society for Paediatric Gastroenterology, Hepatology and Nutrition) guidelines for coeliac disease diagnosis in children allow clinicians to diagnose the disease in certain cases without upper endoscopy and intestinal biopsy. This approach can be used in children and adolescents that have very high levels of TGA and a positive confirmatory EMA test in a second blood sample. Since both of these tests typically determine only the presence of IgA class antibodies, total immunoglobulin A (total IgA) concentration needs to be determined as well. If low total IgA is found, different tests determining IgG antibodies should be used.

Point of care testing

Point of care tests for determining auto-antibodies in capillary blood (finger-prick blood) are widely available in many regions. However, these tests are not sufficient to diagnose coeliac disease and the results need to be discussed with a clinician. Exclusion of gluten from the diet based solely on these tests can seriously influence the performance and interpretation of laboratory blood tests, which are more reliable and need to be performed to confirm the diagnosis.

Intestinal biopsy

If the initial auto-antibody test is suggestive of coeliac disease, further investigations are always needed to confirm the diagnosis. In some cases, it is necessary to perform an intestinal biopsy. However, in children and adolescents, this can be avoided in certain circumstances.

Upper endoscopy with tissue sampling (biopsies) from the upper small bowel (duodenum) enables the pathologists to determine the changes typical of coeliac disease:

-Increased number of intraepithelial lymphocytes (IEL)
-Shortening of the mucosal villi - Villous atrophy
-Elongation of the crypts - Crypt hyperplasia

You should not start with the gluten-free diet before the diagnosis has been confirmed!

The pathologist will describe the degree of damage (or changes) by using “Marsh (Oberhuber)” Classification.

It is recommended to take at least one sample from the first part of the duodenum (bulbus) and at least 4 samples from the distal part of the duodenum.

Histology report alone indicating coeliac disease without positive auto-antibodies is not sufficient to diagnose coeliac disease!

HLA testing

Genetic testing is especially helpful in excluding coeliac disease. Individuals who are negative for HLA-DQ2 or HLA-DQ8 have no risk to develop the disease and further tests are not necessary. Genetic risk markers specific to the disease, i.e. HLA-DQ2 and HLA-DQ8, can be found in approximately one-third of the general population.

Diagnosing coeliac disease without intestinal biopsy

Based on the current ESPGHAN (European Society for Paediatric Gastroenterology, Hepatology and Nutrition) guidelines, when all specific criteria have met the diagnosis of coeliac disease in children and adolescents can safely be made without the need for upper endoscopy and intestinal biopsy.

1. The TGA-IgA levels must be very high, i.e. more than 10-times the upper limit of the cut-off value.
2. Auto-antibodies against EMA must be positive in a second blood sample.
3. Paediatric gastroenterologist should be involved in the process and should explain the no-biopsy approach to parents and patient.

Risk groups

There are certain groups of people who have a higher risk for the development of coeliac disease. It is very important to actively search for the disease in these groups. The initial step can be genetic testing for HLA-DQ2 or DQ8, and if the genetic risk is confirmed, these individuals need to be further tested with serological tests. Since coeliac disease can occur at any age individuals with positive HLA-DQ2 or DQ8 haplotypes should be followed regularly to detect the disease with delayed onset.

Family members

Coeliac disease is more common among family members due to the genetic predisposition of the disease. About 1 out of 10 first-degree family members of a known patient can be affected.

Other high-risk groups

Apart from family members, there is an increased risk for the development of coeliac disease among other specific groups.

One of the most important groups represent patients with other autoimmune diseases:
-Type-1 diabetes mellitus
-Autoimmune thyroid disease
-Autoimmune liver disorders

Another important risk group are patients with relatively common immunoglobulin A (IgA) deficiency. In these patients, special care must be taken to determine IgG class coeliac disease-specific antibodies, since IgA tests will remain negative due to the low concentration (or even absence) of the total IgA antibodies.

Patients with certain chromosomal abnormalities, such as Down syndrome, Turner syndrome, or Williams syndrome are also considered to have an increased risk for the development of coeliac disease.

Patients with coeliac disease should be followed up regularly to monitor improvement and to avoid the development of serious complications and comorbidities.

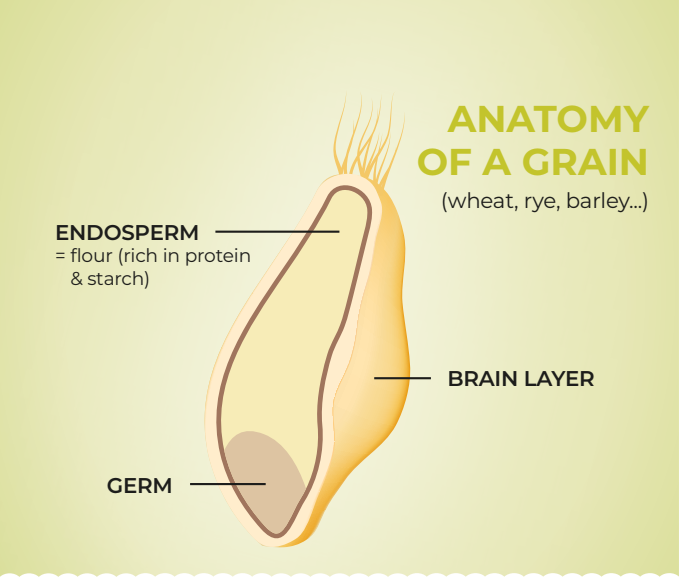
Treatment

The only treatment of coeliac disease is a strict and lifelong gluten-free diet (GFD). No other reliable treatment options are currently available.

About gluten

Gluten (meaning glue in Latin) is the common name for a protein complex that can be found in grains of certain types of cereals. It is mostly found in the endosperm of grains (larger inner part of grains) such as wheat, rye, barley, spelt, triticale, khorasan wheat (kamut), emmer, einkorn. Gluten can also be found in products usually made from wheat, such as bulgur, couscous, udon noodles, panko, tempura flour, sago, and kritharaki.

Gluten is often used in the food and cosmetics industry because of its characteristics, which give viscosity, elasticity, and better structure to the final product. It is especially utilized in bread production giving the bread higher volume and typical structure. It is a complex mixture of proteins, but the main classes of proteins are prolamins and glutelins, and prolamins are mainly responsible for the development of symptoms in coeliac disease. Prolamine fraction in wheat is called gliadin. Prolamins of different gluten-containing grains differ from each other, but in grains closely related to wheat these proteins (secaline in rye, hordein in barley) differ only slightly and are collectively referred to as gluten. Oats are less closely related to wheat, rye and barley, and its prolamin fraction (called avenin) is sufficiently different. This is the reason why almost all people with coeliac disease tolerate oats very well as long as the cross-contamination with gluten-containing grains is excluded. Since oats can frequently become contaminated with gluten due to close contact with wheat, rye and barley during cultivation, storage and processing, it is allowed to consume only certified gluten-free oats.



If previously excluded from a diet, the introduction of oats in a gluten-free diet should be under the supervision of a physician.

Gluten-free diet

As soon as the diagnosis has been confirmed, even traces of gluten have to be avoided. If there is no gluten in the diet, there is nothing the immune system can react against, and symptoms usually resolve. However, just because symptoms disappear, this does not mean that the disease is cured. As soon as gluten is ingested again, immune cells would immediately start reacting, leading again to a systemic reaction.

On a strict GFD, the coeliac disease-associated antibody levels gradually normalize, and affected tissues usually fully recover. However, this may take several months, whereas symptoms may improve much faster, particularly in children.

Although the GFD requires a thorough change in lifestyle, patients should keep in mind that it has no side effects. Undertaking it mindfully and supervised by a clinician and/or dietitian, the diet will benefit the overall patient's health in coeliac disease patients.

Different food groups need to be considered when talking about the gluten-free diet.

Naturally gluten-containing foods

Only a few grains contain gluten, however, they are produced in huge quantities worldwide due to their properties, including their gluten content responsible for the proper baking quality. These are wheat and all wheat cultivars, rye, and barley. Grains that naturally contain gluten and all products made from these grains, including bakeries (bread, cakes, and pizza), pasta, fried food, and beer have to be avoided.

Naturally gluten-free foods

There are many more naturally gluten-free foods than gluten-containing foods. Some are not related to grains at all, e.g. fruits, vegetables, animal products (meat, milk, and eggs), potatoes and, roots.

In addition to that, there are gluten-free cereals naturally available, such as rice and corn. Naturally, gluten-free cereals can be successfully used to substitute gluten-containing cereals.

Processed non-cereal foods

Gluten can be found in many foods where one would not expect it normally (cheese, sweets, sauces, spices, some meat products, and many dairy products). These products may contain gluten in the form of a food additive that is supposed to enhance the properties of food.

Other products

Gluten can also be found in non-food products, mainly medications, cosmetics and toys, but even on envelopes or stamps, which could lead to the same consequences to a person with coeliac disease as gluten ingested with food, but only when they get into the gastrointestinal tract. Simple contact with the skin is not harmful.

Drugs and cosmetics in coeliac disease

Gluten-containing medical products in coeliac disease

The composition of medications is complex and contains ingredients known as excipients (active component, absorbents, binders, colouring agents). These excipients can include wheat starch, wheat gluten and other related grains. According to FDA, possible sources and amounts of gluten in oral drug products are: wheat gluten as an ingredient, wheat gluten as an impurity in ingredients derived from wheat, wheat gluten as an adventitious contaminant.

In the EU, the European Pharmacopoeia and European Medicines Agency (EMA) imposes a limit of 0.3% protein content in wheat starch, thus limiting the gluten content to 100 ppm. Because the medication is taken in small amounts, the ingested amount of gluten from drugs taken for a short period is considered harmless. Labelling of medicine products as „gluten-free" is allowed if the amount of gluten is less than 20 ppm. The content of gluten per tablet is required to be specified in the package leaflet of the medicinal product. In the case of long-term or multiple drug treatment, an individual plan should be discussed with the physician, for the total amount of ingested gluten to be taken into consideration. Alimentary supplements, vitamins and medical devices are not covered by the above-mentioned regu-

lations. Coeliac disease patients should carefully check the labels for gluten content.

Skincare, make-up and hygiene products and coeliac disease

There are many non-food substances, such as toothpaste, make-up, and skincare products used in everyday life which can contain gluten. Skincare products containing gluten can be safely used by individuals with coeliac disease as the skin barrier does not allow substances as large as gliadin to get through. The application of large quantities of gluten-containing skincare products on injured skin allows systemic absorption of gluten that could potentially induce gluten-driven autoimmune phenomenon.

The total amount of gluten contained in cosmetics products depends on the industrial processing used. Regular use of lip products containing a high amount of gluten could in theory lead to the coeliac-type gluten-induced phenomenon in coeliac disease patients. However, published studies in the US and Europe suggest that the amount of gluten in the majority of lipstick, skincare lotion products, toothpaste, and oral hygiene products varies from undetectable to less than 20 ppm.

How strict should the gluten-free diet be?

It is extremely difficult to follow a diet completely free of gluten. Although patients react differently to gluten, it was found that a daily intake of up to 10 mg of pure gluten is very unlikely to cause any signs or symptoms in the majority of patients. It is now widely accepted that the maximum level of gluten in foods may not exceed 20 mg/kg (usually referred to as 20 parts per million (ppm)).

Patients should not be confused by the terms “safe” or “low” amount of gluten in food. There is no such thing as a safe amount of gluten, and every effort should be made to assure the complete elimination of gluten from the patient’s diet.

This schematic presentation of a nutrition circle shows recommended proportion of each food group in the daily diet. Each serving is as big as the patient's palm or fist. It is recommended to consume one serving of sweets or salty snacks a day at maximum.

Cross-contamination

Cross-contamination can occur during any stage of food processing - from the initial harvest to final food preparation and it is difficult to avoid it. Unintentional cross-contamination can be an important problem for patients and might lead to tissue damage, especially in the long term. Cross-contamination can happen at any place. Patients should identify these “hot-spots” of possible cross-contamination, and try to avoid them or prevent them from happening.

Compliance

Compliance with the gluten-free diet must be high. Compliance issues which can arise at any time for various reasons are usually more pro-

nounced in adolescents and the elderly. Factors affecting the lower compliance can be of financial, cultural, or psychosocial nature, and every effort should be made to detect or to address them at regular visits to the clinician and/or dietician.

Long-term consequences of unrecognized/untreated coeliac disease

When a patient is diagnosed with coeliac disease and maintains a strict gluten-free diet, usually all symptoms resolve. However, if the gluten-free diet is not adhered to strictly or if the disease is diagnosed in adults or with substantial delay, the risk of complications increases. These complications, which rarely present in children, can be irreversible and the introduction of a strict gluten-free diet might not bring complete resolution of the damage already made. These complications can affect the gastrointestinal tract or any other organ system.

One of the possible gastrointestinal consequences in adult patients is refractory sprue. This is a rare, but serious complication, characterized by severe mucosal damage despite the introduction of a strict gluten-free diet. Another rare long-term health consequence affecting the digestive system is exocrine insufficiency of the pancreas.

Apart from the digestive system, reproduction may be impacted by ongoing inflammation and nutrient deficiencies. Untreated coeliac disease can be related to neurologic complications, such as ataxia or epilepsy. Bone mineral density can be affected leading to bone fractures. In some patients, the untreated disease was associated with myocarditis and psychiatric disorders, however, these associations can be considered very rare. Endocrine disorders, such as type-1 diabetes mellitus and thyroid disease, are also more frequent in not treated coeliac disease.

Development of the long-term complications of undiagnosed and/or untreated coeliac disease is another important factor that calls for early detection (and appropriate treatment) of the disease in all symptomatic patients as well as in patients that belong to the so-called risk groups for coeliac disease.

Basic recommendations for a balanced gluten-free diet

The more varied diet you have, the more probably you have sufficient intake of all essential nutrients, which is important for your health. There are quite a lot of products excluded from a gluten-free diet, so the risk of an inadequate intake of nutrients is slightly higher. It is necessary to properly compensate for excluded food. A balanced gluten-free diet should include not only enough gluten-free grains, but also enough fruit, vegetables, legumes, meat, fish, eggs, nuts, seeds, milk, and oils. All food groups should be consumed in a balanced proportion (see the figure of an example of the healthy food pyramid below). There are some basic recommendations for a balanced gluten-free diet:

1. Each meal should contain fruit or vegetables, a protein-rich food (meat, fish, egg, legumes, milk, or dairy product), and starch-rich food (rice, potatoes, gluten-free pasta, legumes, etc.).
2. Adults and children above 10 years should prefer whole grain gluten-free products; children under 10 years should combine whole grain and refined grain products.
3. Preference for high-quality oils rather than animal fat is recommended.
4. Cut down on highly processed foods.
5. Limit your salt intake (recommended maximum intake of salt is 2g daily for children under 3 years and 6g for adults).
6. Limit your sugar intake (added sugars should represent a maximum of 10 % of energy intake).

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Coeliac disease and diet adherence

Coeliac disease is treated with a gluten-free diet. This diet restores the intestinal mucosa and improves symptoms in most patients. Since the diet should be followed very strictly and gluten can be present in all kinds of foods and non-foods, referral to a dietician specialized in coeliac disease should take place at diagnosis.

The gluten-free diet may be difficult to follow and may lead to social constraints due to the fear of gluten exposure outside one's household. Dietary adherence is known to differ between individual patients, with non-compliance varying from 25-50% in children and adolescents. Intentional and unintentional gluten exposure can have multiple causes.

Unintentional exposure is mostly due to cross-contamination taking place during food preparation or meals with other people eating gluten at the same time. It can also be due to insufficient labelling of food products or inadequate reading of these labels. Intentional gluten exposure is more likely to occur in patients who lack symptoms when consuming gluten. It may also occur in adolescence, with peer pressure and risk behaviour causing dietary transgressions. It is also known that transition from childhood to adulthood leads to increased non-compliance, possibly due to lack of medical care since many patients get lost to follow-up.

In most patients, diet adherence is evaluated during follow-up by their medical doctor or dietician. A common opinion is that it is best assessed by a dietary review in combination with laboratory tests measuring the coeliac-specific antibodies. These antibodies are known to disappear on a gluten-free diet, usually taking 12-24 months to disappear completely. One should not rely on blood tests alone, since they are not sensitive enough by itself to detect dietary transgressions in children with coeliac disease. Short dietary questionnaires have been developed instead of the time-consuming dietary reviews, but unfortunately, these short questionnaires don't detect all transgressions. A promising new tool is the detection of gliadin immunogenic peptides (the so-called GIPs). If ingested, gluten is excreted through the stool or urine, which can be measured. GIPs could be helpful for example in patients with declining but still positive coeliac antibodies after 2 years or in patients who question their diet or still have complaints even though they follow the gluten-free diet. However, whether or not GIPs will be useful in daily practise depends on more information about the relationship between the quantity of and time between ingested and excreted gluten in stool/urine.

Follow-up

How often are follow-up visits needed?

After the diagnosis of coeliac disease is established, patients must adopt a strict gluten-free diet. The first follow-up visit should be performed 2-4 months after the diagnosis to confirm adherence to the diet and to address possible issues with disease management. After the first visit, patients should be followed yearly, if clinically stable.

What are the follow-up visits needed for?

At the follow-up visits, patients should report any possible disease-related symptoms and their experience and adherence to the gluten-free diet. Serological testing (CD-specific antibody tests) should be performed together with a complete physical examination (including the patient's weight, height, and body mass index). Special attention must be paid to the growth and development of children. Repeated blood tests (i.e. complete blood count, liver enzymes, iron, calcium, vitamin D, magnesium, zinc, B-vitamin complex) ought to be performed, if they were abnormal at previous visits or when the clinical picture suggests possible abnormalities. The titres of TGA IgA antibodies can be expected to fall below the cut-off of the normal values within 12 months after starting a strict gluten-free diet. In many patients, they may normalize much earlier. Bone densitometry should be performed every 2 years to exclude osteopenia or osteoporosis in selected patients.

Should I visit any other specialist except paediatric gastroenterologist/gastroenterologist?

It is advisable to consult a dietician about the gluten-free diet. Follow-up by a dietitian during a gluten-free diet is recommended because a strict gluten-free diet can lead to nutritional deficiencies, such as fibre, folate, thiamine, and vitamin A deficiency and may pose a nutritional risk (e.g., higher fat intake can lead to adiposity and increased risk for cardiovascular complications).

For better adjustment to the life changes associated with the presence of chronic disease, some patients will also benefit from psychological counseling.

Is repeated endoscopy needed?

Repeated endoscopy is not needed if the patients are in good clinical condition and in whom TGA IgA antibodies have normalised. However, if there is no clinical response to the gluten-free diet in symptomatic patients and lack of adherence to the gluten-free diet is excluded, further investigations are required, including further biopsies in some cases.

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Coeliac Disease Secondary Prevention by Early Diagnosis

Coeliac disease is a common disorder. Research data shows that approximately one per cent of the general population has coeliac disease.

This means that, in the European Union alone, at least 5 million people suffer from coeliac disease. However, this is not reflected in the statistics on the number of diagnoses. Epidemiological data indicate that for every child diagnosed with the coeliac disease there are at least seven undiagnosed. In addition, the diagnosis of coeliac disease is often made too late and many patients report a delay in diagnosis that may last for years. This all results in a large number of people with undiagnosed, and thus untreated, coeliac disease.

The untreated coeliac disease results in serious health problems. This has been demonstrated, among other studies, in the analysis of the data from six-year-old children from the general population, participating in the "Generation Rotterdam" project. Undiagnosed, and therefore untreated, coeliac disease in these children resulted in osteopenia, growth retardation, emotional problems, and disturbances in attention and behaviour. In pregnant women, undiagnosed coeliac disease resulted in reduced fetal growth and low newborn weight.

Why is the Diagnosis of Coeliac Disease Missed?

The problem with the diagnosis is that coeliac patients come to the doctor with a huge scale of different symptoms and signs. The clinical picture of coeliac disease is highly variable and often difficult to recognize. First, the presenting symptoms may be gastrointestinal, such as chronic abdominal pain or diarrhoea, distended abdomen, weight loss, and in children, poor growth. Second, the disease can manifest itself with extra-abdominal symptoms, for example, joint pain, neurological disorders, osteoporosis, or anaemia. Third, some patients have non-specific symptoms, such as chronic fatigue. Furthermore, coeliac disease can be asymptomatic. In summary, making a clinical diagnosis of coeliac disease is not easy and physicians must be aware of many symptoms and signs that may be associated with it.

Diagnosis of Coeliac Disease: Biomarkers in Serum and Blood Tests

The presence of specific antibodies in the blood and serum of people with coeliac disease, such as antibodies against the enzyme tissue-transglutaminase (TGA test) and against endomysium (EMA test) makes the diagnosis possible using non-invasive laboratory tests (10). The reliability of both tests is very high and levels of TGA equal to or greater than 10 times the upper limit of normal levels correlate with severe gluten-dependent alterations of the small bowel mucosa. Point-of-care (POC) tests offer a promising way to determine TGA quickly and efficiently. With these rapid tests, a doctor can determine with high probability if someone has coeliac disease in a droplet of blood in about 10 minutes, without special laboratory facilities. These POC

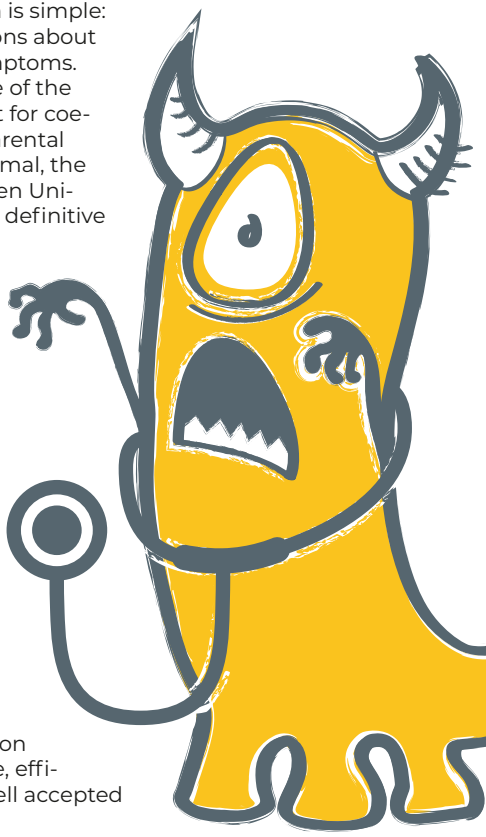
tests thus open the possibility of early detection and treatment of coeliac disease on a large scale, even in entire population groups. That is the possibility of secondary prevention of coeliac disease through its detection and treatment in the early stages.

Secondary Prevention by Screening of the General Population

The most effective form of secondary prevention is general population screening. However, population screening is subject to very strict conditions, the so-called Wilson and Jungner criteria. In addition, scientific evidence on the cost-effectivity of such screening and its acceptance by the population is scarce. For this reason, our research group started the project GLUTENSCREEN - Coeliac disease screening in Child Preventive Care Centers in the Netherlands. The intention was to establish a mini-screening for coeliac disease in the general population of children aged 1 to 4 years in the Kennemerland region in North Holland. However, the project was not approved by the Leiden University Medical Center Ethics Committee, nor by the National Human Research Committee. The arguments referred to were based on the fact that in a general population screening asymptomatic coeliac cases are also detected. According to the committees, this group of people represents an ethical problem. In asymptomatic subjects diagnosed by screening, there would be no balance between the expected health benefits after treatment and the disadvantage of knowing that they are affected by chronic disease. However, the Leiden University Medical Center Ethics Committee judged that there was sufficient scientific evidence to approve the early detection of coeliac disease in undiagnosed symptomatic children, that is, a “case-finding” project, instead of screening.

“Case-finding” as an Alternative to Screening for Secondary Prevention of Coeliac Disease

We adapted the original project to the current GLUTENSCREEN (www.glutenscreen.nl). In GLUTENSCREEN, parents, and children between 12 months and 4 years of age who visit a Child Preventive Care Center in the Kennemerland region are invited to participate. Participation is simple: Parents answer ten questions about coeliac disease-related symptoms. If the child has one or more of the symptoms a rapid POC test for coeliac disease is done after parental consent. If the test is abnormal, the child is referred to the Leiden University Medical Center for a definitive diagnosis following official guidelines.



The GLUTENSCREEN project is performing above expectations. From its start in February 2019 till November 2020 (with interruption of 5 months due to the COVID19 pandemic), the rapid coeliac disease test was performed on 1,923 children. With this project, we expected to detect 1% of coeliac cases, but the preliminary results show 2% detection. With this project, we want to demonstrate that this form of secondary prevention of coeliac disease is feasible, efficient, cost-effective, and well accepted by the population.

Other gluten-related medical conditions

Lately, it has become clear that in addition to patients with coeliac disease and wheat allergy there are also people who react to gluten without proven allergic or autoimmune mechanisms.

Wheat allergy

Wheat is one of the most common allergens and wheat allergy is an undesirable immune response to wheat protein (albumin, globulin, gliadin, and glutenin) which results in the development of respiratory or gastrointestinal symptoms or sometimes even systemic reactions. The incidence of proven wheat allergy is estimated to be about 0.4-9%.

Wheat allergy is a condition different from coeliac disease. Gluten allergy is an allergy to wheat since it is a protein specific for wheat. If a person allergic to wheat eats food that contains gluten, following reactions can follow:

- rapid onset reaction: urticaria (hives), angioedema (swelling of the face), breathing difficulty, nausea, and abdominal pain or in some cases anaphylaxis – a life-threatening reaction
- late reactions that occur after 24 hours of ingestion (digestive symptoms, skin changes).

Wheat allergy is treated by avoiding wheat in the diet.

Non-coeliac gluten sensitivity

Lately, it has become clear that in addition to patients with coeliac disease and wheat allergy there are also people who react to gluten without proven allergic or autoimmune mechanisms. This condition is generally referred to as non-coeliac hypersensitivity to gluten or simply gluten hypersensitivity/ intolerance. It was estimated that the frequency of this disorder in the general population is 0.63-6%.

Clinically, the disease may resemble coeliac disease or wheat allergy and may present with several intestinal (diarrhoea, abdominal pain, bloating, etc.) and/or extraintestinal symptoms (weakness, headaches, etc.) that occur shortly after ingestion of food with gluten, and improve with introducing a gluten-free diet. There is no specific test to diagnose gluten intolerance and the diagnosis is made by double-blind placebo-controlled challenge after exclusion of both coeliac disease and wheat allergy.

	Coeliac disease	Non-coeliac gluten sensitivity	Wheat allergy
Definition	Life-long, genetic, autoimmune disease; gluten intake leads to damage of the small intestinal mucosa	Intolerance to gluten or some other component of wheat that does not elicit a specific autoimmune response and does not cause overt damage to the small intestinal mucosa	Immune response to one or more cereal proteins (could be gluten)
Gastrointestinal symptoms	Diarrhoea, bloating, abdominal pain	Diarrhoea, bloating, abdominal pain	Nausea, vomiting, diarrhoea, bloating, mouth and throat irritation
Extraintestinal symptoms	Weight loss, stunted growth, arthritis, osteoporosis, dermatitis, tooth enamel damage, recurrent aphthae, amenorrhea, infertility, joint pain, neurological disorders	Fatigue, neurological disorders, foggy mind, joint pain	Rash, nasal congestion, eye irritation, shortness of breath
Diagnostics	Clinical picture Serological tests (total IgA and TGA) Small intestinal biopsy	Exclusion of coeliac disease and wheat allergy	Skin prick tests Patch tests Tests to determine the concentration of specific immunoglobulin E Food challenge
Presence of auto-antibodies	Yes	No	No
Small intestinal biopsy	Typical damage of the small intestinal mucosa	NO overt damage of small intestinal mucosa	NO overt damage of small intestinal mucosa
Treatment	A life-long strict gluten-free diet	Gluten-free diet and wheat-free diet (degree of sensitivity is individual)	Strict wheat-free diet

Source: CeliVita – Living with coeliac disease and Children's Hospital Zagreb.

Psychological aspects of life with coeliac disease

Coeliac disease is a chronic inflammatory disease with a known environmental trigger, which is gluten, and with a known therapy, which is a gluten-free diet.

The onset of each chronic disease – regardless of the diagnostic and therapeutic procedures and its consequences – brings along worries, fears as well as many changes and distress to an individual's life and his or her close ones.

Each new and unknown situation raises insecurity and searches for an answer on what is going on, about the disease and the nature of this disease, its causes, consequences, and ways to help ourselves and help our children. We are in an active process of creating our understanding of the disease we and our close ones are facing. It is important to get the answers to all our questions, concerns, and insecurities as well as establish a common understanding of the disease and lay the foundations for a more constructive approach to the disease, cooperation during treatment, and improving the quality of life.

We must first intimately accept and internalize the losses and changes related to the disease, and then through reassessment gradually learn to live a full life with the disease. The intensity of emotional reactions on this path differs among individuals (anxiety, fear, disappointment, anger, depression, etc.) and this can lead to major or minor physical, psychological and social imbalance. We confront this imbalance differently – depending on our personality, age, stage of development, our experiences, our mechanisms of coping and defending. We must be all aware that confrontation with a chronic disease also has an emotional component to it which is why it requires time, space, and the opportunity to express these emotions, support, and in certain cases also professional help.

Treating coeliac disease is inevitably related to the gluten-free diet. Maintaining the diet is the foundation of physical and psychological improvement and consequently the improvement of the quality of life. For most patients, a gluten-free diet represents a major change to their usual eating habits and behavior. This change also affects their families and their social environment. Each change is a process and getting used to a gluten-free diet requires proper preparation, education, assistance, and cooperation of the entire health care team, individuals, and families. The path to this change may bring many insecurities, stress, and distress, therefore it is important to cooperate and together identify the problems in applying this diet and the obstacles in maintaining the diet. Together we search for solutions, new ways of facing the change and building a positive attitude towards the change, and by being persistent we live a more quality-based and full life.

A special challenge represents children, as their understanding and acceptance of the disease as well as cooperation during treatment continuously changes through different stages

of development, the roles and relations within the family, and their social environment. Their needs and expectations as well as topics and forms of help required within the family and their environment vary as well. Growing up with a chronic disease should be incorporated into the processes of developing one's identity, self-image, and self-respect. It is essential to emphasize that chronic disease in a child affects the entire family whose task is to re-establish balance, look for new active forms of facing the problems, and improve the quality of life.

Life with coeliac disease includes many changes on different levels. It is important to ensure physical and psychological well-being and minimize the negative physical symptoms and psychosocial consequences of the coeliac disease. Individuals and families require integrated care and assistance on this path to improving the quality of life with this disease.

Coeliac disease and COVID-19

Coronaviruses, a large family of viruses, may cause illness in animals or humans. Several coronaviruses were found to cause infections of the respiratory tract in humans. The majority of infections present as common cold, however, severe diseases such as Severe Acute Respiratory Syndrome (SARS) and Middle East Respiratory Syndrome (MERS) are also caused by coronaviruses.

Recently, a new type of coronavirus that caused the COVID-19 pandemic was discovered. This virus is called SARS-CoV-2 (Severe Acute Respiratory Syndrome CoronaVirus 2).

Despite many fears that SARS-CoV-2 can cause a more severe infection in individuals with immunological traits, there have been no reports suggesting patients with coeliac disease are at increased risk of severe illness from COVID-19 compared to patients without coeliac disease. A survey of more than 10,000 people with the coeliac disease around the world found the risk of getting COVID-19 was not increased compared to the general population. And more importantly, as shown by a recent study conducted by researchers from the USA and Sweden, the coeliac disease did not increase an individual's risk for hospitalization, admission to intensive care, or death attributed to COVID-19.

It is important to note that coeliac disease patients, in general, are not considered to be immunocompromised, and only patients with severe malnutrition and weight loss, patients with very rare refractory coeliac disease who are on immunosuppressive medications, or patients with other serious illnesses may be at increased risk of having a more severe course of COVID-19. It is also highly unlikely that occasional gluten exposure (intentional or unintentional) will change the course of COVID-19 infection in coeliac disease patients, however, coeliac disease patients should by all means continue to follow a strict gluten-free diet.

Regardless of this reassuring data regarding the outcomes of SARS-CoV-2 infection in people with coeliac disease, there is an important risk that has to be addressed. By restricting the mobility of people and by redistribution of medical personnel to fight the COVID-19, the accessibility of healthcare is substantially decreased for people with diseases that have less severe course, such as coeliac disease. This has already shown to increase diagnostic delays and could have important long-term implications.

As COVID-19 is a new illness, new data are emerging continuously. It is therefore advisable that coeliac disease patients carefully follow the situation and recommendations provided by medical authorities and discuss any concerns with their health care provider.

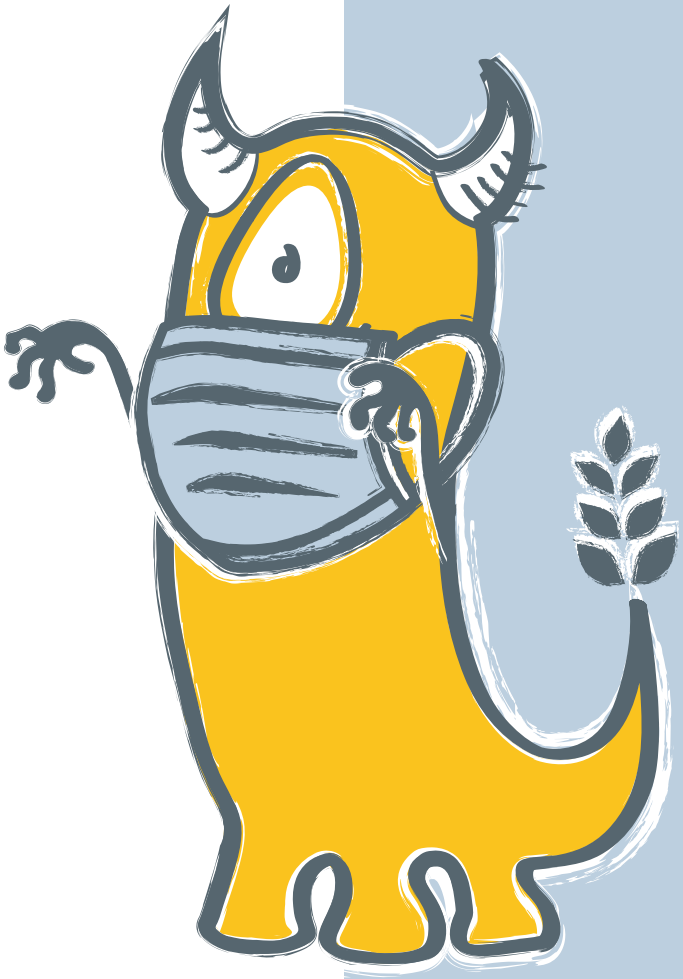
Coeliac Disease and COVID-19 Vaccination

The development of efficient vaccines against SARS-CoV-2 as a measure of active defense against infection together with passive measures such as social distancing, use of personal

protective equipment, and strict personal hygiene represents a true breakthrough in the fight against high morbidity and mortality caused by COVID-19.

It is therefore advisable that people with coeliac disease receive a COVID-19 vaccine that has been approved by medical authorities in their respective countries. This includes RNA and peptide vaccines. As the data on the safety and efficacy of vaccination is increasing, there is no evidence to suggest that people with coeliac disease are more prone to an adverse effect of vaccination. Since the coeliac disease is not considered an allergy, this also does not increase the risk of allergic adverse effects of vaccination.

Patients with concerns about vaccination and their particular circumstances should of course be free to speak openly about their concerns with their health care provider.



Patients' stories

NUŠA AND HER MOM FROM SLOVENIA

The day, when our oldest daughter was diagnosed with coeliac disease was one of the happiest days for our family. The diagnosis of coeliac disease was among the suspicions of doctors for the best and the least harmful disease. We were happy that the marathon from one doctor to another had finished, and that we finally identified what was wrong and how we can help our daughter to live and develop into a healthy and happy woman. Our daughter's health problems did not develop overnight as a rapid deterioration of her health condition. The changes were very gradual, but still not unnoticed. From the early age of two, she had weakened immunity (hypogammaglobulinemia) and was more prone to infections, this is why she was managed by specialists in an allergy outpatient clinic. To avoid diseases, she did not attend organized care (kindergarten). Somehow our happy but quiet girl became even more tired and without appetite after the treatment of her last infection. After consultation with her paediatrician, we did a blood count check, which was fine. Problems with diarrhoea, malaise, pain, constipation, or vomiting were absent. I visited the paediatrician`s office several times a month with my moody and tired daughter. No one thought of coeliac disease, we were not referred to a specialist – a gastroenterologist. As we were blessed with a new family member, we thought that maybe it was the lack of acceptance of her sibling and also visited a psychologist. During the holidays we were hoping for an improvement of her health condition; however, she was rapidly losing weight and her general health was in a bad state. Fortunately, we soon had an appointment with the allergist, who referred us to the gastroenterology department. The diagnosis of coeliac disease was confirmed 10 days thereafter. Our girl, a patient with coeliac disease on a strict gluten-free diet, is now growing up and is thriving into a healthy and happy girl. Soon her sister and father, also coeliac patients, joined her in the gluten-free diet.

> *"We were happy that the marathon from one doctor to another had finished."*

IGOR, PEDIATRICIAN FROM MARIBOR

I was diagnosed with coeliac disease at the age of 44. For many years, I had numerous symptoms typical of coeliac disease, from unbearable abdominal pain, diarrhoea, constant bloating, anaemia, fatigue, and infections all the time. Since I have had insulin-dependent diabetes for thirty years, this diagnosis of coeliac disease should be slightly more expected. The condition was staring me in the face, I just did not see it. As I am a paediatrician who knows about the symptoms I should have got it sorted out sooner. In addition, I know some eminent experts, who are treating the disease in their daily work. A few years before my diagnosis, I was traveling to a gastroenterological congress with a colleague expert in the field of coeliac disease. I suffered from severe pain, cramping, bloating, and diarrhoea at the time, especially when I had eaten a good breakfast of fresh rolls, but we did not see the obvious. In defense of my expert friend, my coeliac test had been repeatedly reported as negative. Afterward, additional problems developed. Both of my ankles were swollen, my anaemia was severe, and iron supplements did not help. Then another colleague of mine saved me and made the diagnosis. My serological tests were negative before because I also have an IgA deficiency. Now, I am on a gluten-free diet, I am 15 kg heavier than when I first started. I feel good, without any medical problems. It is hard when I pass the bakery and there is a delicious smell of freshly baked bread, though. It is also hard when I am in the hotel where they have breakfast with 15 types of delicious bread and bread rolls. Reading labels can be difficult, especially if you need glasses for small print like me. However, it is worth it. I accepted the diagnosis of coeliac disease relatively easily, and I am now accustomed to my chronic condition. This is also probably true because my health is incomparable to that of five years ago. I make gluten-free bread myself. I miss an occasional doughnut for carnival and I miss the Bled cream cake. Nowadays, there is a better variety of gluten-free products available on the market. Unfortunately, gluten-free products are relatively expensive, which can be a big problem.

“The condition was staring me in the face, I just didn’t see it.”

MARINA FROM CROATIA

I was diagnosed with coeliac disease at the age of 30, and I can say that it was one of the happiest days of my life. If you are wondering why, continue reading to get introduced to that quiet, changing, cocooned, and above all painful coeliac disease! For as long as I can remember, I have been listening to my parents' stories about how by the age of 7 I didn't have any appetite and the only thing I would eat was fruit. In that period of my life, while running around carelessly with friends I fainted, and in the hospital, I was later diagnosed with epilepsy. I was given antiepileptic drugs to keep the illness under control. I also remember the pain in my lower limbs. The doctor explained that I grew quickly and that was completely normal. The problem was that the pain was so strong that I could not sleep at night. I was doing many sports and was very active, almost hyperactive. There was not a month during the year when I did not have aphthae in my mouth, I was losing my hair, and after childbirth, I was experiencing enormous mood swings and lack of concentration. Revolution caused by genetic tests for coeliac disease. The biggest problem was the leg pain I was experiencing. In my twenties, I begged the doctors to find the cause of the pain and the weakness that I was experiencing daily. The pain was getting stronger, my knees were shaking, I could barely walk up the stairs, even just walking was exhausting. Sometimes I just couldn't get out of the bed, even if my baby was crying in need of his mother. All the hospitals and medical examinations were not able to determine the nature of my problem. I was told to check with a clinic in the USA to improve my health. I decided to stay brave and to believe that I was young enough to get through everything, even though that period of my life when I was taking painkillers daily just to get through the day. I also decided to completely ignore the comments of my friends and colleagues that maybe I was suffering from multiple sclerosis. In the second decade of my life, I gave birth to two children, both diagnosed with coeliac disease (in infancy). While the genetic testing for coeliac disease was non-existent in my country at that time, my husband and I both underwent testing for coeliac disease-specific antibodies to maybe discover the coeliac disease, but we were both negative. One day we received an invitation for genetic testing which we gladly accepted hoping to find answers to our questions. My results came in positive (the presence of HLA-DQ2 and DQ8 was established). I repeated the serology, which also came positive at this time, as well as the small intestine biopsy, to round up the whole story. I immediately started with the gluten-free diet. The antibodies decreased over the years. The pain started to fade slowly. It was only 5 years after the strict and persistent gluten-free diet that my results came in negative. For so many years I lived my life in pain, got the wrong diagnosis, and took the wrong therapy. After starting the gluten-free diet the pain in my muscles and joints disappeared, along with long and painful menstrual bleeding and aphthae. Finally, I was calm enough to continue my life. My diet consists of groceries, which do not contain gluten naturally, and my mission became to raise the quality of life of people suffering from coeliac disease! In the end, I would like to say that coeliac disease wasn't even considered a possibility in the adult population at the end of the last and the start of this century if it wasn't manifested with clear symptoms: stomach ache, diarrhoea, vomiting. Today, I can say that genetic testing contributed a lot to discovering coeliac disease in family members and first relatives of the diseased, as well as to many people whose coeliac disease was completely asymptomatic. We cannot give up on educating patients and medical staff and raising awareness about coeliac disease as a quiet epidemic that carries a lot more diseases and weak states of our organism.

"Finally, I was calm..."

MOTHER FROM HUNGARY

I have a son and a daughter. My son was 11 years old when his swimming trainer suggested taking him to a doctor. He told me that my boy works well, but still, his muscles do not grow, and his track results are not any better. He did not have any gastrointestinal symptoms. We went to see a pediatric gastroenterologist and very shortly it became clear that my son has coeliac disease. We started the gluten-free diet and the results were spectacular: in the next two years, he gained 15 cm, 14 kg, and won some trophies in swimming competitions!

"A swimming trainer suggested taking my son to a doctor".

On family screening, my daughter also proved positive: she did not have any symptoms either, just a very slight sideropenia. As a brother and sister, they always got along very well, and they are also "sharing" coeliac disease experiences together. We did not ever have any problems with the diet.

Today, my children are 16 and 18 years old and can manage gluten-free shopping and cooking on their own. Needless to say, I am very proud of both of them.

CHRISTINA, PAEDIATRICIAN FROM GRAZ

I am a paediatrician myself – and years ago, when I once saw my sister-in-law who is a bit younger than me I thought to myself "oh, how pale and irritated her skin looks, certainly she has too much stress and not enough sleep", and I booked a spa weekend for her to have her pampered with some expensive beauty treatments.

However, before heading for the lovely spa she saw her physician who diagnosed substantial iron deficiency anaemia and sent her upfront for endoscopy: her coeliac disease was diagnosed right then and there!

Soon after that, her first-degree relatives had a blood test done and one brother was found to be positive. He had suffered for years from "irritable bowel syndrome"!

Therefore, please remember: pale and "cracked" skin might not only be a sign of a stressful life but may also be a consequence of iron deficiency, an important sign of coeliac disease!

"Pale and "cracked" skin might be a sign of coeliac disease".

On a gluten-free diet, my sister-in-law finally has lovely skin again. And she now wants to take on the spa treatments I offered.

PATIENT STORY FROM SERBIA

Mihajlo was first diagnosed with coeliac disease when he was five years old. After about twenty days of diarrhoea, he was referred to a gastroenterologist. Based on his symptoms, the doctor immediately suspected coeliac disease and ordered a test for antibodies, which were very high. Endoscopy was also performed which confirmed that it was a case of coeliac disease.

Since coeliac disease is genetically predisposed, the doctor sent other family members for analysis - Mihajlo's sister, mother, and father. The results showed that the mother was the carrier of the gene, which increases the risk of developing coeliac disease, while the father and sister did not carry that gene. After further analysis, the mother was also diagnosed with coeliac disease. She was surprised since, apart from always having anaemia, she believed to be healthy. She did not consider long-term anaemia as a serious health problem. Unlike his mother, Mihajlo had many problems before he was diagnosed. He was listless and without energy, he made little progress, he weighed 15 kg from the third year on, he was a head shorter than his peers were, and he had asthma.

"Today, Mihajlo and his mother are experts in keeping a gluten-free diet".

That all changed after the diagnosis and elimination of gluten from their diet. However, it was not easy. The only advice they received from doctors was not to eat gluten and they were given a short brochure about coeliac disease. They had to find out for themselves what to eat, what foods to buy, and how to eat properly. Fortunately, they found out about the Association of Patients with Coeliac Disease, where they received great help and practical advice for everyday life difficulties. It took a long time for Mihajlo to recover. Antibodies dropped fast, but iron values returned to normal only after two years. Today, Mihajlo and his mother are experts in keeping a gluten-free diet. And most importantly - they are healthy.

THE STORY OF ANNA (CZECH REPUBLIC)

My daughter Anna was diagnosed with coeliac disease in October 2020, two months before her tenth birthday. I felt desperate, realizing that she has probably suffered from the disease since she was born and that none of the physicians, who have seen her in the past ten years, including a fair number of gastroenterologists, could ever identify her health problem. Although the symptoms she had could give the doctors the idea, no one thought of coeliac disease.

"It never crossed my mind that my daughter might suffer from coeliac disease."

When I complained to the paediatrician that I did not like the look of Anna's stools, light in colour, sometimes greenish, with mucus and residues of undigested food, she just waved it away. She claimed it was just slow digestion. My daughter's conspicuous paleness made the doctor check for possible anaemia, but that was all.

Similarly, no one noticed her distended abdomen even when she was a baby. She had been diagnosed with low muscle tone and Vojta therapy was applied on her, but no one searched for the underlying condition. Even for the paediatric gastroenterologist that we used to see, coeliac disease was completely out of focus, even when he examined her stools for the presence of pathogens.

Anna often had hiccups as a newborn baby, and then belching and bad breath, especially after she woke up, and finally, gastroesophageal reflux (GER) was diagnosed when she was nine years old. However, no one investigated whether this problem is due to coeliac disease, which often happens.

Coeliac disease was identified by chance. We were looking for a new paediatric gastroenterologist and chose the facility at the General University Hospital in Prague, where we got a friendly welcome. Luckily, we were in the capable hands of a real expert, dr. Peter Szitányi, who after having just a glance at Anna suspected she might suffer from coeliac disease. We made an appointment with him as we wanted to confirm the diagnosis of GER because in the summer of 2020 she experienced nausea and vomiting. Doctor Szitányi referred us for a gastroscopy to exclude esophagitis. In addition, he ordered blood tests as well, and these "unfortunately" revealed the presence of a low titre of antibodies against coeliac disease (TGA). The diagnosis, in that case, should only be confirmed by endoscopy. Immediately after histological confirmation of the diagnosis, we put Anna on a strict gluten-free diet, and now we are trying to adapt to this new situation in our life.

It never crossed my mind that Anna might suffer from this disease, and I have difficulties accepting that no one would discover that, although it might have happened very easily. I keep thinking about why the government has not included coeliac disease in the obligatory neonatal screening, which detects a lot of diseases, including some much rarer than this severe autoimmune disease.

I keep thinking why paediatricians who see babies and children at regular preventive follow-ups do not focus on coeliac disease more, as they miss hundreds of cases of coeliac children, which is sad and alarming, considering how a serious disease it is. For us, the diagnosis was a blessing in disguise but, sadly, many families will not receive the appropriate medical care in time. The authorities should definitely think about how to improve this ugly situation.

MAJA FROM ZAGREB (CROATIA)

I was born in the 1970s in Zagreb, Croatia, and one of my first memories, among playing and having fun, were serious digestive issues and complications. My family got rid of all the carpets from our apartment, as my vomiting was frequent and often unpredictable. I also remember that I attended numerous different medical examinations. I was told by my parents that doctors were taking my blood to regularly check it since I was an anaemic little child. Although many different examinations were made, doctors concluded that I was physically healthy but under a lot of stress, because my parents were in the middle of a divorce and that their separation was the main issue of my digestive problems.

During my childhood and adolescence, I often felt nauseous, tired, and frequent vomiting was still part of my life. I adored playing sports and was good at karate, but when training for more serious competitions began, I could not keep the pace - mornings after intense training sessions, I could not get out of bed, but the good thing is that I did not quit karate until late college years.

When I started working, at least once every few weeks I was so sick and vomiting that I could not come to work. I still remember my first boss telling me "Hey, you should seriously check your health". I was 27 years old at that time.

As I was getting older, I began to have ataxia and a lot of pain in my joints, the big ones and the small ones, too. I remember my ankles used to hurt so much and I had awful pain in my finger joints, so I could not walk. I had a Waaler-Rose test, which turned out negative. Besides frequent vomiting, constant nausea, and joint pain my blood work indicated smaller than normal MCV and low thrombo-

cytes. When I complained to my doctor, I got the explanation that I am genetically different from others and that I should visit a mental therapist to help me with my hypochondria. The good thing was that I was exercising regularly and I tried to stay physically active. At that time, other areas of my life were more than fine; I had a good job and I met a wonderful guy who has, later on, become my beloved husband.

At the end of 2011, just as I accepted that I will live forever with vomiting and pain, a solution for my trouble arose, and it was in the form of a food intolerance test. Because of the candida overgrowth in my body, a homeopathic doctor prescribed a very strict diet, which I had to follow for 6 months: I had to cut out gluten, sugar, dairy, beans, and fruits. And after a few weeks of that diet, a miracle happened - for the first time in my life, I felt really good. I had no pain, no vomiting, no nausea, and had lots of energy and my strength in sports (especially in windsurfing) became obvious. My skin cleared up; my bloating disappeared... I was happy, optimistic and enjoyed being in my body.

Soon after stopping with the diet and starting to eat normally, all of my symptoms came back, worse than ever. During 3 weeks I lost 7kg, I looked pale and felt so weak I could not go to work or even walk my dog. I was tested for parasites and bacterial infections and everything was fine, except I was feeling awful.

The good thing was I was curious about what was happening to me and I started reading about coeliac disease and reading the symptoms. It was the year 2012 and coeliac disease in adults in Croatia was something unfamiliar to most of the family doctors and general population. Encouraged with a period of feeling good I was persistent and went to take a screening test for coeliac disease in Croatia and after that, I was examined at the University Hospital Centre Zagreb and finally got a diagnosis and confirmation that vomiting and nausea weren't only in my head and that this is a real, but manageable disease.

"I have a positive outlook on life."

Following a strict gluten-free diet, since 2012 resulted in improving my overall health, my pain and nausea went away and life became much better without regular vomiting. I feel much stronger and I have a positive outlook on life. A year or two after starting a gluten-free diet I was able to drink yogurt again :), and nowadays I can even drink a glass of milk without getting diarrhoea.

Living with coeliac disease and following a strict gluten-free diet is not easy, as it may seem at a first glance. The way we eat affects our family and friends and dictates many activities - almost every social event includes food and we have to plan our every meal. Some people in our lives are caring and understanding and others see us as picky and demanding. One doctor told me "You can't have coeliac disease, you look fit and strong", "Yes, I do, but I am following a gluten-free diet, it wasn't always like that", I replied.

There is a lot of misinformation about coeliac disease out there and there is a huge amount of space for raising awareness and helping children and adults and their families to get the diagnosis on time and to encourage them to stick to the gluten-free diet. I consider myself lucky because after being diagnosed at the age of 38 and removing gluten from my diet I regained good overall health. The major problem is weight gain and I was diagnosed with a serious vitamin D deficit, which I managed to cure with proper supplementation.

To help others, I joined CeliVita - Living with coeliac disease as a volunteer. I hope that unrecognized patients with coeliac disease can benefit from my experience and I can spread awareness about being diagnosed and living on a strict gluten-free diet.

The first few gluten-free days

In the beginning, the preparation of gluten-free meals will require reflection, organization, and special attention. Over time, it will become your way of life and bring you a sense of well-being as well as become your routine.

In the store, get food that is clearly marked with a crossed grain - the official sign of the gluten-free food that has only gluten-free ingredients and foods that are declared »gluten-free« on their label.

When preparing meals, be very careful to avoid cross-contamination with gluten. Before preparing the food, clean the kitchen surfaces, use clean dishes, kitchen utensils, and kitchen towels - as described in the chapter on the regulation of gluten-free kitchen.

FIRST PURCHASE AT THE DIET ISLE IN THE GROCERY STORE

- Gluten-free bread
- Gluten-free flour
- Gluten-free cereals
- Gluten-free polenta (yellow and white)
- Gluten-free pasta
- Gluten-free cocoa
- Gluten-free cookies / pastries
- Tea - check the ingredients
- Sugar, salt
- Fresh fruits and raw legumes

Some basic menus

BREAKFAST

Gluten-free bread + butter / jam / honey / gluten-free chocolate spread / gluten-free salami / cheese / gluten-free cheese spread + fresh vegetables (peppers, carrots, cucumbers, tomatoes) with fresh fruits (raspberries, blueberries, peaches, oranges, etc.) and freshly squeezed fruit juice / tea / coffee / gluten-free cocoa

Gluten-free pancakes + jam / gluten-free chocolate spread/curd or fresh cheese + apple jam (prepared at home: apples, cloves, water)

Eggs poached / fried / soft or hard-boiled + gluten-free bread + fresh vegetables

Gluten-free cereals with milk + fresh fruits (raspberries, blueberries, peaches, oranges, mandarins, etc.)

Rice cereals – milk porridge (if you add gluten-free cocoa, it is a good substitute for chocolate flavoured porridge)

Gluten-free white polenta prepared on milk

Rice pudding (rinse the rice thoroughly before use)

VARIOUS SPREADS (butter, jam, honey, fresh cheese spread, chocolate spread, etc.) - choose either a portion size packaging or use new package of product (not used before). It is important that you do not spread them on regular bread (containing gluten) and gluten-free bread / pancakes with the same knife or / and from the same container, in order to avoid contamination.

POWDER INGREDIENTS (salt, sugar, cocoa, coffee, tea) – due to the possible contamination of salt / sugar containers, etc. - take the new package of ingredients.

MILK - if you have lactose intolerance at the beginning, replace milk with declared gluten-free rice or soy milk.

LUNCH

SOUPS

Beef soup - Use only fresh meat, fresh vegetables, fresh herbs, and salt, pepper. Do not use mixtures of spices or the premade soup base (egg soup cubes)! In the case of premade soup base, choose only the gluten-free certificate variants. You can cook/add gluten-free pasta to the soup or make homemade gluten-free soup pasta from gluten-free flour and eggs.

Vegetable Cream Soups - Use only fresh vegetables, add potatoes for thickening, fresh herbs, and salt – mix completely. You can add a tablespoon of sour cream, e.g. PUMPKIN SOUP; heat garlic on olive oil, so that it starts to smell, add a Hokkaido pumpkin cut into cubes, stir a little, add salt, and pour water over the mix. Cook until soft and mix with a stick mixer. Sprinkle nutmeg*, optional you can add a spoon of sour cream.

MAIN DISHES

Gluten-free pasta with meat sauce - Cook the gluten-free pasta in fresh water and drain it through a clean strainer. Use fresh meat, fresh onions, and garlic for sauce, fresh tomatoes, fresh herbs, and salt. Tur- key breast meat strips with vegetables and gluten-free polenta - Fresh turkey breast cut into strips with fresh vegetables, add salt and fresh spices. Separately cook gluten-free polenta. Risotto with fresh mushrooms/asparagus/fresh chicken breast/fresh vegetables. Wash rice under the running water before use (use a clean strainer). Use fresh herbs and salt. Fresh fish / fresh salmon file grilled in a casserole, potatoes in pieces with kale - Cook potatoes in fresh salted water; add fresh kale at the end. When cooked, drain through a clean strainer and fry together on olive oil with garlic (use fresh garlic). Grilled steak with mashed potatoes - Fresh steak (chicken, turkey, veal, pork) grill on a spoon of olive oil in a clean pan, use salt and pepper if desired. Boil potatoes in clean salt water, drain through a clean strainer, crush (you can add butter/tablespoon of sour cream).

SALADS

Fresh salad (green, cabbage, chicory, etc.) seasoned with salt, oil, wine, or apple vinegar. Sliced tomato with mozzarella and olive oil. Freshly cut vegetables.

DESERTS

Gluten-free cookies/pastries.
Ice cream – should be checked/confirmed that it is gluten-free.
Compote - cooked at home (fruit, sugar, cloves).

SPICES – be careful with minced spices, which can often contain gluten. We advise the use of fresh herbs. In regards to the use of specific spices consult the dietetic, ask which spices are gluten-free.

OILS - you can safely use rape, sunflower, olive oil, pumpkin oil, to make meals.

VEGETABLES IN A JAR (pickles, red beets, sour peppers, olives, etc.) - check that they are gluten-free.

CANNED LEGUME (corn, peas, beans) - check that they are gluten-free.

FROZEN VEGETABLES - check that they are gluten-free.

POLENTA, OTHER CEREALS, OR PSEUDOCEREALS (which are naturally gluten-free).

SUPPER/DINNER

Vegetable soup with gluten-free bread – *use only fresh vegetables, potatoes, fresh herbs, and salt.*

Gluten-free pancakes + homemade compote (fruit, sugar, cloves).

Egg omelette with home grated hard cheese* / fresh vegetables / gluten-free ham + bowl of green salad (wine or apple vinegar, oil, salt). Gluten-free cereal with milk or plain yoghurt.

Gluten-free bread + tuna* in olive oil / gluten-free salami / cheese / gluten-free fresh cheese spread + fresh vegetables (peppers, carrots, cucumbers, tomatoes).

CANNED TUNA - ingredients on the declaration should be only tuna and olive oil.
GRATED CHEESE may contain gluten.

SNACKS

Yogurt and / or fruit + gluten-free bread / gluten-free crackers / gluten-free cookies.
Gluten-free Hot dog + gluten-free bread + fresh vegetables (peppers, carrots, cucumbers, tomatoes).
Fruit + some home husked-up walnuts or hazelnuts.

HOT DOG (Carniolan sausage, etc.) - must be declared gluten-free
MAYONNAISE / KETCHUP / MUSTARD / AJVAR - you need to select verified gluten-free products.

BEVERAGES

Plain water (sparkling water as an option) / natural juices without flavour and/or other additives.

BEVERAGES need special caution because they can contain gluten due to flavour and colouring additives and various other additives.

Seven ideas for daily gluten-free menu for children with coeliac disease

	BREAKFAST	SNACK	LUNCH	SNACK	DINNER
MONDAY	Gluten-free bread 70 g 2 eggs “sunny side up” Avocado 30 g Tomato 80 g Kefir* 250 ml	Orange 150 g Tea 250 ml Honey 10 g	Vegetable soup 150 ml Roast chicken 80 g Grilled zucchini 150 g Baked potato 200 g Mixed salad 150 g	Banana 150 g Walnuts 15 g	Risotto with vegetables and chicken 280 g Parmesan cheese 15 g Beetroot salad 100 g
TUESDAY	Gluten-free bread 70 g Cheese and sesame balls 50 g Cucumber 100 g Tea 250 ml	Apple 200 g Cottage cheese* 50 g	Fish fillet (grilled) 150 g (marinade: lemon juice, parsley, 10 ml olive oil) Tomato salad 100 g (seasoned with olive oil – 10 g and vinegar) Baked potato 200 g	Fruit salad 150 g	Vegetable stew 200 ml Gluten-free bread 70 g Stuffed tomatoes 250 g (meat, rice, vegetables) Mixed salad 100 g

	BREAKFAST	SNACK	LUNCH	SNACK	DINNER
WEDNESDAY	Gluten-free polenta with cheese and egg yolk 200 g Milk* 200 ml	Hummus 50 g Cucumber 50 g Carrot 50 g Gluten-free bread 70 g	Broccoli soup 150 ml Burger 140 g Sautéed potatoes 200 g Sautéed green beans or pea 70 g Mixed salad 100 g	Fruit purée: Melon 50 g + Apple 50 g + Blackberries 50 g + Cornflakes 15 g + Honey 10 g + Yoghurt* 100 ml	Chicken spread (chicken 30 g, carrot 5 g, egg 5 g, sour cream 15 g, cream cheese 15 g, sunflower seeds 1 g) Gluten-free bread 70 g Bell pepper 80 g Kefir* 250 ml
THURSDAY	Gluten-free bread 70 g Butter 15 g Jam 20 g Milk* 250 ml	Banana 150 g Sour milk* 150 g Almonds 20 g	Veal soup 150ml Swiss chard parcels stuffed with minced beef 150 g Mashed potato 200 g	Cooked buckwheat (on milk) with banana 100 g and ground walnuts 10 g (de-shell the walnuts, grind, and add)	Omelet (2 whole eggs, vegetables 70 g) Gluten-free bread 70 g
FRIDAY	Millet breakfast porridge (millet 50 g, water 90 ml, milk* 80 ml, cinnamon) Banana 150 g Almonds 10 g Tea 250 ml	Dried fruit and nuts 50 g Cottage cheese* 50 g	Stewed or roasted chicken 80 g A side dish of vegetables with pumpkin 100g Cooked quinoa 150 g Baked potato 100 g Seasonal salad 100g	Frappé 250 ml: Yoghurt* 100 ml + pineapple 80 g + blackberry 80 g + Banana 150 g + Cornflakes 30 g (blended)	Tuna and kidney bean salad 120 g Lettuce 100 g Gluten-free bread 70g

	BREAKFAST	SNACK	LUNCH	SNACK	DINNER
SATURDAY	Chicken spread 60 g Gluten-free bread 70 g Bell pepper 70 g Yoghurt* 250 ml Tea 250 ml	Banana 150 g Almonds 30 g	Moussaka (with gluten-free béchamel sauce) with beef 300 g Green bean salad 150 g	'Crispy porridge' 250 g: rice porridge mix 50 g + fruit 30 g + 5g honey + Milk* or yoghurt* 100 ml	Mushroom risotto 200 g Roasted chicken 100 g Beetroot salad 100g
SUNDAY	Omelette (2 whole eggs, vegetables 70 g) Avocado 50 g Gluten-free bread 70 g Tea 250 ml	Mandarin 200g Kefir* 200 ml	Potato stew with chicken (230 g + 70 g meat) Buckwheat bread 100 g or Polenta 200 g Beetroot salad 100 g + 10 ml olive oil	Boiled millet (with milk*) 200 g + Ground walnuts 20 g + Dried fruit 30 g	Fish fillet (grilled) 150 g (marinade: lemon juice, parsley, 10 ml olive oil) Boiled potatoes with Swiss chard 250 g

* 7-days meal plan is designed with low-fat dairy products

Daily average energy and nutritional values of the seven-day menu for children with coeliac disease:

Energy (kCal)	Proteins (g)	Fats (g)	Carbohydrates (g)	Ca (mg)	Fe (mg)	Vit. A (µg)	Vit. B_1 (mg)	Vit. B_2 (mg)	Vit. C (mg)	Vit. B_{12} (µg)
≈ 2034	90	82	233	910	12	879	1,07	1,73	138	3,8

* 24 g – plant protein + 66 g animal protein

Daily energy intake is sufficient for children up to 12 years of age. For other age groups, the daily energy intake should be adjusted according to the dietary recommendations and individual's needs.

How to set up a safe gluten-free kitchen?

To the health of patients with coeliac disease, even the smallest mistakes and contamination of gluten-free products can be harmful.

To ensure a safe, strict gluten-free diet it is important to buy gluten-free products, but also to store and prepare them properly to be able to produce a real gluten-free meal as a result.

To help with tips and suggestions on how to prepare the kitchen surfaces and rearrange the articles in the kitchen, check the "Gluten-free Kitchen" video.

https://youtu.be/RBq7htEYPp0

REORGANIZE THE KITCHEN

1

Remove all products which contain gluten: bread, pasta, flour, pulp, breadcrumbs, and spices, or organize a separate shelf/ cupboard.

2

Remove all types of glutinous products that may be contaminated with gluten.

3

Discard: old sponges used for cleaning and washing the dishes, baking brushes and other utensils, strainers, pans, and baking trays, which cannot be thoroughly cleaned, toasters, grinders, and/or mixers where we ground biscuits / dried bread, bread making machine.

4

Discard or donate (because of contamination these devices are unsuitable for preparation of gluten-free food): wooden cooking utensils, cooking hobs, cutting boards, old chopsticks, rollers, wooden decorative cookware for biscuits, decorative spoons, bread baskets, hand-powered or electric wood /stone cereal mills.

5

Thoroughly clean: , knives, shelves, dishes, pots, drawers, refrigerator, stove, oven, areas for preparing food – kitchen countertops, cutlery, metal strainers (in dishwashers or hand wash), plastic containers for storing food (in dishwashers or hand wash), grinders for nuts, mixers, blenders, juicers, baking trays, baking models, textile, and plastic covers.

In case of combined kitchen used to prepare both regular and gluten-free meals:

The combined kitchen needs to be organized as a completely gluten-free kitchen, and only part of the working area should be defined for the preparation of gluten-based meals. If you can afford it, even in a combined kitchen, use exclusively gluten-free flour and starch and any other bulk/minced ingredients. In the combined kitchen the toasters, bread machine, various mixers must be separated for the preparation of regular and gluten-free bread.

1. Reorder: Clearly mark all gluten-free products and stock all gluten-free products separately, away from regular products containing gluten, to the top shelves and, if necessary, use additional plastic containers with a lid for packing them safely. In the refrigerator, mark all regular products containing gluten distinctively differently from the gluten-free products. The gluten-free products must be put on the highest shelves and, if necessary, one should use additional plastic containers with a lid for packing them safely. It may help to put bright stickers on foods that are to remain gluten-free (e.g. margarine, peanut butter, cream cheese, etc.)

2. For the preparation of gluten-free meals, clean or buy new dishes, kitchen utensils (cooking utensils, knives, etc.), kitchen boards, toaster, kitchen towels, and sponges for washing the dishes. We advise you to buy utensils of a different colour to prepare gluten-free meals so that there will be no confusion and consequently contamination while preparing gluten-free meals will be minimal.

3. Before preparation of gluten-free meals in the combined kitchen, it is necessary to carefully clean the working surface each time. Please keep in mind that gluten is invisible to the naked eye. If you share the kitchen with non-coeliac people, make sure everyone understands the rules.

Some basic instructions for successful gluten-free baking

Home-made gluten-free bread is far superior to the bought one. We have selected two basic recipes for bread that people who give up gluten usually miss the most.

Some baking tips

- All ingredients should be warmed up to room temperature, colder products rise more slowly.
- Salt should never come into direct contact with the yeast.
- Always use lukewarm liquids for dough preparation.
- Always mix the dough according to the DIRECT METHOD; it is important to dissolve the yeast in the lukewarm liquid, then adding it to all the other ingredients and hand-knead or machine mix the dough.
- Machine mixing is of higher quality and results in a more even distribution of flour and liquid; it makes the dough smoother.
- The freshly prepared dough should rise to the double amount after kneading.
- Before using the raisins gently boil them in some water and drain well before adding them to the mixture.
- Cover the molded products with foil so that they do not dry out.
- Molded products must be raised to a double amount before baking.
- Large dough products must be pierced with a wooden needle to the bottom before baking so that excess moisture and air can dry out.
- Place a pot of boiling water on the bottom of a heated oven, which evaporates between the baking and provides the necessary moisture to form a higher quality crust.
- Leave the baked products for a few minutes in the model, then slip them out of the models, or take them out of the baking tray and cool on a baking grate or a washcloth; to make the crust soft, you can also wrap them into a wet napkin for a while.
- Fillers must be applied smoothly but must not consist of too much liquid.
- The filling should be 80% of the weight of the dough, exceptionally more.
- We use declared and/or verified ingredients without gluten.

Cook's tip

Turn any left-overs into breadcrumbs and store them in the freezer to use when preparing fried food. The bread will keep for 3-4 days wrapped in a plastic bag. Share the recipes with other people around the world that are in the same situation as you.

Gluten-free bread recipe

Ingredients

- 1 kg gluten-free flour (mix b)
- 1 L of water (optionally half milk and half water)
- 1 teaspoon of sugar
- 1 teaspoon of salt
- 1 cube of fresh yeast (42 g)
- A few drops of oil, if desired

	kJ/kcal	Proteins	Fats	Saturated Fats	Carbohydrates	Fibres
Total (approx. 2 kg)	14250/3355	57 g	16 g	0.7 g	745 g	61 g

Process

Sift the flour into a large bowl, make a well in the center and crumb the yeast to the middle. Add sugar and salt to the edge of the bowl. Measure 1L of lukewarm water in a jug, add the liquid to the yeast and mix well with an electric mixer or turn the ingredients onto a lightly floured surface and knead to form the dough Add a little oil if desired (not necessary) and knead for about five minutes until smooth. Shape the dough into a rectangle, ball, fat roll, or some other shape, and place in the prepared tin. Make two or three slashes on the top with a sharp knife. Cover loosely and leave in a warm place to rise for 1 hour or until doubled in size. Preheat the oven to 200°C. Bake the bread in the oven for 35-40 minutes or until it is risen and golden brown. Remove from the oven and allow to cool for a few minutes in the tin, then turn out and cool on a wire rack.

From the raised dough you can prepare buns, cheese buns, pizza, braids, bread, curd potica, herbal buns, and other types of buns.

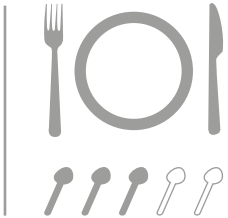
Cook's tip

Add the seeds according to preference: poppy, pumpkin, sunflower, sesame, etc. If you like, double the quantities and bake two loaves at the same time, then freeze one. Bread can be frozen for up to six months.

Holiday bread recipe

Ingredients

- 1 kg gluten-free flour (mix b)
- 1 liter of water (optionally half milk and half water)
- 1 teaspoon of sugar
- 1 teaspoon of salt
- 1 cube of fresh yeast 42 g
- small amount of oil, as desired
- 1 egg for coating



Process

Sift the flour into a large bowl, make a tiny hole in the middle, add crushed yeast into a well in the centre, and add sugar and salt along the edge of the bowl. Measure 1L of lukewarm water into a jug, add to the yeast, and stir a little, slowly add some oil, if desired (not necessary), but be careful that the oil does not come into direct contact with the yeast. Turn onto a lightly floured surface and bring together with your hands to form a dough. Knead for about 5 minutes until smooth. Cover the dough with a cloth and leave it in a warm place to rise until doubled in size, for about 1 hour.

Preheat the oven to 50°C.

From the prepared dough, you can prepare small bakery products (buns, cakes, braids, cheese buns, etc.) or simply put it in the prepared, lightly greased tin.

Let the dough rise again for 15 minutes. Preheat the oven to 175°C.

Bake small bakery products in the oven for 30 minutes or bread for 45 minutes until golden and crusty. Cool in the tin covered with a cloth.

	kJ/kcal	Proteins	Fats	Saturated Fats	Carbohydrates	Fibres
Total (approx. 2 kg)	15925/3755	80 g	39 g	13 g	770 g	61 g

Gluten-free shopping

If you have been diagnosed with coeliac disease and are making the shift to a gluten-free diet your grocery shopping experience is going to change!

Trying to follow a strict gluten-free diet can be overwhelming, and your first few gluten-free shoppings will be challenging; however, it will become easier over time. If you have just started eating gluten-free, you will be glad to learn tips and tricks on how to find safe gluten-free products, which products are naturally gluten-free, which may contain hidden gluten, how to organize your shopping, where you have to be careful, and much more.

The most important part of gluten-free shopping for those following a strict gluten-free diet is reading and decoding the labels (the ingredients). We will provide you with some tips.

The best advice comes from experienced coeliac disease patients. Get in touch with them and check with the manufacturers if you have any questions.

To ensure a safe and strict gluten-free diet it is of vital importance to buy verified gluten-free products and to properly store these products at home.

STEP-BY-STEP SHOPPING

STEP 1
Prepare the shopping list of gluten-free products at home and include tested and certified products, e.g. those listed in the journal Celiakija by the Slovenian Association for Celiac Disease (SDC).

STEP 2
Once in the store, choose a clean shopping basket. If you notice remains of breadcrumbs or flour in the basket, choose another one that is clean.

STEP 3
When choosing products, stick to the shopping list and verified producers. Make sure that the product packaging is undamaged.

STEP 4
When buying fresh fruit and vegetables, the possibility of contamination with gluten should be neglible or at least not expected.

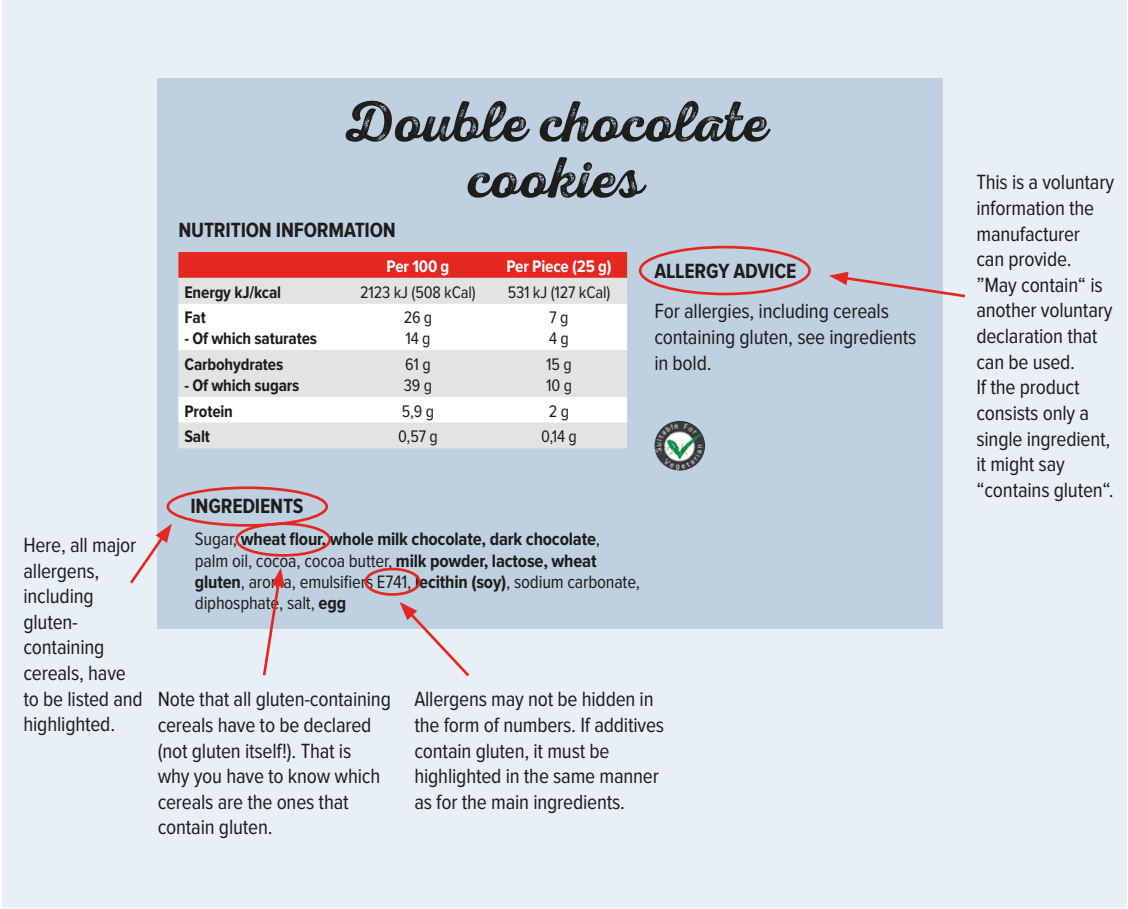
STEP 5
When choosing/ buying fresh meat, mind the distribution of meat in the showcase and pay attention to the possible proximity of products coated in breadcrumbs. Remind the butcher to maintain hygienic standards, not to use the same spoons, slices, etc.

STEP 6
Deli counter: pay attention to cleanliness of the meat slicer; in smaller shops you might want to check whether they serve bread or make sandwiches on the same part of the counter as meat, check if the staff has clean hands, etc.

STEP 7
Products should be kept in an unopened (and undamaged) package. It is suggested to use plastic bags in order to avoid contamination on conveyor belt. Be careful when placeing products on conveyor belt.

1. READING AND UNDERSTANDING DECLARATIONS (FOOD LABELS)

When buying products, read carefully the declaration and ingredients, and compare the translation with the original label. Do not choose products containing wheat, rye, kamut and bulgur, barley, spelt flour, or various groats. Choose the following grains instead: buckwheat, millet, corn, rice, quinoa, and others. Caution is nevertheless necessary when buying flour and grain products. Gluten-free products must be marked with the internationally recognized Crossed Grain symbol, “gluten-free” mark, or tested for gluten content. It is recommended to use gluten-free products listed in a registry maintained by coeliac societies. Do not choose products, which may contain traces of gluten.

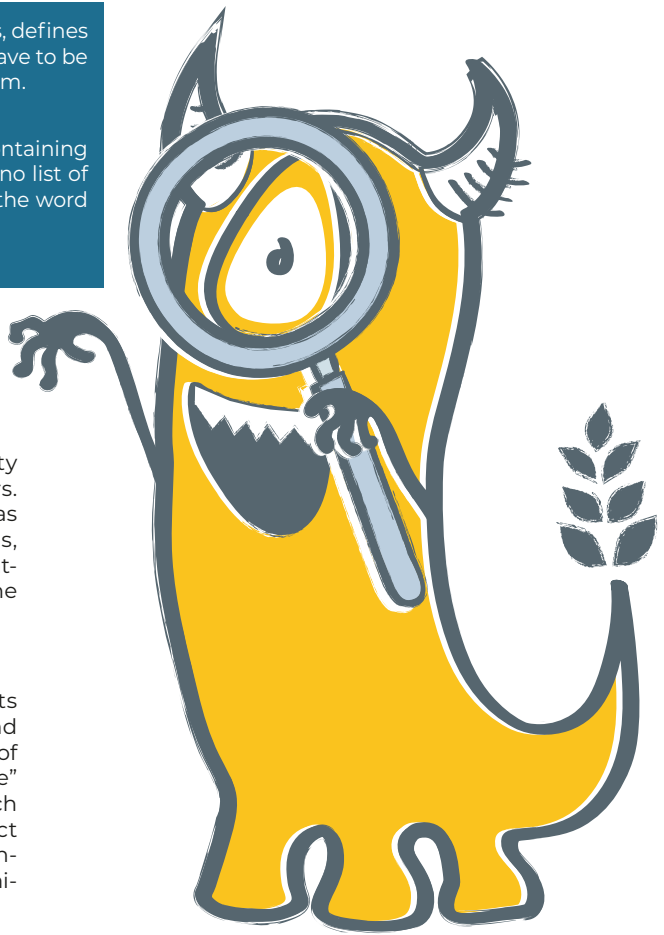


Source: Focus IN CD e-learning tool for patients

EU regulation No. 1169/2011 on the provision of food information to consumers, defines the 14 most common causes of allergies and other food sensitivities, which have to be stated on the food label. Gluten and gluten-containing cereals are one of them.

Prepacked food: when there is no list of ingredients
Some products do not have to have a list of ingredients, e.g. beverages containing more than 1.2% by volume of alcohol. However, even in cases when there is no list of ingredients, the listing of allergens is mandatory. The citation must include the word "contains" followed by the name of the allergen, for example:

Contains: wheat, or Contains: wheat (gluten)



Exceptions: non-hazardous ingredients

Certain ingredients, although derived from raw materials that may originally cause allergies or intolerances, are unlikely to cause allergies or intolerances because they have undergone a process to remove allergens. Such ingredients have been evaluated by the European Food Safety Authority (EFSA) and concluded that they do not pose a risk to consumers. Therefore, these ingredients do not need to be specifically highlighted as allergens in the list of ingredients. In the case of gluten-containing cereals, exceptions apply to wheat-based glucose syrups, including dextrose, wheat-based maltodextrin, barley-based glucose syrups, and to cereals used in the production of alcoholic distillates, including ethyl alcohol.

Other claims about gluten are forbidden!

Regulation (EU) No. 828/2014 prescribes the exact text of the statements on the absence and reduced presence of gluten in food: "Gluten-free" and "Very-low gluten". Manufacturers may put a statement on the absence of gluten only in those words. In this way, using clearly prescribed “gluten-free” or “very low gluten” statements allow consumers to know exactly what each statement means and what the maximum amount of gluten in that product is. The manufacturer's versions of the statements are not permitted, f.e. "Ingredients without gluten", "Naturally gluten-free ingredients" or other similar statements.

2. TRAPS DURING SHOPPING, SPECIAL CAUTION REQUIRED

Avoid shopping at the deli counter and rather choose the already sliced and vacuum-packed products: salami, cheese, hot dogs, etc. Cash desks and conveyor belts: flour and breadcrumbs are often scattered on the conveyor belts, for protection put the products onto the shopping bag or ask the cashier to scan them without placing them back on the belt. Consider using a self-service cashier whenever possible.

3. GLUTEN-FREE PRODUCTS WITH THE CROSSED GRAIN LABEL

Labeling products with the Crossed Grain symbol and the logo of the National Coeliac Disease Society are intended for products for which the production, purchase, storage, and packing is managed, monitored, and tested for gluten content by a national society. Such products are awarded a label, which is a type of license for use and labeling products. Without any doubt, these products are the safest and most tested gluten-free products for patients with coeliac disease. Use of the internationally registered symbol is protected with the registered trademark (®) and can be used by registered coeliac disease societies. Under the label, you will find the country code and testing code number: SI-3512345 (Slovenia), AT-3418763 (Austria), I-24517453 (Italy), etc.

SI-123-123

Certain manufacturers label their products with various symbols of a crossed grain. Please note that these products might not be tested to the same degree and their release to the market might not have been approved by the coeliac disease society.

4. GLUTEN-FREE PRODUCTS WITH THE LABEL “GLUTEN-FREE”

Many manufacturers do not label their products with the crossed grain symbol but only place the “gluten-free” mark on the product. Please check if these products have been tested for gluten content and are listed in the gluten-free products registry.

- Bonbons
- Chocolate
- Pudding
- Ice-cream
- Pâté
- Meat products and charcuterie: bacon, salami, sausages, tartare
- Ready-to-eat dressings – pasta sauces
- French fries
- Potato chips

5. PRODUCTS WITHOUT ANY LABELS AND TESTED FOR GLUTEN CONTENT

Please check if these products have been tested for gluten content and are listed in the gluten-free products registry.

6. PRODUCTS NATURALLY NOT CONTAINING GLUTEN

When buying fresh fruit and vegetables there is practically no possibility of contamination or at least it is not expected.

- Fresh fruit, vegetables, meat
- Milk, butter, cream

Homemade fresh cheese and cream and can be contaminated with flour.

7. PRODUCTS NATURALLY NOT CONTAINING GLUTEN WITH THE POSSIBILITY OF CONTAMINATION DURING PRODUCTION AND PACKING

Check if the declaration contains information about possible traces of gluten. Choose tested products. Food inspection is recommended.

- Rice, millet, buckwheat, and other gluten-free cereals
- Frozen vegetables, fish
- Dried fruits, nuts

8. PRODUCTS CONTAINING TRACES OF GLUTEN

Products containing information of possible traces of gluten on the declaration should be avoided. These may include the following:

- Chocolate
- Potato chips
- Ice-cream
- Sugar powder
- Tea bags
- Meat products: pâté, sausages, salami
- Spices (ground paprika, garlic powder, ground cinnamon, ground cumin, etc.)
- Ketchup
- Mayonnaise
- Mustard
- Corn starch – polenta
- Porridges, groats from naturally gluten-free grains

9. PRODUCTS WHICH MAY CONTAIN GLUTEN

Pay attention to products from unverified manufacturers, which may contain traces of gluten, and choose tested and verified products instead.

- Ready-to-eat vegetable condiments: ajvar (pepper-based condiment), horseradish
- Frozen items: fruit, vegetables, meat, fish
- Fish – canned sardines, tuna fish
- Canned meat products
- Canned beans, corn, lentils, chickpeas, peas, beans
- Cocoa powder, hot chocolate
- Soya sauce
- Ice tea
- Pudding
- Cheese
- Bonbons
- Sugar powder
- Juice
- Fruit syrup
- Yoghurt
- Prosciutto

Naturally gluten-free foods

Foods containing gluten are not health-friendly for a person suffering from coeliac disease. Thus, gluten-free diet planning involves choosing food that naturally does not contain gluten or has not been contaminated with gluten, or food from which gluten was removed by technological processes. Such food should be marked by a recognizable symbol of a crossed wheat class.

Gluten-free grains, unprocessed meat, fish, eggs, vegetables, fruit, and milk products are naturally gluten-free foods recommended for coeliac disease patients. A healthy gluten-free diet must be complete, sufficient, and balanced. Therefore, keep in mind that it is recommended that you eat cereals, grain, and starchy foods several times a day. The full-grain products are preferred for their higher content of vitamin B group, minerals, and fibre. Daily intake of fruits and vegetables contributes to the intake of vitamins, minerals, phytochemicals, fibre, and water, especially when it is varied and colourful. It is advisable to consume at least five servings of fruit and vegetables (minimum 400 grams) per day. Milk and dairy products are rich in calcium, which is important for bone building. Meat, fish, and eggs are an important source of protein, iron, and certain vitamin B groups in the diet. It is desirable to consume fish twice a week, poultry meat several times a week, and red meat less frequently. Sweets and added sugar can be consumed occasionally; as an alternative, fresh or dried fruits and nuts are recommended. Always read the declaration and pay attention to possible sources of gluten: **cereal extract, malt flavouring, modified starch, gelatinized starch, hydrolyzed vegetable protein, vegetable gum, vegetable starch, and liquorice.**

Successful elimination of gluten is the first step in implementing a gluten-free diet. The second step is certainly to avoid possible cross-contamination. Contamination means mixing foods containing gluten with gluten-free. How to avoid it? With proper storage of gluten-free products (store them separated from products containing gluten), careful preparation of meals (separately or before meals containing gluten) with new or well-cleaned cooking tools and utensils.

Safe, risky, and not allowed foods

GROUP OF FOODS	SAFE	RISKY	NOT ALLOWED
CEREALS AND GROCERIES RICH IN STARCH	Corn, rice, millet, buckwheat, amaranth, quinoa, tapioca, teff, soy, rogue flour, chestnuts flour, potato starch (all duly declared with a cross-section mark or "gluten-free" label for possible contamination in production, storage and packaging); oats (if not contaminated, safe for consumption of more than 95% of coeliac disease patient)	Oats (very often contaminated with gluten), potato chips, instant corncob, cornflakes with various additives, expanded rice, all kinds of gluten-free cereals and products made from gluten-free cereals if not declared (may be contaminated in the process of production, packaging, storage)	Wheat, rye, barley, triticale- crunchy wheat and rye, revel, einkorn, spelt, emmer, kamut, bulgur - cooked, chopped and dried wheat (processed wheat), durum- hard high protein wheat
FRUITS	Fresh (unprocessed) fruits; frozen fruits (without the addition of ingredients with gluten, it is imperative to read the product declaration); nuts	Candied fruits, dried fruits	Fruits with forbidden grains, frozen fruits containing wheat and / or its derivatives
VEGETABLES	Raw, cooked, dried and frozen vegetables and legumes (with no added ingredients with gluten, check the product declaration); canned vegetables in oil, salt ...; Vegetable products without flavour, preservatives and flavour enhancers; peeled or pasteurized tomatoes.	Cooked meals (ready meals) with a vegetables base	Vegetables with forbidden grains, breaded vegetables in forbidden flour, frozen vegetables containing wheat or its possible derivatives
MILK AND DAIRY PRODUCTS	Fresh milk or milk in tetra pack; natural yogurt; fresh cream; fresh and mature cheeses, mascarpone, mozzarella, cheese like edam, emmental, parmesan	Ready-made milk-based drinks, fruit yogurt, flavoured cooking cream (with mushrooms etc), whipped cream, cream and pudding, melted cheese, processed cheese. Homemade fresh cheese and cream and can be contaminated with flour	Yogurt with malt, cereals or biscuits
MEET, FISH AND EGGS	All types of meat and fish, fresh or frozen (without the addition of ingredients with gluten, read product declaration); Eggs are naturally gluten-free.	Pork products, hot dogs, sausages, preserved and tinned meat, sauces based on meat or fish.	Meat and fish prepared with flour containing gluten or gluten-containing sauces, meat and fish prepared with breadcrumbs, surimi
DRINKS	Carbonated drinks, mineral water, fruit juices (with 100% fruit share), coffee, tea (no additives), wine, sparkling wine and champagne	Fruit syrups, ready-made mixtures for hot chocolate, cocoa and frape	Beer (except that with crossed wheat class allowed for consumption), some instant drinks (coffee, cocoa), oat-based drinks
SWEETENERS AND SWEETS	Honey, sugar, fructose, dextrose, glucose syrup	Chocolate, pralines, cocoa powder, ice cream, candy, chewing gum	Cakes, strudels with wheat, rye, barley and oats, instant pudding, cream filling, chocolate with cereals, and biscuits
OTHER FOOD	All oils, butter, margarine, fat, apple and wine vinegar, gluten-free raw spices, salt, pepper, yeast	Cooked sauces, soy sauces, spices and mixtures, soup cubes, baking additives (for example, baking powder), mustard, ketchup	All sauces with ingredients containing gluten

Source: Panjkota Krbavčić I. Prehrana kod celijakije. Medicus 2008; 17:87-92

Health alphabet

AMARANTH - Contains high amounts of amino acids and is rich in calcium, fibre, and iron. It is an excellent source of protein and iron, and only one grain contains twice as much calcium as milk and three times as much fibre as wheat.

BUCKWHEAT - This is an excellent source of high-quality and easily digestible proteins. Also, buckwheat is rich in two amino acids - lysine and arginine that have important functions in heart health and the immune system. This food has a remarkable health effect and it contains a range of minerals, such as iron, magnesium, phosphorus, and fibre.

MAIZE - Is abundant with dietary fibre that lowers cholesterol levels, folic acid that keeps the bloodstream system, vitamin B1 that is important for good brain function, and carbohydrates that give us fast-available energy.

MILLET - Rich in magnesium and iron, it is an excellent source of protein (100 g contains 10 g protein), calcium, phosphorus, zinc, nickel, vitamin E, and vitamin B complexes. Millet is an alkaline cereal easy to digest.

QUINOA - This is a great source of magnesium, iron, copper, phosphorus, and amino acid lysine that stimulates the growth and recovery of tissues. Quinoa also contains riboflavin (vitamin B), which stimulates metabolism in brain and muscle cells.

RICE - Brown or wholegrain rice is much more valuable nutritionally than white rice. It keeps the part of the coating and slice, which is why it contains more nutrients. Brown rice contains 3.5-times more magnesium, four times more vitamin B1 and fibre, five times more nicotinic acid, and 1.6-times more folic acid than white rice. The cup contains vitamin E, while the envelope is rich in almost all B vitamins.

SOY - It contains a very high percentage of fat - 19.9%, carbohydrates - 30.2%, and proteins - 36.5% of vitamins A and B.

TAPIOCA - Is a very useful type of starch as it stimulates the growth of good bacteria in the intestines. Vitamin B complexes that give energy and improve immunity are present in tapioca flour. They also contain a large number of minerals - iron, zinc, calcium, magnesium, potassium, and manganese (important for tissue binders and joint health).

TEFF - A grain the size of a poppy seed that hails from Ethiopia, teff is naturally high in minerals and protein. It has more calcium and vitamin C than almost any other grain. It is high in protein and iron, and much of its fibre is a type known as resistant starch, which has been linked in studies to health benefits such as improved blood sugar.

Eating out

Diagnosis of coeliac disease does not have to mean an end of eating out or going to restaurants with family members and friends.

Nowadays, eating gluten-free is becoming a worldwide trend, and more and more restaurants offer gluten-free options. Eating out means not only the restaurants or hotels but also school catering, social services, and hospital stay.

How to find a „reliable" gluten-free restaurant? The majority of associations/societies for coeliac patients collect good experiences based on reports of their members, and in many countries, they have a 'Gluten-free Eating out' restaurant program. These programs include education and training for restaurant staff, accreditation programs with regular audits; they also publish updated lists of safe locals and restaurants on their website regularly.

The most favoured type of gluten-free restaurant is the 'dedicated gluten-free' restaurant where the whole process and choice of dishes is free of gluten. It means that they offer excellent food – gluten-free for all. Typically, these restaurant owners are affected by the coeliac disease in their family (or themselves) and they pay careful attention to the strict food safety rules.

To fulfill the strict food safety and security rules is not an inexhaustible condition as we can see in many European countries or even worldwide. On the other hand, conditions are indeed strict and the restaurant's staff has to be deeply engaged and well trained.

HOW TO CHOOSE A „GLUTEN-FREE" RESTAURANT

- Check the website of coeliac societies.
- Read opinions available on the coeliac societies' website or forums, where other coeliac people share their positive or negative dining experience.
- Check the website of the restaurant where you want to go. Many restaurants list the menus on their website. If there are no gluten-free options, it may be worth giving a call to check whether they can alter some of their menu options to make them gluten-free.
- It could be useful if you would consult with the chef (it may be better if you called them when the staff is less busy) to explain the most important requirements. But don't forget to tell them that you are a diagnosed coeliac person rather than someone who prefers to eat gluten-free and that your gluten-free meal must be prepared gluten-free by all standards.
- When you order, politely explain to the waiter what you need of your gluten-free diet as you are a coeliac patient, and ask if they can offer some meal options to you. If they do not seem to know what you need, it is advisable to minimize your risk and order only foods which are completely gluten-free, like salads, steamed vegetables, and rice, grilled meat (not marinated or fried in bread crumbs).
- Don't forget to ask and draw attention to the urgently needed hygiene regime when handling and preparing gluten-free food to avoid cross-contamination of your gluten-free meal.
- Be the last person who places an order so your request is more likely to be communicated in the kitchen.
- Be careful and bring with you some slices of your gluten-free bread from home. Bear in mind that some Asian restaurants (Thai, Vietnamese, Indian, etc.) originally are gluten-free, but in Europe, the raw materials they use for cooking may be different - some ingredients could be replaced by others that could contain gluten.

✓ If you do not feel confident about the reaction of the staff, choose another restaurant.

✓ Be prepared that sometimes you will have to pay more for the gluten-free alternatives, reflecting the increased cost of the gluten-free ingredients.

✓ If you have any doubt, please ask immediately. Do not make any own assumptions and better check your food options twice. It would be worth your while.

Travel tips

The world is open to coeliac disease patients on a gluten-free diet. With good preparation and planning, coeliac patients can adhere to their strict gluten-free diet during holidays or business trips. It is strongly advisable, though, to research in advance to collect any information you may need when you are away.

Traveling domestically or abroad can be challenging and may contain hidden pitfalls. To avoid them, it is important to plan your trip carefully in advance. Traveling is a good opportunity to taste and know local meals. Foreign cuisines can be challenging to eat gluten-free safely. Be aware of the possibility of cross-contamination. In Europe, the consumer information regulation requires informing the customers about the gluten and other allergen content (labels of the pre-packed prepared foods and menu in restaurants), which makes it easier to identify products that contain gluten.

Coeliac disease treatment is “only” a lifelong gluten-free diet, but because of other possible chronic or acute diseases that can develop or worsen while you are traveling, you may need some medications. It is advisable to bring with you enough prescription and OTC pills (drugs that are for general use without a prescription), vitamins, and supplements, so you do not need to search pharmacies and check hidden gluten of a replacer medicament.

Here are some useful tips for preparing your travels

- Call the hotel to ask if a refrigerator is available in the room and check on the hotel's website to find nearby restaurants with gluten-free menu or stores that sell gluten-free foods.
- If there are no reliable hotels which would guarantee a gluten-free environment, consider choosing an apartment where you can prepare your own food.
- Search good restaurants on the web or blogs of the local coeliac association. Check if there is a specific logo of the local coeliac association to mark the accredited 'gluten-free' restaurants, cafes, or pizzerias.
- For breakfast ask for simple foods, if necessary, such as cheese, fruit, vegetables, and nuts which are naturally gluten-free foods and widely available.
- Use coeliac disease cards or learn the words for basic information in the local language, which can be helpful to explain your dietary needs to restaurant staff.
- Eat ethnic foods, fresh, local cuisine. Many local, cultural foods are naturally gluten-free and choose those rather than processed foods. Keep in mind that it is better to check the ingredients and the preparation method of your food twice to avoid having a dietary failure.
- Travel with non-perishable "back-up" food, like bars, chips, cereal, etc. Order a gluten-free meal when you book your flight (for international flights or business class) because many airlines have a gluten-free meal option. When you check-in at the airport have them confirm with the airline that your gluten-free meal will be available on-board for you. In some European cuisines, it can be challenging to navigate gluten-free, but many European countries include allergen labeling on packaged foods and in restaurants, making it easier to identify products that contain gluten.
- Do not forget to bring with you a few slices of your preferred gluten-free bread or buns, and some chips, cakes, or other snacks – just in case.

IN ASIA: rice, rice noodles, seafood, and meat or fish sauces are naturally gluten-free, but be careful with the soy sauce, which is usually made with wheat.

IN MEXICO AND SOUTH AMERICA in general the basis of most dishes are rice, beans, corn, and tapioca, so it is easy to find gluten-free meals.

IN AFRICA AND THE MIDDLE EAST, the meal bases are teff, millet, lentils, and tapioca (known also as cassava) which are all naturally gluten-free.

Patients rights

Each national health system of the Central European countries has a different system and approach to patients' rights.

Some systems have patients' rights charters, specific laws, administrative regulations, and charters of services. Patient's rights include different kinds of system support: informational, educational, financial in-

SUPPORT / COUNTRY	SLOVENIA	CROATIA	HUNGARY	GERMANY	AUSTRIA	BULGARIA	CZECH REPUBLIC	SERBIA	ROMUNIA	MOLDAVIA
Monthly allowance	YES (up to 26 of age)	ONLY SOME	YES (up to 18 of age)	NO	Higher child allowance	YES (if disability status is available)	ONLY SOME (depending on health insurance, 1,6-19,2 18 € monthly)	NO	YES (upon request for handicap certificate)	YES
Tax deduction for parents	YES	YES	NO	Only in some cases	YES (in case of 25% disability)	YES (if disability status is available)	NO	NO	YES	NO
Additional vacation days for parents	3 additional days	NO	2 additional days	NO	NO	NO	NO	YES	NO	NO
Material Aid: as gluten-free products	For families with lower financial income monthly and from Slovenian Coeliac disease society 2 times per year	YES Monthly aid	NO	NO	NO	YES	NO	YES (gluten-free flour on doctor's prescription in the amount of 7 kg per month)	NO	NO
Road tax deduction for parents	YES	NO	NO	NO	NO	YES (if disability status is available) -free ticket two times per year with railway transportation for child until 16 years old and parent - in some municipalities – free in-town bus tickets if disability status is available	NO	NO	YES	NO
Rehabilitation	YES	NO	NO	NO	NO	YES (if disability status is available)	NO	NO	NO	YES (once a year)
Medical scholarship	NO	NO	NO	NO	NO	NO	NO	YES (exemption from payment or reduction of the price for attending a preschool institution for a child)	YES	NO

centives, and additional medical services due to health condition. In the two tables below, we present an overview of patient's rights (separately for children and adults) for coeliac disease patients in Central European countries participating in our project. The results of the overview are oriented towards existing financial and material rights and are based upon the project survey "Analysis of existing financial incentives".

ADULTS RIGHTS

SUPPORT / COUNTRY	SLOVENIA	CROATIA	HUNGARY	GERMANY	AUSTRIA	BULGARIA	CZECH REPUBLIC	SERBIA	ROMUNIA	MOLDAVIA
Monthly allowance	NO	NO	NO	Only in case of receiving social benefits (Hartz IV)	NO	YES (if disability status is available)	ONLY SOME (depending on health insurance, 1,6-19,2 18 € monthly)	NO	NO	YES
Tax deduction	NO	YES	YES	YES (In case of 30% disability)	YES (in case of 25% disability)	YES (if disability status is available)	NO	NO	NO	NO
Additional vacation days	NO	NO	NO	NO	NO	YES (if disability status is available)	NO	YES	NO	
Material Aid as gluten-free products	NO	YES	NO	NO	NO	YES (only in one hospital in the capital)	NO	YES (gluten-free flour on doctor's prescription in the amount of 7 kg per month)	NO	NO
Road tax deduction	NO	NO	NO	NO	NO	YES (if disability status more than 71% is available- with comorbidities) – free tickets twice per year with railway transportation – in some municipalities – free in-town bus tickets if disability status is available	NO	NO	NO	NO
Rehabilitation	YES	NO	NO	NO	NO	YES (if disability status more than 90% is available - with comorbidities)	NO	NO	NO	YES (once a year)
Rights to part-time work	NO	YES	NO	NO	NO	NO	NO	YES (special child care under the age of five and is some specific occasion)	NO	NO
Prolonged maternal leave	NO	YES	NO	NO	NO	NO	NO	NO	NO	NO

BIG 6-pieces of advice on how to lower everyday risks

Living with coeliac disease comes down to risk management, risk of gluten ingestion.

Every day, every decision one makes while choosing what to eat, where to eat, or how to prepare one's food, results in more than 0% risk, even if the amount of ingested gluten is smaller than 20 ppm. Those risks get higher in a new situation, outside one's home, during a social event, or with new food products. Therefore, one's job is to lower that risk, to keep it at a minimum, to be always „on a safe side "and at the same time to keep normal living and mental health. Not easy at all, one would say. There are several useful pieces of advice we would like to share on how to keep the risk low and your spirits high:

About the project

CD SKILLS project is addressing existing challenges of the healthcare sector in coeliac disease management in the Danube region.

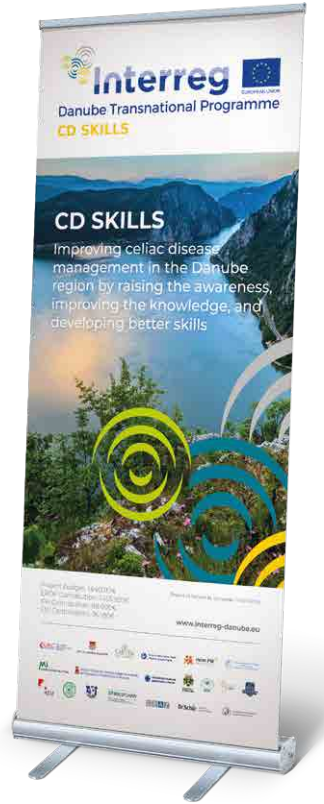
Coeliac disease is a lifelong systemic reaction against gluten found in wheat, barley, and rye. It can occur at any age but usually starts in early childhood. Women are affected twice as common as men. Without a very strict exclusion diet, severe complications can develop. More than 1% of the population (about 1.2 million) in the Danube region could have coeliac disease, with a much larger population affected indirectly. It has an impact on families and friends, as well as on childcare institutions, food producers, catering services, and especially on the healthcare sector. About 80% of patients are diagnosed with a long delay or remain undiagnosed, increasing the risk of complications, resulting in high morbidity and mortality, low school performance, and high work absenteeism. This has an important negative impact on sustainability of the healthcare sector and society. Possible reasons are low awareness and knowledge about the disease, limited access to diagnostic tools, limited opportunities for innovative learning, and inefficient information exchange.

CD SKILLS project aims to overcome these shortcomings to ensure a sustainable public healthcare sector, which will efficiently meet the health-related and social needs of patients and the general public affected by coeliac disease.

The important initial activity of the project is the assessment of regional practices in CD management, which will be followed by the introduction of an innovative learning strategy combining traditional lectures and modern e-tools, supported by the new information exchange platform, development of efficient disease detection strategies, and testing of innovative pilot services focusing on early detection and improved diagnosis of the disease and its complications and improvement of patients' quality of life.

The main long-term goals of the project are improvement of the knowledge, skills, and competencies of health care professionals and patients as well as other stakeholders and increased capacity of healthcare service in the Danube region to better meet the needs of coeliac disease patients and to improve their quality of life.

More about the project:
http://www.interreg-danube.eu/approved-projects/cd-skills



About the partnership

The transnational multidisciplinary partnership of the CD SKILLS project is composed of highly competent partners with different competencies and roles, including healthcare service providers, such as university hospitals, which also serve as research, education and training institutions, patient support organizations (NGOs), public authorities, gluten-free producers/suppliers, and professional associations ensuring exchange of different perspectives addressing common challenges of coeliac disease.

Partners are coming from eight Danube region countries: Romania (National Institute for Mother and Child Health Alessandrescu-Rusescu), Czech Republic (General University Hospital in Prague), Croatia (Children's Hospital Zagreb and CeliVita - Living with Celiac Disease), Serbia (University Children's Hospital and Serbian Coeliac Society), Moldova ("Nicolae Testemitanu" State University of Medicine and Pharmacy of the Republic of Moldova, Kishinau), Slovenia (University Medical Center Maribor and Municipality of Maribor), Hungary (Heim Pal National Paediatric Institute and the University of Debrecen), Austria (Medical University of Graz) and Germany (Ludwig Maximillian's University Munich). Interested Associated Strategic partners of the project are coming from Austria, Bulgaria, Croatia, Hungary, Italy, and Romania, and are composed of patient organizations, gluten-free food products producers, medical societies, healthcare policymakers, and public authorities.

Many partners have successfully collaborated in international initiatives and are known internationally for their work in the field of coeliac disease. The partnership has been involved in many projects addressing public service including coeliac disease-related projects: Interreg CE Focus IN CD, bilateral SI-HU LQ CELIAC, FP7 CD MEDICS, FP6 PREVENTCD, MediCel, ProCeDE, Trans-2-Care, and many others.

Project partners

University Medical Centre Maribor, Slovenia

The University Medical Centre (UMC) Maribor is a public healthcare institution providing secondary and tertiary healthcare services in north-eastern Slovenia. It is a research organization that also serves as an educational and training institution for future healthcare professionals. The UMC Maribor employs approximately 3,500 people, of which around 600 are medical doctors and around 1,800 associated healthcare professionals. Annually, about 60,000 patients are treated as inpatients and almost 400,000 as outpatients in different sub-specialty units. Its Medical Emergency Unit is a professionally and organizationally homogeneous unit providing non-stop 24-hour medical care. In addition to healthcare services, the UMC Maribor is included in research projects and cooperates with major research centres at the national and international levels. It employs a multidisciplinary team of experts in different fields including the Medical Research Department with the Project Office experienced in project management. UMC professionals are members of the ESPGHAN Celiac Disease Working Group. Paediatric Department UMC MB has been involved in many national and international coeliac disease-related projects LQ CELIAC, Focus IN CD, CD-MEDICS, PreventCD, ProCeDe, and others. https://www.ukc-mb.si/

Municipality of Maribor, Slovenia

City Municipality of Maribor (MOM) is a self-governing local community consisting of the city of Maribor and 33 other settlements. It is the second biggest city in Slovenia. In the field of health, we are responsible for social security, health protection, and family matters, for elderly care, health insurance for citizens without insurance, awarding scholarships, for awarding concessions in the field of health and pharmacy services. The city municipality is also the founder of many public institutions. In the last few years, we have been actively involved in mainly soft-measure European projects in the field of preventive health care. We have been a lead partner in bilateral Slovenian – Hungarian project LQ – CELIAC as well as in Focus IN CD project (Interreg Central Europe programme) with the main aim to increase the quality of life of celiac disease patients and to raise awareness among professionals and the general public. The Office of project development is focused on the preparation of project applications, management, implementation, and reporting of European projects. https://www.maribor.si/

Medical University of Graz, Austria

The Medical University of Graz (MUG) was founded in 2004, originating from the previous Medical Faculty of centuries-old Karl-Franzen's-Universität: Approximately 2,500 employees are working here in academic and non-academic areas and over 4,300 students are enrolled in diploma (medicine, dentistry, nursing science) and doctoral programs (medical science), with PhD-programs as a hub of innovative and high-end medicine. The MUG research community bundles its innovative capacity in four research fields and the general approach of sustainable health research. The Centres for "Medical Research" and "Knowledge and Technology Transfer in Medicine", the Biobank Graz (with > 20 million biological samples), and many other facilities provide a perfect research infrastructure. Students, instructors, and staff learn and work together according to the principles of the biopsychosocial model, which places the person with all his or her needs at the centre of attention. Not only do students gain from expert knowledge, so does the whole population, thus taking

advantage of a great range of knowledge, also in the context of media coverage and a great number of events. Postgraduate education for doctors and other target groups completes this broad range of services. https://www.medunigraz.at/en/

University Children's Hospital Belgrade, Serbia

One of the most important medical institutions not only in Serbia but also in the region, the University Children's Hospital in Belgrade was founded in 1924 under the leadership of Professor Franz Groer, an eminent associate of Vienna's School of Paediatrics. Later, in 1926, Professor Matija Ambrožić, also from the Vienna School, was appointed head. The first Department of Paediatric Surgery was founded by MD Dimitrije Jovičić, who had trained in France and was the first qualified paediatric surgeon in Serbia. In its first three years, the Children's Clinic was located in a private building in Kneza Milosa Street and had four rooms. Construction began on a new building on 4th October 1936 by Royal Decree of King Petar Karadjordjević and under the highest protection of Her Majesty Queen Marija. Today, the building is classified as a cultural monument. For more than 90 years, the University Children's Hospital has been a centre for the provision of specialized care and treatment in all areas of paediatrics and paediatric surgery, for the education and training of students from the University of Belgrade's School of Medicine, and scientific research.

http://tirsova.rs/

Children's Hospital Zagreb, Croatia

Children's Hospital Zagreb is a unique tertiary healthcare institution for children in Croatia. Since 1997, its Department for paediatric gastroenterology and nutrition has been the Referral Centre of the Croatian Ministry of Health for children with gastrointestinal disorders and specific nutritional requirements. The team includes paediatric gastroenterologists, dietitians, psychologists, working therapists, and nurse specialists. The centre is fully equipped for all necessary diagnostic procedures and various treatment modalities, including enteral and parenteral nutrition. Concerning celiac disease, this department runs the Croatian largest clinic for paediatric celiac disease patients with about 20–30 newly diagnosed patients per year. The team members have participated in the work of the ESPGHAN Celiac disease Working Group and in several national (Screening for celiac disease in first-grade school children) and international projects on celiac disease (PreventCD, ProCeDe, MediCel). https://www.kdb.hr/

General University Hospital in Prague, Czech Republic

General University Hospital in Prague (GUHP) is one of the largest hospitals in the Czech Republic. Together with the 1st Faculty of Medicine of Charles University, it creates a broad base not only for diagnostic, therapeutic, and nursing care but also for teaching, science, and research. The Department of Paediatrics and Inherited Metabolic Disorders represents the Centre of excellence for children with metabolic, rheumatologic, inflammatory bowel disease, and other gastrointestinal disorders, and for children with specific nutritional requirements. A multidisciplinary approach is a part of daily routine. The team includes paediatric gastroenterologists, dietitians, and nurse specialists. The centre fully covers all diagnostic and therapeutic procedures, including endoscopy, enteral and parenteral nutrition. Concerning Celiac disease, this department runs the country's largest clinic for paediatric Celiac disease patients, with about 100 newly diagnosed patients each year. The employees are members of the ESPGHAN and actively participate in different international projects. https://www.vfn.cz/

Serbian Coeliac Society, Serbia

Serbian Coeliac Society was founded in 2005 by a group of mothers with coeliac children. The main motive was lack of knowledge about the disease, educational material, counseling about the gluten-free diet, and difficulties in finding safe gluten-free food products. Since then, the association has grown into a national organization that works closely with associations in the region and Europe, doctors, scientists, and other experts as well as the institutions and organizations in the field of food production. The Serbian Coeliac Society has been an AOECS member since 2008. Our goal is to ensure that we

live in an educated, well-aware society where early detection and diagnosis of coeliac disease is possible, followed by labeled, safe food, at a price available for our patients.

www.celijakija.rs

National Institute for Mother and Child Health Alessandrescu-Rusescu, Romania

The National Institute for Mother and Child Health "Alessandrescu Rusescu" Bucharest (INSMC) is one of the institutes of the Ministry of Health in Romania with expertise in population research in the field of maternal and child health status. In the field of population research, INSMC collaborates with international institutions (United Nations Children's Fund, United Nations Population Fund, Center for Celiac Disease (CD) Control USA, US Agency for International Development). INSMC research led to health policies by the Ministry of Health in Romania and the research results were used as reference data by international organizations (WHO). INSMC includes 2 University Clinical Departments (Gynaecology and Paediatrics) as part of the University of Medicine and Pharmacy "Carol Davila" Bucharest and 4 National and Regional Centres focused on specific medical fields: Materno-Foetal Medicine Centre, Cystic Fibrosis Centre, CD Centre, and Clinical Genetics Centre. The CD Centre is a tertiary centre focused on CD diagnosis, management, providing medical care, educational programs for professionals and the general population, and running clinical research in collaborative national and international networks.

https://www.insmc.ro/

CeliVita - Living with Celiac Disease, Croatia

CeliVita is a patient association founded in 2014, to protect health and improve the overall life quality of people who suffer from Celiac disease, wheat allergy, and gluten sensitivity. CeliVita has members from all over Croatia, as well as a branch office in the Slavonia region. Its activities are focused on raising awareness about CD, as a general health problem, but also on providing practical help to the patients and family members. Its volunteers provide comprehensive support and tools, necessary for successfully overcoming everyday challenges and maintaining a proper gluten-free diet. Preserving the overall physical and mental health of those affected, including family members is one of CeliVita's missions. Support provided by the association includes counseling about gluten-free diet implementation and legal rights, educating about CD and risk factors for complications, cooking classes, nutritional and psychological workshops and lectures, manuals, and brochures, raising awareness programs in nurseries and schools, members meetings, and gatherings and many other activities. CeliVita's s members enjoy many benefits from various partnerships.

https://www.celivita.hr/

Heim Pál National Paediatric Institute, Hungary

Heim Pál National Institute of Paediatrics, Budapest is a multidisciplinary children's hospital for specialist care, which is also responsible for the coordination of clinical guidelines and specialized post-gradual teaching. The Coeliac Disease Centre is an independent department in the hospital for the integrative care of celiac disease patients and families regardless of age, which includes diagnosis, regular follow-up, dietetic counselling, and screening of family members at risk. The team consists of paediatric gastroenterologists, clinical and research nurses, full-time dieticians, and laboratory technicians. We operate an open-access outpatient facility for the direct referral of cases from primary care and we closely collaborate with the Department of Gastroenterology and Nephrology and with the Department of Pathology. The Coeliac Disease Centre has its own diagnostic laboratory providing transglutaminase and endomysial antibody testing for 19 other institutions in the central and western parts of the country. It also provides a second opinion on all celiac-related questions at the national level, develops management strategies, and disseminates knowledge among all medical professionals.
http://heimpalkorhaz.hu/

University of Debrecen, Hungary

The University of Debrecen is a leading teaching institution with approximately 30,000 students, 12,000 of them coming from abroad. This represents a very good possibility for the dissemination of knowledge and new findings. The University of Debrecen is responsible for tertiary-level medical care for the whole of North-Eastern Hungary (approx. 1.8 million inhabitants). The Coeliac Disease Study group was founded in 2002 and consists of clinical staff at the Department of Paediatrics (paediatricians, paediatric gastroenterologists, nurses, social workers) and basic researchers (biochemists, molecular biologists), and closely cooperates with the transglutaminase research group at the Institute of Biochemistry and Molecular Biology. Transglutaminase is the most important autoantigen in celiac disease and also plays an important role in modern diagnosis. Further, the group is currently investigating innovative diagnostic tools, standardization of antibody testing, and disease features at the cellular level. https://www.edu.unideb.hu/

Ludwig Maximilian University of Munich, Germany

Ludwig-Maximilians-Universität (LMU) München is a public corporation with the right to self-governance. It is one of the leading research universities in Europe, with a more than 500-year-long tradition. LMU Klinikum is a centre of high-tech medicine, innovation, and medical and technical progress, at the same time has the sense of individual care, security, and trust. The Children's Hospital was founded in 1846 by August Hauner and is named after him. With 15 paediatric subspecialties and paediatric surgery, it is one of the largest tertiary academic paediatric centres in Germany. The division of paediatric gastroenterology has high experience in Celiac Disease (CD), and was leading and participating in several national and international research projects on CD, e. g. the ProCeDE study, PreventCD, TEDDY, the German Celiac Registry. Together with the Child Health Foundation, it was a partner of the Interreg program Focus In CD, leading the work package on different online tools. https://www.lmu.de/en/

"Nicolae Testemitanu" State University of Medicine and Pharmacy of the Republic of Moldova

The State University of Medicine and Pharmacy "Nicolae Testemitanu" in Moldova is the only institution for the education of doctors and pharmacologists in the country. It includes many departments with 23 laboratories, 2 scientific centres, and 1200 specialists (8 academics, 5 corresponding members of the Academy of Sciences of Moldova, full and honorary members of academies from other states, 172 doctors habilitated in the medical sciences, 528 doctors in medical sciences, 15 laureates of the state award in the field of science and technology). It offers specialized pre-university higher education integrated into the cycle I, II, doctoral higher studies (cycle III), postdoctoral programs in Romanian, Russian, French, and English (ISO 9001: 2008; since 2016 applies the ISO 9001: 2015 standard). The University is a member of the Association of International Universities for European Medical Education (2013). Since 2019, it is internationally accredited by the World Federation of Medical Education, an independent accreditation and evaluation agency. It collaborates with over 90 international universities.

https://www.usmf.md/ro

Associated strategic partners

Health Service, Youth and Family Office, City of Graz, Austria

The city of Graz is the second-largest city in Austria. The city is divided into 28 urban districts and is the fastest-growing region in Austria. Graz is a statutory city (that is, a city with statutory privileges). This is an important characteristic, as it implies that the city itself bears full administrative responsibility for all social services. The administrative core of all preventive measures in child- and youth welfare in Graz is the Youth and Family Office in the city's administrative body. Health service is integrated into this structure. It also provides services for public schools, kindergartens, nurseries, and day-care. The team amongst other paediatricians includes general practitioners and one nutritionist. The Health Service mainly provides preventive medical check-up and medical advice services. When signing up for nurseries, kindergarten, day-care, etc., parents have to fill in a health form; coeliac disease is one of the interrogated points. Accompanied by their parents, all pupils, attending a public school in Graz, undergo a medical check-up in their first year (age about six to seven). At this time, parents are asked again about chronic diseases, such as coeliac disease. A further medical check-up is provided until the end of compulsory school attendance.

https://www.graz.at/cms/beitrag/10015960/7751496/Amt_fuer_Jugend_und_Familie.html

Romanian Association for Gluten Intolerance, Romania

Romanian Association for Gluten Intolerance (ARIG) is the national coeliac patient's association, a non-governmental, independent organization and its main mission is to improve the quality of life for coeliac patients in Romania. Romanian Association for Gluten Intolerance is a member of the Association of European Coeliac Societies since 2018 and is running the ELS scheme for gluten-free products since 2019 with over 600 Romanian certified gluten-free products. ARIG focuses its activities on four main pillars: legislation and patients' rights, patient education and coeliac disease awareness for the general public, coeliac community support, coeliac disease awareness gluten-free business sector development support. The association's activity is based exclusively on volunteer work since 2017. The activity of the association is supported by active coeliac community members. https://celiac.org/eat-gluten-free/gf-services/celiac-association-of-romania/

Bulgarian Coeliac Association, Bulgaria

Bulgarian Coeliac Association was established on 31. 3. 2009 by a diverse group of volunteers with coeliac disease from Bulgaria. At that time there were only a few specialists who knew about the disease. The association was dedicated from the very beginning to helping people with coeliac disease and other gluten-related conditions, get support and understanding from the community, have an easier life, have access to gluten-free food. We are striving for people with gluten-related conditions to get independent, trustworthy advice and support from the medical specialist, have more rights from the state, and not only manage the impact of gluten, but also find all answers to how to live well and happy with coeliac disease. The main activities are fulfilled with the Facebook group, where people ask questions and get answers. We regularly update it with recent information materials for gluten-free nutrition, Celiac Disease, and the life and obstacles for people with this entity in Europe.

We are trying to help the availability of gluten-free products and food in more and more places. In a collaboration with municipalities and medical specialists, we helped the introduction of a gluten-free diet in nurseries and kindergartens in some areas in Bulgaria.

Bulgarian Society for Paediatric Gastroenterology, Hepatology and Nutrition, Bulgaria

The Bulgarian Society for Paediatric Gastroenterology, Hepatology and Nutrition is a voluntary, politically and socially independent non-profit association of individual and legal entities who meet the conditions set out in this statute, acting by the principles of the Constitution of the Republic of Bulgaria and the regulation of the Law

on non-profit legal entities and the current Bulgarian legislation. The aim of the Society to spread awareness in the area of paediatric gastroenterology, hepatology, and nutrition, to stimulate the research in the same field, and to disseminate this knowledge through meetings and in other ways. The Society fulfills its goals through the development and participation in programs, projects, and other activities related to the activities of the society in Bulgaria and abroad provides scholarships for training on issues of the paediatric gastroenterology, hepatology and nutrition, organizes congresses, symposia, workshops and provides dissemination and assistance for implementation in the country of new methods in the field of paediatric gastroenterology, hepatology, and nutrition.

http://bulspghan.org/za-nas/

Croatian Institute of Public Health, Croatia

Croatian Institute of Public Health (CIPH) is a central public health institute in the Republic of Croatia, founded in 1893 to promote the health and welfare of the population. CIPH deals with public health, health promotion and education, disease prevention, microbiology, environmental health, school medicine, mental health care, and addiction prevention. CIPH's main tasks are to plan, promote and implement measures for the enhancement of population health and reduction of health problems. It prepares and implements prevention programs and other health care measures aimed at promoting a healthy lifestyle. The Institute functions as a statistical authority, which maintains national public health registries, supervises data storage, and coordinates the work of other health registers. It coordinates the network of regional public health institutes, actively participates in the creation of health policy and public health regulations, and engages in international cooperation to improve public health and welfare.

https://www.hzjz.hr/

Hungarian Paediatric Gastroenterology Society, Hungary

The organization is an umbrella society for all medical professionals in the field of paediatric gastroenterology in Hungary (specialist physicians taking care of patients with celiac disease, primary care doctors, and other HCPs, like specialized nurses and dieticians) with significant teaching activity and dissemination potential. Furthermore, society plays important role in health care policymaking and maintains relationships with health authorities and various industrial partners, as well as with gastroenterologists looking after adults. The society disseminates European guidelines and regularly comments on new directives and various planned changes in medical practice. Therefore, society is interested in contributing to the improvement of diagnostic tools and diagnostic strategies for celiac disease, particularly in professional aspects. These activities and results will be incorporated into the annual teaching activities and postgraduate courses for HCPs and young doctors. Society is committed to promoting high-quality medical care and reducing the invasiveness of diagnostic procedures and costs.

Dr. Schär - Innovating special nutrition, Italy

Our story began in 1922 in South Tyrol, the heart of the Italian Alps, with a vision to improve the lives of people with special nutritional needs. Ever since the company was founded, proximity to the consumer has been our guiding commitment. Our core competence combines the specific, complex requirements placed on nutrition with dedication and joie de vivre. Responsibility, progress, and proximity are the values that give us our stability and reliability. We are a family-run company with a global reach, with 18 sites in 11 countries and more than 1,300 employees worldwide. We are the market leader in Gluten-Free nutrition and leverage our expertise to develop new, pioneering nutrition solutions. Our products are available in about 100 countries.

www.drschaer.com

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Interreg

EUROPEAN UNION

Danube Transnational Programme

CD SKILLS

UKC MARIBOR | University Medical Centre Maribor

MESTNA OBČINA MARIBOR

CeliVita
ŽIVOT S CELIJAKIJOM

Klinika za dječje bolesti Zagreb
Children's Hospital Zagreb

Heim Pál
Gyermekkórház

Institutul Național pentru Sănătatea Mamei și Copilului "Alessandrescu-Rusescu" București

Medical University of Graz

NICOLAE TESTEMITANU STATE UNIVERSITY OF MEDICINE AND PHARMACY OF THE REPUBLIC OF MOLDOVA

VŠEOBECNÁ FAKULTNÍ NEMOCNICE V PRAZE

UNIVERSITY of DEBRECEN

TIRŠOVA

LMU KLINIKUM
DER UNIVERSITÄT MÜNCHEN

HZJZ

BULSPGHAN
Bulgarian Society for Paediatric Gastroenterology Hepatology and Nutrition

GRAZ

Dr. Schär
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Asociația Română pentru Intoleranță la Gluten