

Focus IN CD

Living with Coeliac Disease



**Coeliac
disease?**

**NO
FEAR!**



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Our e-learning tool for patients will be available in autumn 2018. Visit our website and stay informed.



Gluten-free living

You have probably just been diagnosed with coeliac disease and you have to change to a gluten-free diet which is a great opportunity to control your health.

First steps will not be easy and your head is probably spinning with information overload, but a coeliac diagnosis isn't the worst thing although it can feel like the end of your world.

This e-brochure will give you information about coeliac disease, symptoms, diagnostic methods and about the treatment, follow-up as well as about the recommended screening of family members. It will offer you guidance about how to live your life gluten-free, how to change 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 web site <http://bit.ly/FocusINCD>.

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 which 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, oats or their cross-bred varieties, and its derivatives out of your diet. By simply cutting out gluten, your body will begin to recover, however, it is also crucial to assess your diet to assure it 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 – of course, as long as they are not contaminated with gluten. This e-brochure 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 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, organize 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 wish to learn more about coeliac disease, please refer to our web site and join our e-learning course for patients, which will become available in autumn 2018.

Dear reader, we hope that you will find a lot of helpful information reading our e-brochure. We sincerely hope that it will help you in better organizing 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.

Your Focus IN CD team





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. Many of patients, however, 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 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 genetically predisposed individuals. In some cases, the diagnosis can be made without 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, normalises the level of antibodies, and restores the damaged intestinal lining. Following a strict diet is also the only way to prevent development of serious long-term effects of the disease. The most significant risk factor for long-term complications is an inadequate gluten-free diet compliance.

The coeliac iceberg is large, representing 1% of 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 is detected due to symptoms and signs, whereas 90% can remain undiagnosed for a longer period of time.



The size of the submerged part depends very much on patients' awareness and knowledge of HCPs 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 for these damages is uniform and not all kind 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. 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 is causing 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 character-

ized 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 increase of the stool volume. Harmless bacteria normally present in the lower part of the gut may further degrade the gut content which may lead to an 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 a 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 permanent condition, the secondary lactose intolerance caused by 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 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 in 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 may be the only clinical complaint of coeliac disease. It is often resistant to household reme-

dies. 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.

Coeliac crisis has two forms; one resembles an acute abdominal catastrophe with intense pain, distension and poor general condition. These patients are usually referred to a surgical department; however, surgery could be avoided by detection of coeliac antibodies and introduction of treatment for coeliac disease. Rapid bedside antibody screening tests can be useful in such situations. The second form of coeliac crisis is characterised by severe disbalance of body fluids as a consequence of intense diarrhoea, characterized not only by fluid loss, but also by 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, and are commonly seen in children with coeliac disease.

Mouth ulcers are only weakly associated with coeliac disease. They can 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. 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 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 on 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 blood coagulation process). Vitamin K deficiency can also cause prolonged haemorrhage during menstrual bleedings or after dental procedures. 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 have been shown to be 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 sign 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 have been found to be 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 prior to 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 and often have low mood or may be even depressed. Moodiness is also frequent in young children who cannot properly explain their uncomfortable bodily feelings.

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 synthesised proteins throughout the body and even improving the absorption of minerals may fail to cover 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.

Itching rash on the elbows, knees and buttocks or other extensor surfaces can be a leading symptom in some coeliac disease patients. It is usually resistant to local ointments and due to scratching leads to formation of crusts, wounds and depigmentation. Importantly, the rash affects the extremities symmetrically. This skin disease is called dermatitis herpetiformis or Dühring's disease, and it is caused by immune deposits in the skin. These immune deposits contain epidermal transglutaminase (type-3) and antibodies against this transglutaminase, which are slightly different from the antibodies against the main transglutaminase (type-2). Patients with dermatitis herpetiformis produce antibodies against both type-2 and type-3 transglutaminases,

and have similar gut histopathology as coeliac disease patients without any rash. However, only 10% of patients presenting with dermatitis herpetiformis have abdominal complaints.

The rash can be treated with gluten-free diet, but its disappearance may need a longer time, even up to 2 years. The rash can be symptomatically treated by special drugs, but these do not treat internal manifestations of coeliac disease and may have severe side effects.

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 gluten-free diet. Lack of energy and proteins due to impaired absorption can greatly influence the 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, whose 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 long-standing coeliac disease diagnosed in adults. Hyposplenism may compromise defence 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 secretion of digestive enzymes. Furthermore, pancreas can be damaged by the lack of proteins. Such insufficiency is reversible after treatment of coeliac disease and pancreatic enzyme

supplements may be useful for the initial treatment, if needed. In adults diagnosed after a long-standing malabsorption, permanent pancreatic failure can develop due to 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 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 walking.

Muscular weakness and decreased muscular tone is a common sign in patients, especially in young children with coeliac disease. Vitamin E deficiency can be related with muscular weakness in elderly patients. In some patients, antibodies against neuromuscular proteins can cause weakness. The myalgia syndrome can occur in coeliac disease, but 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 introduction of gluten-free diet.

Osteoporosis and osteopenia – reduced mineral density often occurs in adults with clinical picture of malabsorption and in patients with a 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 the 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 coeliac disease is recognized. Lack of energy and anaemia can contribute to lower results in academic performance.

Sensoric 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 often a presenting sign 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. Birth weight of children born to 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 protein blood 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 a number of other diseases, including type-1 diabetes mellitus, thyroid diseases, IgA deficiency, Down's syndrome, Turner syndrome, Williams syndrome, and others. In these conditions, coeliac disease can be asymptomatic and needs to be detected by screening.





Diagnosing coeliac disease

Diagnosing 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 tested is consuming normal amounts of gluten. 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 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 (TG2/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 t-TG antibodies, 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 t-TG antibodies test.

The current ESPGHAN (European Society for Paediatric Gastroenterology, Hepatology and Nutrition) guidelines for coeliac disease diagnosis allow clinicians to diagnose the disease without an upper endoscopy and intestinal biopsy in certain cases. This approach can be used in children and adolescents with symptoms and signs suggestive of coeliac disease that have very high levels of t-TG antibodies and a positive confirmatory EMA test.

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 a 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 majority of cases it is necessary to perform an intestinal biopsy. However, in children and adolescents this can be avoided in certain circumstances.

An 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

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

A histology indicating coeliac disease without positive auto-antibodies is not sufficient to diagnose coeliac disease!

Diagnosing coeliac disease without intestinal biopsy

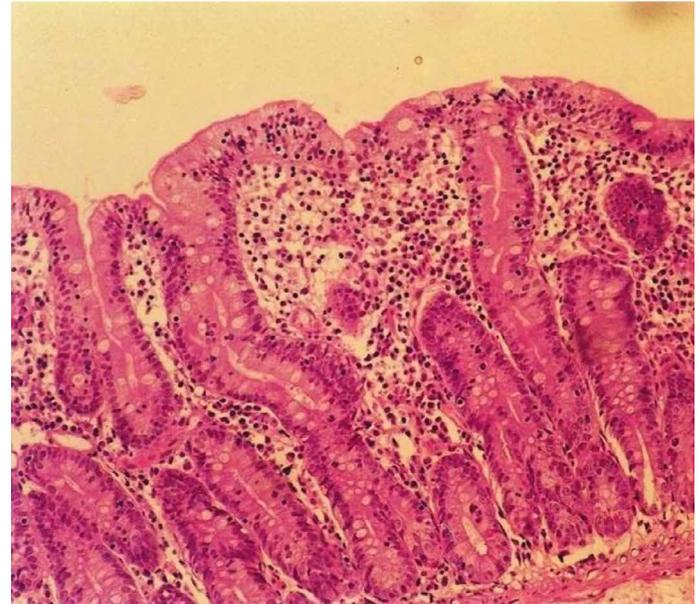
Based on the current ESPGHAN (European Society for Paediatric Gastroenterology, Hepatology and Nutrition) guidelines, when all specific criteria are met the diagnosis of coeliac disease in children and adolescents can safely be made without the need for upper endoscopy and intestinal biopsy.

1. The child/adolescent must have signs or symptoms suggesting coeliac disease.
2. The t-TG-IgA levels must be very high, i.e. more than 10-times the upper limit of the cut-off value.
3. Auto-antibodies against EMA must be positive in a second blood sample.
4. Patient also must have specific HLA-DQ8 or DQ8 genes.
5. A paediatric gastroenterologist should be involved in the process and explain the non-biopsy approach to parents and patient.

HLA testing

Genetic testing is especially helpful in excluding the 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 for the disease, i.e. HLA-DQ2 and HLA-DQ8, can be found in approximately one third of the normal population.





Treatment

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

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 over all patient's health in coeliac patients.

There are different food groups that need to be considered when talking about the gluten-free diet.

Naturally gluten-containing foods

Only a few grains actually 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. There are also certain others but are not so common and well known. 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, soy sauce, sausages, and in many dairy products). These products may contain gluten in the form of a food additive that is supposed to enhance 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. A simple contact with the skin is not harmful.

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 a 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 term “safe” amount of gluten in food.

There is not such a thing as a safe amount of gluten, and every effort should be made to assure the complete elimination of gluten from a patient’s diet.

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 on 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

It is extremely important that compliance with the gluten-free diet is high. Compliance issues which can arise at any time for various reasons are usually more pronounced in adolescents and elderly. Factors affecting the lower compliance can be of financial, cultural, or psycho-social nature, and every effort should be made to detect or to address them at regular visits at clinician and/or dietician.

Long-term consequences of unrecognized/untreated coeliac disease

When a patient is diagnosed with coeliac disease and keeps 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 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, which is rare, but a more serious complication, characterized by severe mucosal damage despite the 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 the ongoing inflammation and certain 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, 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 which 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.

Risk groups

There are certain groups of people who have a higher risk for 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 in order 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 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 development of serious complications and co-morbidities.

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 in order to confirm adherence to the diet and to address possible issues with disease management. After the first visit, patients should be followed on a yearly basis, 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. The serological testing (CD specific antibody tests) should be performed together with complete physical examination (including 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 clinical picture suggests possible abnormalities. The titres of anti-t-TG IgA antibodies can be expected to fall below the cut-off of the normal values within 12 months after starting strict gluten-free diet. In many patients they may normalize much earlier. Bone densitometry should be performed every 2 years in order to exclude osteopenia or osteoporosis in selected patients.

Should I visit any other specialist except paediatrician/gastroenterologist?

It is advisable to consult a dietician about the gluten-free diet. In order to better adjust to the life changes, associated with the presence of chronic disease, some patients will also benefit from a psychological counselling.

Does my child need a repeated endoscopy?

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



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 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 their close ones.

Each new and unknown situation raises insecurity and a search for answers 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 own 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, co-operation 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. It is vital that we are 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 gluten-free diet represents a major change to their usual eating habits and behaviour. 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 co-operation 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 co-operate 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 represent children, as their understanding and acceptance of the disease as well as co-operation during treatment through different stages of development, the roles and relations within the family, and their social environment are continuously changing. Their needs and expectations as well topics and forms of help required

within the family and the environment are changing 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 a 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 psycho-social 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.



Patients' stories

NUŠA, 11 YEARS, AND MOM SIMONA

The day, when our oldest daughter was diagnosed with coeliac disease was one of the happiest days for our family. The diagnosis "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 in 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 (a hypogammaglobulinemia)

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

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 organised 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 at 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.

IGOR, 47 YEARS

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 didn't 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 prior to my diagnosis, I was travelling 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 didn't see the obvious. In defence of my expert friend, my coeliac test

"The condition was staring me in the face, I just didn't see it."

had been repeatedly reported as negative. Afterwards, additional problems developed. My both 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 fresh 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 my own gluten-free bread. I miss an occasional donut 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.

MARINA, 43 YEARS

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

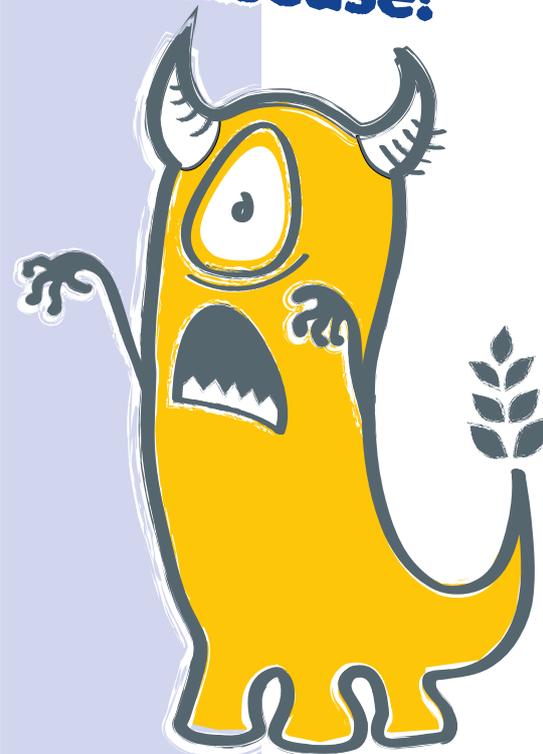
Revolution caused by genetic tests for coeliac disease.

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's explanation was that I grew quickly and that was completely normal. The problem was that the pain was so strong that I couldn't sleep at night. I was doing a lot of sports and was very active, almost hyperactive. There was not a month during the year when I didn't have aphthae in my mouth, I was losing my hair, and after childbirth I was experiencing enormous mood swings and lack of concentration.

The biggest problem was the leg pain I was experiencing. In my twenties, I literally 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 USA to improve my health. I decided to stay brave and to believe that I was young enough to get through everything, even through 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 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 (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 don't 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 adult population at the end of the last and in 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 a lot of people whose coeliac disease was completely asymptomatic. We can't give up on educating patients and medical staff and raising awareness about coeliac disease as a quiet epidemic which carries a lot more diseases and weak states of our organism.

Coeliac disease?



NO FEAR!



The first few gluten-free days

At the beginning, 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 a routine.

In the store, get food that is clearly marked with a crossed grain - the official sign of the gluten-free food that have 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, 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) or fresh fruits (raspberries, blueberries, peaches, oranges, etc.) + 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)! You can cook/add gluten-free pasta to the soup or make your own 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. Turkey 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.

DESSERTS

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 with 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.*

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 yogurt.

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

Plain 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.





How to set up a safe gluten-free kitchen?

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

In order 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:

REORGANIZE THE KITCHEN

- 1. Remove all products which contain gluten:** bread, pasta, flour, pulp, breadcrumbs, spices.
- 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, baking trays, which cannot be thoroughly cleaned, toasters, grinders and/or mixers where we ground biscuits / dried bread.
- 4. Discard or donate (because of contamination these devices are unsuitable for preparation of gluten-free food):** wooden cooking utensils: cooking hobs, cutting boards, used chop sticks, 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 and pans, 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:

Basically, the combined kitchen needs to be organized as a completely gluten-free kitchen, and only part of the working area should be defined for 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 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 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. Prior to 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-coeliacs, 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 a 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 moulded products with foil so that they do not dry out.
- Moulded products must be raised to a double amount before baking.
- Large dough products must be pierced with a wooden needle all the way 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 in the freezer to use when preparing fried food.

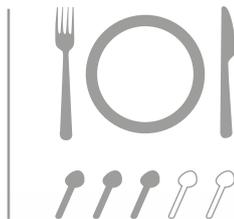
The bread will keep for 3-4 days wrapped in a plastic bag. Share the recipes with other people around the world that are in the same situation as you.



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



Process

Sift the flour into a large bowl, make a well in the centre 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 type of buns.

| | kJ/kcal | Proteins | Fats | Saturated Fats | Carbohydrates | Fibres |
|----------------------|------------|----------|------|----------------|---------------|--------|
| total (approx. 2 kg) | 14250/3356 | 571 g | 16 g | 0.7 g | 745 g | 0 g |

Cook's tip

Add the seeds according to preference: poppy, pumpkin, sunflower, sesame, etc.

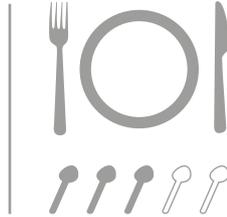
If you like, double the quantities and bake two loafs at the same time, then freeze one. Bread can be frozen for up to six months.



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 dough. Knead for about 5 minutes until smooth. Cover the dough with a cloth and leave 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 | 80.2 g | 39 g | 13.0 g | 771 g | 0 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.

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 negligible 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 placing products on conveyor belt.

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.

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 that they are listed for example in the Celiakija journal of the Slovenian Association for Coeliac Disease. Do not choose products, which may contain traces of gluten.

DOUBLE CHOCOLATE COOKIES

| NUTRITION INFORMATION | | |
|-----------------------|-----------|-----------------|
| | Per 100 g | Per Piece (25g) |
| Energy kJ/kcal | 2123/508 | 531/127 |
| Fat | 26 g | 7 g |
| - Of which saturates | 14 g | 4 g |
| Carbohydrates | 61 g | 15 g |
| - Of which sugars | 39 g | 10 g |
| Protein | 5,9 g | 2 g |
| Salt | 0,57 g | 0,14 g |

ALLERGY ADVICE

For allergens, including cereals containing gluten, see ingredients in bold.



INGREDIENTS

Sugar, **wheat flour**, whole milk chocolate, dark chocolate, palm oil, cocoa, cocoa butter, milk powder, **lactose**, **wheat gluten**, aroma, emulsifiers E741, **lecithin (soy)**; sodium carbonate, diphosphate, salt, **egg**

ALLERGENS may not be hidden in the form of additives. If additives contain gluten it must be highlighted in the same manner as for the main ingredients.

Note that all gluten-containing cereals have to be declared (not gluten itself!). That is why you have to know which cereals are the ones that contain gluten.

Here, all major allergens, including gluten-containing cereals, have to be listed and highlighted.

This is a voluntary information the manufacturer can provide. „May contain“ is another voluntary declaration that can be used. If the product consists only of a single ingredient, it might say „contains:gluten“.

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.

3. GLUTEN-FREE PRODUCTS WITH THE CROSSED GRAIN LABEL

Labelling products with the Crossed Grain symbol and the logo of the Slovenian Association for Coeliac Disease (SDC), for example, are intended for products for which the production, purchase, storage, and packing is managed, monitored and tested for gluten content by a local association (e.g. SDC). Such products are awarded a label, which is a type of license for use and labelling 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 (without the SDC logo) is protected with the registered trade mark (®) and can be used by other associations for coeliac disease. Under the label, you will find the country code and testing code number: SI-3512345 (Slovenia), AT-3418763 (Austria), I-24517453 (Italy), etc.



Certain manufacturers label their products with various different symbols of a crossed grain. Please note that these products are not tested properly and their release to the market was usually not certified by an official authority, such as an association for coeliac disease. The SDC association often tests products which are marketed as gluten-free, results of these tests are then published in the Celiakija journal.

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 are on the list of certified and tested products and published in your society’s journal, e.g. the Celiakija journal.

- 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

Use the list products published in your society’s journal, e.g. the Celiakija journal, published by the Slovenian Association of Coeliac Disease (issues not older than two years).

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

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.

- rice, millet, buckwheat
- 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 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 with 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
- cocoa powder, hot chocolate
- soya sauce
- ice tea
- pudding
- cheese
- bonbons
- sugar powder
- juice
- fruit syrup
- yogurt
- 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 doesn't 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 CD patients. A healthful 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 fibers. Daily intake of fruits and vegetables contributes to the intake of vitamins, minerals, phytochemicals, fibers, and water, especially when it is varied and colourful. It is advisable to consume at least 5 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, hydrolysed 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, rye 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); oat (if not contaminated, safe for consumption of more than 95% of coeliac disease patient) | Potato chips, instant corn cob, 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, oat (very often contaminated with gluten); triticale- crunchy wheat and rye, rye, 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 flavor, preservatives and flavor enhancers; peeled or pasteurized tomatoes. | Cooked meals (ready meals) with a vegetable 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 tetrapak; natural yogurt; fresh cream; fresh and mature cheeses, mascarpone, mozzarella, cheese like edamer, emmentaler, parmesan | Ready-made milk based drinks, fruit yogurt, flavored cooking cream (with mushrooms etc), whipped cream, cream and pudding, melted cheese, processed cheese. | Yogurt with malt, cereals or biscuits |
| MEAT, 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), oats based drinks |
| SWEETENERS AND SWEETS | Honey, sugar, fructose, dextrose, glucose syrup | Chocolate, pralines, cocoa powder, ice cream, candy, chewing gum | Cakes, strudels and chopsticks of 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 - Is an excellent source of high quality and easy digestible proteins. Also, buckwheat is rich in two amino acids - lysine and arginine that have important functions in heart health and 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 fibres that lowers cholesterol levels, folic acid that keeps the bloodstream system, vitamin B1 which 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 (also considered as anticancer food because the alkaline food does not cause the acidity of the organism), easy to digest.



QUINOA - Is a great source of magnesium, iron, copper, and phosphorus, and amino acid lysine that stimulates 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, going to restaurants with family members and friends.

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

How to find a „reliable” gluten-free restaurant? The majority of coeliac patients' associations 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 program with regular audits; they also publish updated lists of safe locals and restaurants on their website on a regular basis.

The most favoured type of gluten-free restaurants 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 coeliac disease in their family (or themselves) and they pay careful attention to the strict food safety rules.

To fulfil 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, it is true that conditions are 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 great (or even 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 to give 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 (but it's better if you call them when the staff is less busy) to explain the most important requirements. But don't forget to tell him that you are a diagnosed coeliac person rather than someone who prefers to eat gluten-free, and your gluten-free meal must really 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 absolutely 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 the gluten-free food in order 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 which 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 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.*
- ✓ *If everything was all right, never forget to thank the staff's professionalism and hospitality.*



Travel tips

The world is also opened to coeliac patients following a gluten-free diet. With good preparation and planning, coeliac patients can adhere to their strict gluten-free diet during a holiday or a business trip. It is strongly advisable, though, to do research in advance to collect any information you may need when you are away.

Travelling domestically or abroad can be challenging and may contain hidden pitfalls. To avoid them, it is important to plan your trip carefully.

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.
- 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 in order 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 labelling on packaged foods and in restaurants, making it easier to identify products that contain gluten.
- Don't 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.

Travelling is a good opportunity to taste and know local meals. Foreign cuisines can be challenging to eat safely gluten-free. 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 usually menus in restaurants), which makes it easier to identify products that contain gluten.

- *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 Middle-East the basis are teff, millet, lentils, and tapioca (known also as cassava) which are naturally gluten-free.*



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 travelling 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.



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 incentives, and additional medical services due to health condition. In the two tables below we present an overview of pa-

tient'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 project survey 'Analysis of existing financial incentives'.

CHILDREN RIGHTS

| SUPPORT /COUNTRY | SLOVENIA | CROATIA | HUNGARY | ITALY | GERMANY |
|---------------------------------------|--|----------------------------|-----------------------|--------------------|--------------------|
| Monthly allowance | YES (up to 26 of age) | ONLY SOME (up to 8 of age) | YES (up to 18 of age) | NO | NO |
| Tax deduction for parents | YES | YES | NO | NO | Only in some cases |
| Additional vacation days for parents | 3 additional days | NO | NO | 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 | Vouchers available | NO |
| Road tax deduction for parents | YES | NO | NO | NO | NO |
| Rehabilitation | YES | NO | NO | NO | NO |

ADULTS RIGHTS

| SUPPORT /COUNTRY | SLOVENIA | CROATIA | HUNGARY | ITALY | GERMANY |
|--------------------------------------|----------|---------|---------|--------------------|--|
| Monthly allowance | NO | NO | NO | NO | Only in case of receiving social benefits (Hartz IV) |
| Tax deduction | NO | NO | YES | NO | YES In case of 30% disability |
| Additional vacation days | NO | NO | NO | NO | NO |
| Material Aid as gluten-free products | NO | YES | NO | Available vouchers | NO |
| Road tax deduction | NO? | | | | |
| Rehabilitation | YES | | | | |



Association of European Coeliac Societies (AOECS)



Patient organizations or more precisely patient advocacy groups are organizations that promote the needs and priorities of patients with lifelong diseases and conditions. This includes supporting research for a specific disease, promoting awareness of a disease, and educating the community about a disease, among other activities.

Because of the specific treatment of coeliac disease, i.e. the lifelong strict gluten-free diet, the coeliac organizations concentrate on food safety and security rules and on the composition of 'normal' and special products, which are manufactured especially for those who are diagnosed with coeliac disease or simply want to eat gluten-free for other reasons.

The Association of European Coeliac Societies is the umbrella organization of European national coeliac societies with currently 37 Full Member societies across Europe.

In 1992, AOECS received observer status for the Codex Alimentarius Commission - an organization consisting of the Food and Agriculture Organization of the United Nations (FAO) and the World Health Organization (WHO) with the task to adopt standards as guidelines for food legislation in the various countries. AOECS participates regularly at the sessions of the Codex Alimentarius Commission and several Codex standards and guidelines to protect the gluten intolerant population have been modified and improved since.

AOECS aims to improve the quality of life for people with coeliac disease, for example by ensuring wide availability of safe gluten-free



products across member countries. The AOECS licensing scheme permits the use of the trademark-protected Crossed Grain symbol on tested gluten-free products across Europe. This highly visible symbol is easily recognizable irrespective of language barriers. So even when travelling, coeliac consumers are able to follow a strict gluten-free diet and remain healthy. Due to the strict licensing requirements for the use of the Crossed Grain symbol, surveys have shown that coeliac consumers see the symbol on gluten-free products as a safety

guarantee. Every licensed product has undergone testing in an accredited laboratory to ensure its gluten content is less than 20 mg/kg. In addition, each product's manufacturing plant is audited once a year to ensure a consistent gluten-free production.

AOECS Member societies have currently licensed up to 12,000 gluten-free products across Europe.

The Crossed Grain symbol is a registered trademark and we work very hard to protect it by ensuring that all infringements are dealt with swiftly and appropriately. Look out for the license number under the symbol on the packaging to be sure the product is under an authentic license.



About the Focus IN CD project



Innovative patient centred health care services – advantages of establishing a close CE network in coeliac disease patient health care.

Coeliac disease is a lifelong systemic autoimmune disorder, requiring extremely meticulous dietary treatment. It affects 1-3% of population (up to 5 million in CE) of all ages.

80% of people with coeliac disease remain undiagnosed or are misdiagnosed, and diagnostic delays reach 10 years in many regions. Undiagnosed or untreated disease is associated with a number of severe complications and comorbidities.

The Focus IN CD project with full name “Innovative patient centred health care services – advantages of establishing a close CE network in coeliac disease patient health care” addresses specific issues of coeliac disease management. It focuses on the innovative potential in the public sector, better integration of social innovations into the healthcare system with the objective to bring the system closer to the patient, establishing an integrated treatment and ensuring a healthy and active ageing of the population. Focus IN CD project is supported by the Interreg Central Europe Programme, funded by the European regional development Fund. A total budget of the project is approximately 1,900,000€. The implementation started in June 2016 and will end in May 2019. Project partners are Municipality of Maribor, University Medical Centre Maribor, E-institute – Institute for Comprehensive Development Solutions, Klinikum der Ludwig-Maximilians-Universität München, Heim Pal Hospital Budapest, Università degli Studi di Trieste, Istituto Burlo Garafolo Trieste, Klinički bolnički centar Rijeka, Udruga oboljelih od celijakije Primorsko – goranske županije Rijeka, Coeliac Association from Budapest, Stiftung Kindergesundheit and Primorsko – Goranska županija.

Within the project, we will develop E-tools for healthcare professionals, implement pilot testing on 10 new services and prepare an integrated management model for coeliac disease patients, which can also be applied in other environments, and for other chronic diseases.

Key outputs are Assessment of Coeliac Disease management practices; three developed and implemented E-tools: E-learning tool for HCPs for up-to-date management of CD patients, E-learning tool for patients for necessary every-day life of CD patients and ICT App for HCPs to help them in everyday practice. Ten pilot actions will be implemented and tested to improve skills and competences of health care professionals. The project will demonstrate development and pilot testing of an innovative healthcare service model in management of coeliac disease (CD), which will enable us to develop a patient centred health care service. “Policy recommendations” based on patient centred CD management model will include guidance on how to effectively address the challenges of CD management in the framework of existing healthcare systems.

Early prevention of chronic diseases that have severe impact on general well-being of patients is extremely important if we want to reach the goals and ensure sustainable health care systems in CE. Education and an effective self-management of patients are very important topics.

We will tackle this problem with our E-learning tool for patients, which will be available in autumn 2018. Visit our website <http://www.interreg-central.eu/Content.Node/Focus-IN-CD.html> and stay informed.



Feel free to contact us for any additional information

1. Municipality of Maribor

Office of Project Development – Project Office
Ulica heroja Staneta 1, 2000 Maribor, SI

Jasmina Dolinšek, M.Sc., Focus IN CD,
Project Manager
jasmina.dolinsek@maribor.si

2. University medical centre Maribor

Department of paediatrics
Ljubljanska ulica 5, 2000 Maribor, SI

Asst. prof. Jernej Dolinšek, M.D., Ph.D.
jernej.dolinsek@ukc-mb.si

3. E-institute - Institute for Comprehensive Development Solutions,

Čučkova ulica 5, 2250 Ptuj, SI

Anja Prislan, univ. dipl. ekon.
anja@ezavod.si

4. University hospital centre Rijeka,

Department of paediatrics
Istarska 43, 51000 Rijeka, HR

prof. Goran Palčevski, M.D., Ph.D.
goran.palcevski@ri.t-com.hr

5. University of Trieste

Department of Life Sciences
Piazzale Europa 1, 34100 Trieste, IT
Daniele Sblattero, Ph.D.
dsblattero@units.it

6. Association of coeliac patients Primorsko - goranska County

Drage Gervaisa 52, 51000 Rijeka, HR

Marina Milinović,
president of Association of celiac patients
Primorsko - goranska county
celiac_rka@yahoo.com

7. Institute for Maternal and Child Health - IRCCS »Burlo Garofolo«

Paediatric Department
Via dell'Istria 65/1, 34100 Trieste, IT

prof. Tarcisio Not, M.D., Ph.D.
tarcisio.not@burlo.trieste.it

8. Ludwig-Maximilian's University Medical Centre

Dr. von Hauner Children's Hospital, Division of
Paediatric Gastroenterology
Lindwurmstraße 4, 80337 München, DE

Prof. Dr. Sibylle Koletzko, Head of Div. Paediatric
Gastroenterology and Hepatology
Dr. von Hauner Children's Hospital Ludwig
Maximilians-University, Munich, Germany
sibylle.koletzko@med.uni-muenchen.de

Katharina Werkstetter, Dr. rer. biol. hum., MSc,
MPH, Scientific Project Manager
katharina.werkstetter@med.uni-muenchen.de

9. Hungarian Coeliac Society

Palanta utca 11, Budapest 1025, HU

Tunde Koltai,
president of Hungarian coeliac society
tunde.koltai@gmail.com

10. Heim Pál National Pediatric Institute

Coeliac Disease Center
Üllői ut 86, 1089 Budapest, HU

prof. Ilma R Korponay-Szabo, M.D., Ph.D., D.Sc.,
coeliakia@heimpalkorhaz.hu

11. Child Health Foundation

c/o Dr. von Haunersches Kinderspital
Lindwurmstrasse 4, 80337 München, DE

Giulia Roggenkamp, M.A., General Secretary
roggenkamp@kindergesundheit.de

Berthold Koletzko, Prof. Dr. Dr. h.c. mult. Prof. h.c.,
Chairman
berthold.koletzko@med.uni-muenchen.de

12. Primorje - Gorski Kotar County

Department for Health
Slogin kula 2/I, 51000 Rijeka, HR

Alemka Mirkov, univ. dipl. ekon.
alemka.mirkov@pgz.hr

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Authors: Jernej Dolinšek, Jasmina Dolinšek, P. Rižnik, T. Krenčnik,
M. Klemenak, M. A. Kocuvan Mijatov, K. Mijatov, S. Ornik, M. Jurše, J. Vidmar,
A. Prislán, I. Korponay - Szabo, G. Palčevski, M. Milinović, T. Koltai, M. Smoljan,
I. Butorac Ahel, L. Ružman, K. Baraba Dekanič, I. Dovnik, J. Gyimesi Gallisz.

Editor: Jasmina Dolinšek

Proofreading: Tina Kamhi Trop

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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.

This brochure will be regularly updated based on new evidence.