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## For Coeliacs from Finland

SITRA

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# FOREWORD

Sitra, Finnish innovation fund coordinated coeliac cluster during years 2006-2008. The Coeliac cluster promoted the development of international business related to coeliac disease.

The aim of this report was to gather information of coeliac disease and gluten free diet in simple format and English language. This was done to make it easier for non-specialists example salespeople to adapt into this business area.

Marika Pyykönen, M.Sc (nutrition) has, with aid from several Finnish specialists, written this report. I want to thank her and everybody who contributed to the report. I hope that this report will be used by Finnish institutions private or public for good of coeliacs.

Markku Mikola, project manager, Sitra

# INTRODUCTION

Coeliac disease also known as a gluten intolerance, is an autoimmune disease, which means that the body attacks itself. Gluten is toxic for coeliacs but not for other people. Gluten refers to a group of proteins present in wheat, barley and rye. The toxicity of gluten proteins lies in their structure. The careful avoidance of gluten enables a symptom-free healthy life.

Coeliac disease presents itself only in certain circumstances and it cannot be prevented. Coeliac disease runs in families and the genetic risk varies among people. There are also certain risk groups that may have even a higher risk than others (e.g. those suffering from an autoimmune disease such as type 1 diabetes mellitus). The disease may present at any age but not usually in the very young or the very old. Coeliac disease is common in Europe but rare in Asia.

The symptoms are variable and they may vary in severity and time of onset which they appear. Secondary lactose intolerance is quite common when coeliac disease is diagnosed. In the skin disease dermatitis herpetiformis the gluten intolerance presents as a skin rash. It is also possible that coeliac disease is totally symptom-free.

The possible presence of coeliac disease should be investigated at the onset of symptoms and in those people who belong to the risk groups. Symptom-free cases should also be screened for. Blood tests are an important indicator and support the final diagnosis. A correct final diagnosis is always based on a biopsy and a diagnosis is essential before a gluten-free diet is started. Coeliac disease should not be confused with a food allergy.

Once the disease is diagnosed, it is vital that a gluten-free diet is followed to promote health and to reduce the risk of deterioration. The only way to cope with coeliac disease is to follow a gluten-free diet for life.

The dietary recommendations for people with coeliac disease are the same as for the general population. The only exception is the rule of avoiding gluten. In practice, gluten is eliminated from the diet and replaced by gluten-free alternatives. The safe (permitted) and prohibited foods are commonly consulted. In addition, food labels are an important source of information.

In principle, a diet suitable for coeliacs includes all "non-cereal" foods (e.g. fruits, vegetables, berries, meat, poultry, fish, eggs, dairy products, fats, etc.) and drinks (e.g. juices, coffee and tea). In addition, all gluten-free cereals (e.g. rice, corn, millet and buckwheat) are suitable as well as products made from them.

There are two types of gluten-free products. First, there are products that are naturally free from gluten. These are made of gluten-free cereals such as rice, corn, millet, quinoa and buckwheat. Second, there are products that have been treated to reduce the gluten content to a very low level (e.g. wheat starch and beer which have a very low level of gluten). In addition, coeliacs may include oats in their diet if they so desire. However, it has to be ensured that oats have no contamination with wheat, barley or rye.

In coeliac disease, there are some particular nutritional aspects to consider. An adequate fibre intake is a challenge as, on average, only approximately half of the daily recommendation is achieved by those adhering to a gluten-free diet. The use of oats may help to increase the fibre intake. Oats probably also make a diet easier to follow, as the number of food choices

increases. Nutrient supplements are not necessarily required but in recently diagnosed coeliacs they may be useful.

There are special criteria for gluten-free products which are given in the Codex Standard. A revision of the standard was accepted in July 2008. In addition, there exists an international gluten-free symbol, the Crossed Grain Symbol, which is a registered trademark. The criteria for the Crossed Grain Symbol correspond well with the revised Codex standard.

Many special products have been created and produced for coeliacs in Finland. For example, there are products made of special pure oats, barley-malt beers made gluten-free and the Rapid Test Kit for coeliac disease diagnostics for home use. In addition, in Finland Current Care guidelines (standardised treatment practices) are used to achieve high-quality consistent health care.

This report provides basic information on coeliac disease. In addition, the Finnish special products are described. The secrets of Finland's success in coeliac disease management are also included in the report.

The world is full of opportunities. Hopefully this report will help in showing how the needs of people with coeliac disease can be met. The new products and innovations are warmly welcomed in a global coeliac market.

# 1. WHAT IS COELIAC DISEASE?

## 1.1 Coeliac disease is gluten intolerance (gluten sensitivity)

### 1.1.1 Coeliac disease in a nutshell

Coeliac disease is intolerance to gluten (gluten sensitivity). Gluten is a group of proteins present in wheat, barley and rye. Oats also include similar proteins, but pure oats are well tolerated by coeliacs. Coeliac disease is an autoimmune disease, which means that the body attacks itself.

When a person with coeliac disease eats or drinks any food containing gluten, he or she will display various kinds of symptoms, usually in the gut (small bowel), for example diarrhoea, stomach pain, loose stools and/or flatulence. Symptoms that are not directly related to the gut are also possible. These include anaemia (fatigue), bone loss (osteoporosis), dental problems, infertility and itchy rashes due to dermatitis herpetiformis (skin disease).

Coeliac disease is a lifelong (permanent) condition in which the gluten is harmful to one's health. The only treatment is a gluten-free diet. In such a diet, all gluten is eliminated from the person's food intake.

### 1.1.2 Gluten is toxic for coeliacs

Gluten is toxic for coeliacs and it causes inflammation in the gut (small bowel). The inflammation damages the tiny, microscopic "fingers" (villi) on the surface of the gut. In addition little "holes" which exist on the gut's surface are enlarged (crypt hyperplasia). The amount of gluten intake is related to the extent of this damage.

If gluten is eaten over a long period by a coeliac the inflammation may lead to flattening of the internal wall of the gut (villous atrophy). There is an individual variation in the duration of the gluten exposure before the symptoms appear but usually it takes from a month to several years. As a result the absorption area in the bowel is dramatically reduced. This usually leads, e.g., to malabsorption of nutrients, which may have many harmful results – in other words various symptoms and/or complications.

The classical symptoms of coeliac disease after eating foods containing gluten are diarrhoea, stomach pain, loose stools and flatulence. The symptoms may occur immediately or later. It is also possible that no symptoms occur. There is a great intra- and inter-individual difference in what happens after consuming toxic gluten. However, gluten is always harmful even if symptoms are not apparent once the inflammation process starts in the gut. Adherence to a gluten-free diet must therefore be strict.

Gluten intolerance may also present itself as a skin disease called dermatitis herpetiformis. Gluten causes the symptoms but in this case they are in the form of an itchy rash, usually on the knees, elbows, scalp or buttocks. Dermatitis herpetiformis affects fewer people than coeliac disease in the gut. Also, in dermatitis herpetiformis a strict gluten-free diet is essential.

### 1.1.3 Avoiding gluten enables a symptom-free healthy life

A coeliac has a symptom-free life if gluten is avoided. If a person follows a gluten-free diet, the gut (small bowel) recovers and stays healthy. The surface of a healthy gut is covered with tiny, microscopic "fingers" (villi) that maximise the area for nutrient absorption. Coeliac disease is present/active only if gluten is eaten.

A healthy gut works well, nutrients are absorbed properly and symptoms disappear. Life becomes symptom-free and a person feels good.

### 1.1.4 Refractory coeliac disease – uncured condition

In refractory coeliac disease, a patient fails to respond to a gluten-free diet and the gut does not heal even when a strict gluten-free diet is followed. The inflammation continues and symptoms occur. In this situation, when the condition does not improve despite a gluten-free diet, other possible diseases, such as Crohn's disease, bacterial overgrowth, giardiasis, possible lymphomas, etc., should be excluded before diagnosing refractory coeliac disease.

Refractory coeliac disease is rare. As a treatment the gluten-free diet is followed but medication can be used too (e.g. immunosuppressive medication). Refractory coeliac disease is not referred to elsewhere in this paper.

## 1.2 Gluten

### 1.2.1 Gluten is a group of proteins present in wheat, barley and rye

In the context of coeliac disease, gluten is a general term used for the group of proteins (prolamins) present in wheat, barley and rye that are known to be harmful for coeliacs. Gluten proteins are storage proteins of the grains and are mainly situated with starch in the inner parts of the grain. Oats also include similar proteins. The prolamins of wheat are called gliadins and glutenins, prolamins of barley are called hordeins and those of rye are secalins. The prolamins of oats are called avenins. Avenins differ from prolamins of wheat, barley and rye, and based on the clinical studies, oats have no toxic effect in coeliacs. Since 1997, people with coeliac disease may have, according to the Current Care guidelines in Finland, use oats in their gluten-free diet if desired. Also other grass species such as maize and rice contain prolamins; however, they are not harmful for coeliacs.

In the context of baking, gluten refers to a special protein network that gives dough its elasticity and plasticity, thus providing good baking properties. These characteristics are only obtained with wheat flour, which is why wheat flours are widely used in baking. Prolamins of rye or barley, although harmful for coeliacs, do not have this elastic or plastic property.

The presence of gluten in Western diets is very common. Typical products that include gluten are bread, pasta, biscuits, muesli and cakes.

### 1.2.2 The toxicity of gluten proteins lies in their structure

Gluten proteins are toxic for coeliacs. All proteins are composed of amino acids that are linked together with peptide bonds. Typical prolamins protein contains about 200 to 1000 amino acids.

Protein can be broken down into smaller peptides, which are composed of fewer amino acids. Some of the peptides in wheat have been shown to cause a harmful immune reaction in coeliacs. However, the complexity of prolamins and the wide variation in coeliac patients have made it difficult to find and identify all the toxic peptides.

## 1.3 Origin

### 1.3.1 Coeliac disease will present only in certain circumstances

Coeliac disease presents itself only in certain circumstances, many of which are well known but some are still assumptions. It is not fully understood why some people have this disease. The appearance (pathology) of coeliac disease is a complex interplay between genetic and environmental factors. Nonetheless, the following facts appear to be indisputable.

First, gluten is needed to cause coeliac disease. In particular wheat gluten, has a strong relationship with coeliac disease. The toxicity of barley and rye proteins have not been studied as carefully as wheat gluten, but since they have many similarities, they can be assumed to cause coeliac disease. The proteins found in oats are shown not to cause coeliac disease.

Second, both coeliac disease, which affects the gut, and the skin disorder dermatitis herpetiformis need certain hereditary information (genetic factors) for either to present. Wheat, barley and rye are simply not intended to be included in the diet of those people with "coeliac genes". So, it seems that coeliac disease runs in families. If there is a coeliac in a family, the risk of having another incidence is higher than in families without coeliac disease. Coeliac disease is not contagious (it is non-communicable).

### 1.3.2 Coeliac disease cannot be prevented

There is no way to prevent coeliac disease. However it only occurs in people who have a certain genetic predisposition and who include gluten in their diet.

The only rational precaution would be to avoid weaning infants with a family history of coeliac disease onto gluten too early. The current guideline is that gluten should not be introduced before five to six months of age.

### 1.3.3 Age and coeliac disease

Coeliac disease usually presents at the age of 40, but it may appear at any age. In earlier years, it was considered to be a paediatric disease (occurs in childhood). The same applies to dermatitis herpetiformis (skin disease) – it may also present at any age but usually occurs in the 30-40 age range. It is rare that dermatitis herpetiformis would appear in the very young or in the elderly. Once coeliac disease is diagnosed it is permanent.

## 1.4 Genetics

### 1.4.1 Coeliac disease is familial

It is not fully understood why some people contract coeliac disease. The appearance (pathology) of coeliac disease is complex. It seems that coeliac disease is familial. A genetic predisposition seems to be clear. A link exists between coeliac disease and certain tissue types (HLA DQ2 and DQ8). However, about 35% of the Finnish population carries these genes without developing a coeliac disease. If there is a coeliac in a family, the risk of having another is higher than in families without coeliac disease.

Coeliac disease is an autoimmune disease. This means that the body attacks itself. The attack is triggered by gluten. The immune system produces antibodies, and these antibodies cause the inflammation in the gut (small bowel) and as a result its tiny, microscopic "fingers" (villi) are destroyed and the absorption area for the nutrients is dramatically reduced. People without coeliac disease do not react to gluten and this harmful cascade in the immune system is not started.

### 1.4.2 Risk groups

The risk of having coeliac disease is higher in a "coeliac family" than in families without the coeliac disease.

Other risk groups include people with an autoimmune disease, e.g. type 1 diabetes mellitus, Sjögren's syndrome or autoimmune thyroid diseases (e.g. patients with hypo- or hyperthyroidism). In addition, patients with selective Immunoglobulin A (IgA) deficiency have about a ten times higher risk of having coeliac disease than others.

## 1.5 Symptoms

### 1.5.1 The symptoms vary

Gluten intake causes harmful consequences to people with coeliac disease. The symptoms are usually gut related but they may also manifest in many other ways too. There is intra- and inter-individual variation regarding what happens after eating gluten and the symptoms may range between mild and severe. It is also possible that symptoms may not occur at all. In other words coeliac disease can be symptom-free (clinically silent) but the inflammation process has been triggered by gluten in this case too.

The classical symptoms of coeliac disease are chronic diarrhoea, weight loss, anaemia (typically seen as fatigue) and malabsorption. Milder symptoms are, for example, stomach pain, bloating, loose stools, vomiting and flatulence. About 50-80% of the patients diagnosed with coeliac disease have had gut-related symptoms.

If gluten is taken for a longer time the inflammation may lead to flattening of the internal wall of the gut (villous atrophy). Finally the absorption area is dramatically reduced, which may lead to, e.g., malabsorption of nutrients.

The malabsorption means that nutrients including carbohydrates, proteins and fats for energy, vitamins and minerals cannot be absorbed properly. The lack of energy leads to weight loss and to a low intake of other nutrients (nutrient deficiency, e.g. iron, calcium) which in turn may lead to various problems, e.g. anaemia (fatigue), irreversible bone loss (osteoporosis) and/or dental problems. Laboratory blood tests are done to detect any possible nutrient deficiencies (malabsorption).

As already mentioned, the symptoms may also be related to organs other than just the gut, e.g. the bones (osteoporosis), nervous system and teeth. In children coeliac disease can affect growth. Usually many of these symptoms are due to malabsorption. Dermatitis herpetiformis (skin disease) causes an itchy rash. In practice, coeliac disease may lie behind bone loss (osteoporosis) or anaemia while the coeliac disease itself may be symptom-free (clinically silent).

In earlier years the symptoms were often more severe than today. The milder symptoms today are probably explained by correct and earlier diagnosis.

### **Symptoms of coeliac disease**

#### Typical symptoms

- Chronic diarrhoea
- Weight loss
- Anaemia
- Malabsorption

#### Milder symptoms

- Stomach pain
- Loose stools
- Flatulence
- Lactose intolerance (secondary, often disappears once the coeliac disease is treated)

#### Non-gut symptoms

- Dental problems
- Neurological symptoms
- Epilepsy
- Retarded growth in children
- Itchy rashes (dermatitis herpetiformis, skin disease)

## **1.5.2 The symptoms vary in their time of onset and in severity**

The symptoms vary in their time of onset and in severity after eating gluten. Some people may have immediate, strong symptoms (e.g. vomiting). Others may have milder symptoms (e.g. bloating and flatulence), while someone else might have no symptoms at all (symptom-free, clinically silent). The differences between individuals are huge.

Nonetheless, the rule of thumb is to remember that gluten is toxic for all coeliacs and gluten intake is always harmful. Gluten triggers the inflammation process in the gut even if visible symptoms do not occur.

If a coeliac continues eating/drinking gluten, the inflammation in the gut continues too and it may gradually lead to flattening of the internal wall of the gut (villous atrophy). There is individual variation in the time it takes for villous atrophy to occur as a result of the regular

eating of gluten but usually it takes from a month to several years. This condition is serious, e.g. because of the malabsorption and all the unpleasant consequences related to it.

### 1.5.3 Secondary lactose intolerance

It is quite common that a person with coeliac disease has lactose intolerance too. Commonly this is so-called secondary lactose intolerance, which means that lactose is not absorbed because of the inflammation of the gut. Lactose intolerance causes unpleasant symptoms, e.g. bloating, flatulence and diarrhoea.

Secondary lactose intolerance is usually resolved once the coeliac disease is treated. A lactose-free diet is commonly followed together with a gluten-free diet once the coeliac disease diagnosis is made. When the gut has healed lactose is often tolerated again and dairy products can be used once more.

### 1.5.4 Symptom-free (clinically silent) coeliac disease is possible

Coeliac disease can be symptom-free (clinically silent). This explains why some people are unaware that they have coeliac disease up until the diagnosis is suddenly made for one reason or another. In practice, this may arise as a result of laboratory blood tests. The test results may reveal a lack of nutrients and possible malabsorption, which can be a consequence of untreated coeliac disease.

The coeliac disease diagnosis probably comes as a surprise because the actual problem may have been, e.g., anaemia (fatigue). The symptom-free status is one explanation for the delay in diagnosing coeliac disease.

Gluten is also toxic for symptom-free coeliacs. It causes inflammation in the gut (small bowel) and therefore a gluten-free diet is essential. Such a diet helps the gut (small bowel) to heal and stay healthy, which is important in preventing the possible complications related to the inflammation even if the disease is symptom-free. Complications can be severe also in symptom-free coeliac disease and untreated coeliac disease can cause, e.g., malabsorption, which may lead to anaemia (fatigue), irreversible bone loss/osteoporosis, depression or infertility.

### 1.5.5 Symptoms may be seen also in the skin – dermatitis herpetiformis

Coeliac disease can also appear as the skin disease dermatitis herpetiformis. Gluten causes the symptoms, which in this case include an itchy rash, usually on the knees, elbows, scalp or buttocks. Dermatitis herpetiformis affects fewer people than coeliac disease in a gut and it may occur with or without symptoms in a gut. A strict gluten-free diet is essential in dermatitis herpetiformis

### 1.5.6 Neglecting a gluten-free diet will prevent healing and worsens the condition

If a gluten-free diet is neglected the symptoms will remain and become more severe, e.g. chronic diarrhoea and fatigue due to anaemia can influence daily life.

As gluten is toxic for coeliacs, the inflammation will continue and probably lead to various kinds of symptoms, many of which may be irreversible (e.g. bone loss, dental enamel defects). Also, depression and infertility, among many other complications, may occur. In some cases untreated coeliac disease may lead to cancer (lymphoma).

It may take from a month to many years before the inflammation in the gut (small bowel) gradually leads to flattening of the internal wall of the gut. There is considerable individual variation regarding how fast the process proceeds.

## 1.6 Diagnosis

### 1.6.1 The target is a better quality of life

The target of early coeliac disease diagnosis is to improve the quality of life. This includes maintaining a symptom-free condition. The correct diagnosis also aims to prevent malabsorption and possible complications (e.g. bone loss, dental defects, infertility or lymphoma).

### 1.6.2 The possible occurrence of coeliac disease should be investigated when symptoms occur and for people in the risk groups

When symptoms typical of coeliac disease occur and/or there is already a coeliac in the family, the possible occurrence of coeliac disease should be investigated. The same applies to those people who belong to other coeliac disease risk groups.

Typical symptoms for coeliac disease are, e.g., diarrhoea, weight loss, anaemia (fatigue), stomach pain, bloating and flatulence. Non-gut symptoms related to coeliac disease are, e.g., bone loss (osteoporosis), infertility, depression, dental enamel defects, retarded growth in children and itchy rashes.

The risk groups for coeliac disease comprise persons who are related to a coeliac or who have an autoimmune disease such as type 1 diabetes mellitus, Sjögren's syndrome or autoimmune thyroid diseases (e.g. patients with hypo- or hyperthyroidism). In addition patients with selective IgA deficiency have about a ten times higher risk than others of having coeliac disease.

### 1.6.3 Symptom-free cases should also be screened for

An investigation for coeliac disease is worth doing even if the person is totally symptom-free but belongs to a risk group or has other blood test indicators typical of coeliac disease (e.g. signs of bone loss or anaemia). Early diagnosed coeliac disease and a gluten-free diet can enhance the quality of life. In addition it may prevent ill health and further complications.

If coeliac disease is not detected and gluten intake continues the inflammation in the gut (small bowel) will become more severe. This process also affects people who are symptom-free. The situation may lead to various kinds of symptoms that will be seen sooner or later, for example anaemia (fatigue). Some of the symptoms may be irreversible (e.g. bone loss, dental enamel defects).

It may take from a month to many years before inflammation in the gut (small bowel) results in villous atrophy. There is individual variation regarding how fast the process proceeds. The sooner the correct diagnosis is made the faster adequate care can be given.

#### 1.6.4 Blood tests give an important hint and support the final diagnosis

The easiest and fastest way to detect possible coeliac disease is to do a simple blood (serum) test. There are different kinds of tests on the market. These tests detect the special proteins (antibodies, endomysial antibodies (EMA), and/or tissue transglutaminase antibodies (tTGA)) that are specific to coeliac disease. Such proteins (antibodies) are produced by the immune system when a person with coeliac disease has consumed gluten.

A positive result in a blood test indicates that a person quite obviously has coeliac disease. Incorrect test results (false positives) are rare, under 5%. Nearly all, 90-95%, coeliacs are detected through blood tests. Nevertheless, a negative test result does not totally exclude the possibility of having the disease. In Finland a positive blood test will often be followed by frequent laboratory testing and biopsies even in cases where no sign of coeliac disease is found in the first biopsy.

The blood tests are fairly reliable and easy to administer. They are done in a laboratory and the result is available in 1-3 weeks. Also home kits (rapid tests), which can be used also in a doctor's surgery, are available today. The blood test result supports the biopsy, which is always needed for the final diagnosis.

#### 1.6.5 A biopsy is needed to diagnose coeliac disease

A biopsy is required to make a reliable diagnosis. In the operation a flexible tube (endoscope) is passed via the mouth down into the gut and a little piece of gut, is taken. This tissue sample from the small bowel is thoroughly examined under the microscope and if changes typical of coeliac disease are found the diagnosis can be made. These changes are a flat gut (villous atrophy), enlarged holes (crypt hyperplasia) and inflammation of the surface of the gut.

The blood test may speed up and support the right diagnosis but without the biopsy coeliac disease cannot be properly diagnosed. The operation is done in hospital by a specialist (gastroenterologist).

#### 1.6.6 Diagnosing dermatitis herpetiformis (skin disease)

When dermatitis herpetiformis (skin disease) is suspected a skin specialist (dermatologist) takes a sample of skin and examines it for possible changes (abnormalities).

The biopsy is done on healthy skin (an unaffected area), right next to the itchy rash. The skin is checked for the possible presence of "IgA" clusters (Immunoglobulin A) which are typical of dermatitis herpetiformis.

When dermatitis herpetiformis is suspected a blood test may be used as an early step. The blood test easily shows up the special proteins (antibodies, endomysial antibodies, EMA, and/or tissue transglutaminase antibodies, tTGA) that are specific to coeliac disease. These special proteins (antibodies) are produced by the immune system when a person with coeliac disease has consumed gluten. The blood tests are easy and reliable to use.

As it is possible to have both dermatitis herpetiformis and coeliac disease, a biopsy on tissue taken from the gut (small bowel) should be considered too. A biopsy is worth doing even if the person does not have any gut-related symptoms, as many people with dermatitis herpetiformis also have inflammation of the gut but are unaware of the problem.

### 1.6.7 A correct diagnosis is needed before a gluten-free diet is started

A gluten-free diet should not be started before a definitive diagnosis of coeliac disease. The diagnosis cannot be based only on blood tests or symptoms. Therefore a gluten-free diet should not be started if only the blood tests are positive or the symptoms are typical of coeliac disease (stomach pain, bloating, flatulence, etc.). If a gluten-free diet is started too early without a proper diagnosis (biopsy) it may be difficult to verify the diagnosis based on the biopsy.

### 1.6.8 Coeliac disease is not a food allergy

Coeliac disease is different from a food allergy even though both affect the immune system and the diet therapies can be similar. Coeliac disease is an autoimmune disease that is caused by gluten intolerance. Diagnosis always involves a biopsy and coeliac disease is lifelong (permanent). A gluten-free diet heals the symptoms.

A food allergy (e.g. an allergy to cereals) has a different kind of mechanism in the immune system compared to coeliac disease. Symptoms may vary from swelling of the mouth and throat, skin rashes, a cough, to hypotension and may result in anaphylaxis which can be life threatening. A food allergy diagnosis is based on exclusion of the possible allergen from the diet and by then exposing the patient to the allergen. Laboratory tests can be used in addition. The food allergy may be a temporary problem unlike coeliac disease.

Avoiding gluten alone is not enough for a person with an allergy. Gluten-free products won't contain gluten but they may still contain other proteins that may be harmful to the allergic person. It is notable though that a naturally gluten-free diet, which does not include any wheat, barley or rye, suits, e.g., a wheat-free (wheat allergy) diet. Also oats, that have not been contaminated with wheat, can be included to the diet.

## 1.7 Frequency (prevalence)

### 1.7.1 Coeliac disease is common in Europe but rare in Asia

In Europe and in all communities where wheat is common in the everyday diet coeliac disease occurs. Approximately 1% of the population, globally, is estimated to have coeliac disease but it is even more common in some populations. In Finland, the latest estimate of the prevalence is 2%.

In Asia, e.g. in Japan and China, coeliac disease is rare as well as among black people. Nevertheless 5.4% of children in the Sahara are diagnosed as having it.

## 1.7.2 The genetic risk varies

All over the world there is a genetic similarity between people with coeliac disease. A certain type of hereditary information (genetic factor) is needed for the disease to appear. Within black and yellow people coeliac disease is very rare. However, in the Northern African countries as much as 20% of the population has gene factors related to the coeliac disease. Within Arabs the risk of having coeliac disease is higher than usual.

Frequency (prevalence) of coeliac disease based on the diagnosis by biopsy (a small piece of gut)

- In Europe approximately 0.5 – 1% (may approximate the global frequency)
- In Japan and China approximately 0% (very rare)
- In the Sahara (children) approximately 5.4% (highest found)

The frequency (prevalence) of dermatitis herpetiformis in Finland is about 0.1% (1/1000 inhabitants). This is probably the highest rate in the world.

## 1.7.3 Coeliac disease is not gender-specific

Coeliac disease is not gender-specific; however, it is more common amongst women than men. The reverse is true for dermatitis herpetiformis – it is more common amongst men than women.

## 1.7.4 Only the tip of the iceberg of coeliac disease is yet seen

It is assumed that coeliac disease is under-diagnosed and the frequency may be even higher than the numbers reported. If so, it is possible that only the tip of the iceberg of coeliac disease has been diagnosed and there may be many undiagnosed cases to be found. These people are still waiting for a correct diagnosis and the resulting expert care.

# 1.8 What happens if nothing is done and coeliac disease is not treated?

## 1.8.1 The symptoms appear, stay and become more severe

If coeliac disease is not diagnosed or treated properly by following (adhering to) a gluten-free diet, the symptoms will stay and become more severe. The classical symptoms for coeliac disease are diarrhoea, stomach pain, vomiting and bloating.

Inflammation of the gut may also be associated with non-gut symptoms, including, e.g., bone loss (osteoporosis), dental defects, neurological symptoms, infertility, and depression or itchy rashes in dermatitis herpetiformis (skin disease).

Malabsorption can occur because of inflammation in the gut. Malabsorption means that nutrients (including energy nutrients, vitamins and minerals) cannot be properly absorbed. Eventually coeliac disease with malabsorption may lead to malnutrition.

Commonly malnutrition causes retarded growth in children and weight loss and wasting of muscle in adults. Malnutrition is always a severe issue because it affects health negatively in

many ways (failures in immune system, recovery becomes slower, etc.). In some cases coeliac disease may lead to cancer (lymphoma). Finally, malnutrition may even be life threatening.

Luckily, nowadays severe symptoms are not as common as they were in earlier years. This probably can be explained by earlier diagnosis and good compliance with a gluten-free diet.

Following a gluten-free diet is essential even if a person with coeliac disease is symptom-free. A gluten-free diet prevents the gut from becoming inflamed and complications appearing which would eventually happen sooner or later.

## 1.9 How to live with coeliac disease?

### 1.9.1 A gluten-free diet is the only option

Coeliac disease is a lifelong disease. Even if the disease can't be cured the symptoms can be treated. By eliminating all dietary gluten, in other words by following a gluten-free diet, the inflammation in the gut starts to reduce and the symptoms will gradually disappear. In practice, any food or drink that contains gluten must be totally excluded from the diet.

Many people with coeliac disease will feel much better quite quickly, within weeks, even though in some people the symptoms may linger. It may take from six months to two years for the gut's (small bowel) tiny, microscopic "fingers" (villi) to recover fully. A healthy gut will absorb the nutrients normally.

The treatment of dermatitis herpetiformis (skin disease) is also a gluten-free diet. The skin symptoms disappear slowly after starting the diet. Sometimes additional medical treatment (Dapsone) is needed. Combined treatment (gluten-free diet and drugs) may be needed for a period of six months to three years until the drugs can be discontinued completely. However, a gluten-free diet continues permanently.

### 1.9.2 Oats are well tolerated by coeliacs

Recent clinical studies have shown that oats do not cause coeliac disease. In Finland, all people with coeliac disease may use pure oats if they so desire. Oats have been allowed for adult coeliacs in Finland since 1997 and for children since 2000.

Only pure oats (not standard oats) can be used in a diet suitable for coeliacs. This means that the possibility of contamination with wheat, barley and rye is thoroughly excluded. The production of pure oats demands a comprehensive examination of the whole production chain, including the fields, the harvesting process, the mills, the storage, the packaging, the food factories and the grocery stores. Pure oats are considered to be safe and suitable for coeliacs in Finland. In some other countries pure oats may also be included in the diet.

Oats make the diet more flexible and easier to follow by offering a lot of new choices. The food cost may also be reduced. In addition, oats are a good source of fibre and nutrients. Compliance with a gluten-free diet may be enhanced.

### 1.9.3 Managing coeliac disease is possible – gluten-free lifestyle

The only treatment for coeliac disease is a gluten-free diet for life. Fortunately the world is full of gluten-free choices. And more alternatives are to come. Naturally there is a lot to learn when starting a new diet. However, a symptom-free life is very rewarding and it is a relief to find that food and life may still be tasty and enjoyable! A person with coeliac disease may enjoy life as much as anybody else.

## 2. HOW IS COELIAC DISEASE TREATED?

Coeliac disease is a lifelong (permanent) condition. It is always managed by following a gluten-free diet in which all the gluten is carefully eliminated from the coeliac's diet.

A gluten-free diet should not be started before a proper diagnosis is performed. A reliable diagnosis is based on a biopsy that is carried out on a little piece of gut or skin if dermatitis herpetiformis is being investigated.

### 2.1 Diet in practice

#### 2.1.1 The general dietary recommendations for coeliacs are the same as for non-coeliacs

The same dietary recommendations apply to a gluten-free diet as to a diet containing gluten. In a gluten-free diet all foods and products containing any gluten from wheat, barley or rye are strictly excluded and replaced by a gluten-free alternative.

In a gluten-free diet special attention must be given to replacing gluten-containing cereals with gluten-free cereals. Cereals are an important source of dietary fibre and vitamin B, iron and other minerals in a gluten-free diet also. Cereals are also an important source of carbohydrates. An adequate intake of gluten-free cereals helps to keep energy nutrients (carbohydrates, proteins and fats) in balance.

#### 2.1.2 Drawing up a gluten-free diet

A diet suitable for coeliacs consists of the following foods and drinks:

##### **1. All foods and drinks that are naturally free from gluten.**

Usually all fruits, vegetables, berries, potatoes, dairy products, meat, poultry, fish, eggs, fats, juices, coffee and tea, for example, are safe.

However, the food labelling must be thoroughly read as exceptions always exist, especially in processed foods. Many processed foods may surprisingly include gluten, e.g. sausages, soups, sauces, etc. Most of the beverages (except beers) and sweets are safe but again the ingredient list must be checked. Fortunately today there are even some gluten-free alternatives to beers too.

##### **2. Gluten-free products and pure oats**

A. Gluten-free products are made from gluten-free cereals, for example rice, corn, millet, buckwheat, quinoa, tapioca and amaranth. In Finland these cereals and the products made from them are called naturally gluten-free. However, the term will probably change to gluten-free based on the new revision of the Codex Standard (see 4.2).

B. There are also products, in which the gluten has been removed from the product to a trace level in an industrial process (e.g. wheat starch specially prepared). In Finland, these products are called gluten-free. The denomination of these products will probably change when the new EU regulation for gluten-free products is adopted. The term "very low gluten content" is under discussion.

C. Pure oats can also be included in gluten-free diet. It must be ensured that the oats are not contaminated with rye, barley or wheat at any stage of a production chain.

Gluten-free products are identified by "Gluten-free" claim and/or symbol on the package. The claim "gluten-free" as well as the international symbol for gluten-free foods on the package helps to identify safe foods. The gluten-free symbol gives the product added value as it is a guarantee of the safety and makes the identification of a suitable product easier.

### 2.1.3. Availability of gluten-free products

In Finland the selection of gluten-free products is versatile and wide. Gluten-free products are available, for example pizzas, pastas, breads, cakes, buns and snacks. These foods are usually fresh, frozen, or packed in a protective atmosphere. Gluten-free products are sold in basic grocery stores and supermarkets. There are differences between countries in the distribution channels of gluten-free products.

In restaurants and cafeterias gluten-free dining is also fairly easy in Finland. Usually a coeliac can find a gluten-free alternative straight from the menu. On the menu gluten-free alternatives are often marked with a symbol (e.g. grain) or with a letter "G" (gluten). Also, the personnel are usually well informed on what a gluten-free diet means and are able to recommend suitable choices.

### 2.1.4 Health Insurance Allowance

The Social Insurance Institution of Finland (KELA) pays 21 euro per month to adults (16 years of age and above) who have been medically diagnosed as having coeliac disease. The amount for children (under 16 years of age) with coeliac disease is 78 euro per month (2007). This so-called "dietary grant" is a tax-free benefit. It is to compensate for the additional cost of a gluten-free diet. The health insurance coverage varies between countries.

## 2.2 Principles for gluten-free products and oats

In Finland the recommended gluten-free diet includes all gluten-free products, gluten-free products with a very low gluten content (e.g. gluten-free wheat starch and some beers) and oats. A diet containing gluten-free wheat starch is used in some other countries too, e.g. in Sweden, Norway, Denmark and the UK.

The same recommendations are used for both children and adults, including recently diagnosed persons and people with coeliac-related skin disease (dermatitis herpetiformis). In Finland the treatment results and compliance with gluten-free diet are good.

In Finland about 80% of people with coeliac disease follow a gluten-free diet that includes both gluten-free products and products in which the gluten contents are reduced to very low levels (e.g. gluten-free wheat starch).

## 2.2.1 Products whose gluten content has been reduced to a very low level

Products with reduced gluten content are foods and drinks that have been processed to meet the criteria for having a very low level of gluten. In the process, gluten has been removed to a trace level. Gluten-free wheat starch is the most widely known example of these products. Up till now products have been termed gluten-free in Finland. The denomination of the products will probably change when the EU regulation on gluten-free foods is adopted, which is awaited to happen during year 2009. The term "very low gluten content" for these products is under discussion.

Some sensitive coeliacs may react to these products with very low gluten content and the recovery process might not proceed as expected. They have to start following the stricter gluten-free diet, which includes only food that is naturally free from gluten.

In the new Codex Standard, the limit set for the maximum gluten level in gluten-free products with a reduced gluten content is 100 mg gluten/kg. This is the same level as required to obtain the licence for the Crossed Grain Symbol; the exceptions are beer and soy sauce for which the requirement is stricter 20 mg gluten/kg for the Crossed Grain Symbol. In Finland, the authorities have up till now used a level of 200 mg gluten/kg for all gluten-free products including those whose gluten content has been reduced to a very low level. The updated Codex Standard pertaining to foods for gluten intolerants was adopted in July 2008 and a new EU regulation concerning gluten-free foods is under preparation. Finland will follow the new limits which already correspond with the Crossed Grain Symbol for the most part.

## 2.2.2 Gluten-free products

Gluten-free is classified as food that does not contain gluten from wheat, barley rye or oats. A gluten-free diet consists of gluten-free food, e.g. rice, corn (maize) millet, quinoa or buckwheat. Also, products that are made from these cereals are suitable. Up till now, these products have been called naturally gluten-free in Finland.

In Finland, 20% of people with coeliac disease follow a gluten-free diet that consists only of these naturally gluten-free products. Nowadays, the selection of gluten-free foods is fortunately versatile. Nearly every traditional gluten-containing food has a gluten-free alternative, e.g. bread, pizza, pasta, cakes, etc.

The new Codex Standard sets a limit for gluten level in gluten-free foods to 20 mg gluten/kg. This is the same as the requirement to achieve the licence for the Crossed Grain Symbol. When the new EU regulation based on the updated Codex Standard pertaining to foods for gluten intolerants is adopted, Finland will follow the new limits. The limits already correspond with the Crossed Grain Symbol for the most part. The EU regulation should be adopted in year 2009.

## 2.2.3 Pure oats that are not contaminated with wheat, barley or rye

Oats can be included in a coeliac's diet if so desired. Oats are safe for most coeliacs and are well tolerated. Contamination with wheat, barley or rye at every stage of the production chain is carefully excluded in these so called pure oat products. The safety of these products has been ensured by the manufacturer. Oats make the diet easier, tastier and cheaper to follow.

In addition pure oats are also suitable for people with a wheat allergy as they have not been contaminated with wheat.

#### 2.2.4 Special requirements for gluten-free products

As gluten-free products are produced for people with special dietary needs, special food laws have been enacted to ensure the safety of these foodstuffs. These foods are classified as "foodstuffs for particular nutritional uses". In order to secure the safety of foodstuffs in Finland, every manufacturer, marketer, importer, etc., needs to have a so-called in-house control plan. The in-house control plan is the basis for safe gluten-free products, e.g. the avoidance of contamination during processing.

#### 2.2.5 Food labelling may bring some surprises

It can come as a surprise that "wheat starch" or "barley" (e.g. in special gluten-free beers) may be mentioned on the ingredient list of a gluten-free product. The gluten contents of these products have been reduced to the level where they can be classified as gluten-free and the Crossed Grain Symbol for gluten-free products can be used. In the production process the amount of gluten has become so minimal that these products are considered to be safe for many coeliacs. These products must be excluded from the diet if a coeliac is following a gluten-free diet that includes only products that are naturally free from gluten.

Oats, whose purity from wheat, barley and rye is ensured, are considered to be safe for coeliacs in Finland. On the package, however, it can be mentioned that the product "includes oats and gluten-free components" – also "suits a gluten-free diet" is used – but this applies only to pure oats, not standard oats. This Finnish practice is based on strong scientific clinical evidence. It has been shown that for most coeliacs pure oats suit and help to heal the gut. Pure oats are well tolerated and are often used as part of a coeliac's diet. In Finland 76% of coeliacs included pure oats in their diet in 2006. In some countries a consultation with a doctor about the suitability of oats is required.

### 2.3 What happens if gluten is eaten by mistake?

It is very important to follow carefully the gluten-free diet. Sometimes mistakes just happen, especially out of the home.

After eating gluten some coeliacs may have very severe symptoms while others may have no symptoms at all. The differences between coeliacs can be huge. Gluten is always harmful whether the symptoms occur or not.

The inflammation process will be triggered after eating gluten. Unfortunately possible symptoms cannot be prevented. Most people experience them within a few hours (e.g. diarrhoea, flatulence, vomiting) but symptoms can appear after a few days too. The symptoms just take some time and nothing special can be done to avoid them. Drinking enough water is important if vomiting and/or diarrhoea occur. Fortunately the gut will heal quite quickly if a gluten-free diet is followed strictly again and the gluten intake was just a rare accidental mistake.

If gluten is eaten often the inflammation process will continue in the gut. Even very small amounts can maintain the inflammation if gluten intake is continuous. This may lead to villous atrophy, which has serious consequences.

## 3. SPECIAL NUTRITIONAL ASPECTS IN A DIET SUITABLE FOR COELIACS

### 3.1 Fibre

#### 3.1.1 Fibre has many positive effects

A sufficient intake of fibre is essential and this is one of the greatest challenges in a gluten-free diet. Fibre has many positive effects upon health.

The fibre improves the stomach (and bowel) function and it produces a feeling of fullness. A diet rich in fibre helps to cure constipation. Soluble fibre (present, e.g., in oats) helps to stabilise blood sugar levels and to lower blood cholesterol levels. In foods fibre improves the texture and taste.

Pure oats are a good source of fibre in a gluten-free diet. They also help to add carbohydrates to the diet, which usually has a positive effect on fat intake by lowering it.

#### 3.1.2 Cereals are the major source of fibre

Cereals are the major source of dietary fibre for coeliacs also. Gluten-free bread, pasta, rice and porridge contain fibre. Wholegrain products and oats are the best source of fibre. Adding pure oats to the diet of coeliacs helps to ensure enough fibre intake.

Vegetables, fruits and berries also contain fibre but the amounts are small in comparison with cereals. It is very hard to achieve the fibre recommendation by using only them.

#### 3.1.3 An adequate intake of fibre is a challenge

The generally recommended amount of fibre intake is 25-35 grams per day. Only about 50% of the recommended amount of fibre is achieved by coeliacs in Finland. Fibre intake is approximately only 15 grams per day.

To achieve the recommended amount of fibre intake means in practice eating 300 g of cereals. This can be taken as 6-9 slices of gluten-free bread and a portion of rice or gluten-free pasta. One slice of gluten-free bread is comparable to about 1 dl of gluten-free porridge.

Often gluten-free products (e.g. bread) include less fibre than traditional gluten-containing alternatives. Recently industry has started to pay attention to this issue and to raise the fibre content of the gluten-free products. There are special gluten-free dietary fibre products that can be used as ingredients in gluten-free production. These special fibre products are made of, e.g., psyllium and/or fibre of linseed, potato, sugar beet or apple. They help to achieve an adequate amount of fibre.

In Finland some dietary fibre products are sold in pharmacies and grocery stores too. Coeliacs can buy and use them as a part of their gluten-free diet (as dietary supplements).

At least in Finland it is still a challenge to achieve an adequate intake of fibre. The more gluten-free products there are on the shop shelves the easier it is to follow a gluten-free diet and to meet the fibre recommendations.

## 3.2 Oats

### 3.2.1 Oats make a diet more flexible and variable

Pure oats are considered to be safe and suitable for coeliacs. In Finland all people with coeliac disease may use pure oats if they so desire. Contamination with wheat, barley and rye is carefully avoided at every stage of the production chain.

In some other countries (e.g. in Sweden, Norway, Denmark and the UK) pure oats may also be included in a diet, with some precautions. Pure oats make a diet more flexible and easier to follow by offering lots of new choices at lower costs. Sometimes, however, increased stomach pain and/or diarrhoea may occur due to the high fibre content of oats. Beginning with a small amount of oats and gradually increasing it often helps to prevent this. Oats are a good source of fibre and nutrients. Compliance with a gluten-free diet is often improved if pure oats are included.

## 3.3 Wheat starch

### 3.3.1 Gluten can be removed from wheat starch – gluten-free wheat starch

Gluten and starch are situated in the inner parts of the wheat grain. It is possible to remove gluten from the starch. This can be done in a special industrial process. The starch produced in the process is gluten-free. Gluten-free wheat starch has been processed further to ensure the absence of gluten than the standard wheat starch.

There is a new Codex Standard for foods for special dietary use for persons intolerant to gluten that limits products including gluten-free wheat starch to a maximum of 100 mg gluten/kg. This standard was accepted by the Codex Commission in July 2008.

Many people with coeliac disease tolerate well gluten-free wheat starch. In Finland about 80% of coeliacs follow a gluten-free diet that includes gluten-free wheat starch. There are though some coeliacs who cannot tolerate gluten-free wheat starch and they have to follow a diet that consists of naturally gluten-free products.

Gluten-free wheat starch is widely used, e.g. in so-called gluten-free flours. Manufacturers use gluten-free wheat starch as it improves the texture and the taste of the food. The selection of gluten-free products that include wheat starch is versatile which makes the diet easier to follow.

## 3.4 Lactose-free diet

### 3.4.1 Lactose-free diet often helps immediately after the diagnosis

In recently diagnosed coeliac disease 50% of the coeliacs also have lactose intolerance. A lactose-free diet is therefore quite commonly started in addition to a gluten-free diet. Low lactose and lactose-free dairy products (e.g. milk, yoghurt) are usually tolerated.

Lactose intolerance linked with coeliac disease is often referred to as secondary lactose intolerance as it is due to villous atrophy. Lactose intolerance among coeliacs often disappears as the gut heals. The frequency of lactose intolerance among coeliacs is as common as in the rest of the population.

## 3.5 Nutritional supplementation

### 3.5.1 A gluten-free diet includes all nutrients – nutrient supplements are not necessarily needed

A good nutritional status can be obtained by following a gluten-free diet. No supplements are needed if the condition is under control, with adequate exclusion of dietary gluten, and the diet is well balanced and nourishing as recommended for all.

### 3.5.2 In recently diagnosed coeliac disease nutritional supplementation may be useful

In recently diagnosed coeliac disease supplementation is sometimes needed to ensure an adequate nutrient intake. The same procedure applies to when the disease is not fully controlled or to when nutritional deficiencies are found. In practice, supplementation means taking special products such as vitamin and mineral pills. These products make it easier to achieve the recommended amounts of certain nutrients. Possible deficiencies are found in laboratory tests.

A deficient intake is usually due to an inflamed gut (small bowel) because of the decreased absorption of the vital nutrients (e.g. vitamins and minerals). The need to supplement the diet is individually evaluated. In some cases multivitamin supplementation can be useful for up to a year. Calcium, vitamin D or fibre supplementation may be needed if the intake of these from the food is low. Special gluten-free fibre products are usually made of psyllium and/or the fibre of linseed, potato, sugar beet or apple.

Secondary lactose intolerance (lactose intolerance related to coeliac disease) is quite commonly found with untreated coeliac disease because of villous atrophy. At the beginning of a gluten-free diet it is wise to avoid lactose, which in practice means dairy products (milk, yoghurts, etc.). To ensure an adequate calcium intake a calcium food supplement, low lactose and lactose-free products and/or calcium-enriched products should be considered. Once the gut has recovered, lactose is often tolerated again and the traditional dairy products can be returned to the diet.

Osteoporosis may be found in association with coeliac disease. Calcium and vitamin D supplementation can then be used to support the gluten-free diet at the beginning. Sometimes medication for osteoporosis may be needed too.

In the case of malnutrition there has been a long-term deficiency of vital nutrients. During a gluten-free diet the nutrient absorption is improved quite quickly. In addition, vitamin and mineral supplementation can support the recovery process.

In recently diagnosed coeliac disease with pregnancy multivitamin supplementation (not including vitamin A) is used to ensure adequate nutrient intake. Sometimes folic acid may also be needed.

## 4. THE SPECIAL CRITERIA FOR DETERMINING PRODUCTS SUITABLE FOR COELIACS

### 4.1 Analysing the gluten content

#### 4.1.1 The method recommended to be used for the quantification of gluten

The Codex Standard for foods for special dietary use for persons intolerant to gluten that was revised in July 2008 defines the method to be used for the determination of gluten as the Enzyme-linked Immunoassay (ELISA) R5 Mendez Method, which is based on the R5 antibody. The antibody is raised against rye secalin and it can react with similar proteins of wheat, barley and rye.

#### 4.1.2 A reliable method is a challenge for researchers

The accurate analysis of the gluten content of foods or drinks has been a very challenging task for researchers for years. The method should be able to measure very low levels of gluten proteins of all harmful cereals in different foodstuffs.

Immunological ELISA methods based on the antibody R5 and the  $\omega$ -gliadin antibody has been used to analyse gluten contents in gluten-free foods. Unfortunately, both methods have some limitations and therefore more research is still needed. Main problem has occurred with samples containing small amounts of barley. The R5 antibody reacts too strongly with barley proteins, which leads to overestimations of gluten content, on the other hand,  $\omega$ -gliadin reacts only weakly with barley proteins, which in turn leads to underestimations.

### 4.2 The Codex Standard 118-1979

#### 4.2.1 Codex Alimentarius Commission

The Food and Agriculture Organisation (FAO) and the World Health Organisation (WHO) established a Codex Alimentarius Commission in 1963. The purposes of the Codex Alimentarius Commission are to protect the health of consumers, to ensure fair trade practices in the food trade and to promote co-operation of all food standards work undertaken by international governmental and non-governmental organisations. This is done e.g. by developing food standards and guidelines under the Joint FAO/WHO Food Standards Programme.

#### 4.2.2 The Codex Standard for foods for special dietary use for persons intolerant to gluten

The Codex Standard for gluten-free foods was adopted by the Codex Alimentarius Commission in 1979 and it has been revised two times since. The latest revision of the standard is from July 2008.

Some important changes and corrections have been made to the standard due to scientific findings during the last 30 years. The main changes concern the allowed limits of gluten content in different gluten-free products. The products are divided into two groups, gluten-free foods and foods especially processed to reduce gluten content to a level above 20 up to 100 mg/kg.

More in detail below (adapted from the Codex Stan 118-1979):

#### Gluten-free foods

a) consisting of or made only from one or more ingredients which do not contain wheat (i.e., all *Triticum* species, such as durum wheat, spelt, and kamut), rye, barley, oats<sup>1</sup> or their crossbred varieties, and the gluten level does not exceed 20 mg/kg in total, based on the food as sold or distributed to the consumer, and/or

b) consisting of one or more ingredients from wheat (i.e., all *Triticum* species, such as durum wheat, spelt, and kamut), rye, barley and oats<sup>1</sup> or their crossbred varieties, which have been specially processed to remove gluten, and the gluten level does not exceed 20 mg/kg in total, based on the food as sold or distributed to the consumer.

#### Foods specially processed to reduce gluten content to a level above 20 up to 100 mg/kg

These foods consist of one or more ingredients from wheat (i.e., all *Triticum* species, such as durum wheat, spelt, and kamut), rye, barley or oats or their crossbred varieties, which have been specially processed to reduce the gluten content to a level above 20 up to 100 mg/kg in total, based on the food as sold or distributed to the consumer.

<sup>1</sup>Oats can be tolerated by most but not all people who are intolerant to gluten. Therefore, the allowance of oats not contaminated with wheat, rye or barley in foods covered by this standard may be determined at a national level.

It is to be noted that the standard stipulates that decisions on the marketing of the products that are specially processed to reduce gluten content may be determined at the national level. In practice, this would mean that this group of products might be allowed in some countries but not in others. Oats might, also, be allowed in some countries but not in others. In addition, the denomination of these products is to be decided on at the national level. Thus the names of these products might vary from country to country. In this report, the products are described as products whose gluten content has been reduced to very low level or products with a very low gluten content, since the final term is not concluded upon yet.

Since the Codex Standard was adopted in July 2008, the European Union Member States began to work on common legislation pertaining to foods for gluten intolerants based on the Codex Standard.

The levels in the Codex Standard correspond well with the levels used in Finland for the Crossed Grain Symbol.

## 4.3 Legal definitions

### 4.3.1 Legal definition of gluten-free

The legal definition of gluten-free varies from country to country. Many countries, including Finland, have applied the level of an earlier proposal for a new Codex Standard. This standard has referred to a maximum of 200 mg gluten /kg. These gluten-free products have up till now included both "gluten-free" and "naturally gluten-free" in Finland.

The new EU regulation based on the updated Codex Standard (please see Section 4.2.3. for more information) is currently under preparation. Once the regulation is introduced, Finland among with other EU members will follow the new limits. The EU regulation should be drafted in the year 2009.

## 4.4 Licensing – the international Crossed Grain Symbol

The Crossed Grain Symbol is an international registered trademark for gluten-free food. It assures that the food is gluten-free. For example in Finland, the UK and Italy the respective national coeliac societies can grant permission for manufacturers or distributors to use the symbol.

In addition Coeliac UK can grant permission to use the so-called "Pan-European Crossed Grain Symbol" which may be very useful when targeting the British market. The criteria for gluten content may differ from the criteria used by other countries.

For consumers the symbol represents safe decision making. The symbol gives added value to the product. It also makes finding a suitable product easier in a grocery store and therefore saves time.

### 4.4.1 Criteria for gluten-free products in licensing the Crossed Grain Symbol

In many countries (e.g. in Finland) the criteria for licensed gluten-free food is a maximum of 20 mg gluten/kg. The level is the same as is commonly used as a legal definition in many countries.

### 4.4.2 Criteria for gluten-free products with a very low gluten content in licensing the Crossed Grain Symbol

The criterion for the licensed gluten-free products with reduced gluten content is a maximum of 100 mg gluten/kg in many countries (e.g. in Finland). The symbol can be used only if this level is met. In other words, at the moment the criteria for the symbol are stricter than the criterion for gluten-free used by the authorities (200 mg gluten/kg). For beer and soy sauce, the limit is even stricter 20 mg gluten/kg in Finland.

### 4.4.3 Three categories for gluten-free products used in Finland

There are three categories used in Finland for products that can have permission to use the Crossed Grain Symbol. They are the following:

1. All gluten-free foods that are classified as “foodstuffs for particular nutritional uses” in the special food laws (e.g. gluten-free flours, gluten-free wheat starch).
2. The traditional food made without gluten-containing ingredients. Usually there has to be a gluten-containing alternative on the market (e.g. chocolate).
3. The traditional food that includes gluten-containing ingredients but during the process the gluten content has been reduced to a negligible level (under 20 mg gluten/kg). The level for gluten-free food is the same, 20 mg gluten/kg, the strictest level used. Product examples are, for example, beer and soy sauce.

#### 4.4.4 Additional requirements for the Crossed Grain Symbol in Finland

The Professional Advisory Board for the Crossed Grain Symbol may give the right to use the Crossed Grain Symbol to manufacturers or distributors that fulfil the criteria for gluten-free levels and food categories. In addition the Advisory Board requires the in-house control plan, documents about gluten analysis and legal labelling for the package to be checked before permission to use the symbol can be given.

### 4.5 Summary of all gluten content levels for gluten-free products

There are some differences between countries about what actually is gluten-free. There are limits set in the Codex Standard, legal definitions and requirements by the Crossed Grain Symbol.

In Finland, there is one limit of 200 mg gluten/kg for gluten-free which the authorities use. In some other countries the limit is 20 mg gluten/kg.

The Finnish Coeliac Society, which grants permission for the Crossed Grain Symbol in Finland, has two categories for gluten-free products: naturally gluten-free products (suggested to be called gluten-free in the future) and gluten-free products (suggested to be called as products with a very low gluten content in the future). The new terms that are suggested for the two categories have not been decided yet and should not be used until they have. The EU regulation in which they will appear is awaited to be introduced during the year 2009.

Coeliac UK may have differences in the criteria for the so-called “Pan-European Crossed Grain Symbol”. In the following table all gluten-free products and the limits used in Finland are presented.

**Table 1.** Products suitable for coeliacs (Finland)

Organisation	Definition	Criteria of gluten content	Product examples
<b>Authorities in Finland</b> (Legal definition for gluten-free) <i>Please note: The EU regulation will be applied as soon as it is introduced</i>	Gluten-free products	< 200 mg gluten/kg <sup>1</sup>	e.g. rice, corn (maize), millet, buckwheat, quinoa, gluten-free flours, gluten-free wheat starch and products made of them
FAO/WHO (The Codex Standard)	Gluten-free products	< 20 <sup>3</sup> mg gluten/kg	e.g. rice, corn (maize), millet, buckwheat, quinoa and products made of them <b>and/or</b> products consisting of one or more ingredients from wheat, rye, barley and oats <sup>1</sup> which have been specially processed to remove gluten, and in which the gluten level does not exceed 20 mg gluten/kg in total, based on the food as sold or distributed to the consumer
	Foods specially processed to reduce gluten content	>20 but no more than 100 <sup>3</sup> mg gluten/kg	Gluten-free wheat starch, gluten-free flours
<b>Finnish Coeliac Society</b> (Criteria of gluten content for the Crossed Grain Symbol)	Naturally gluten-free products	< 20 mg gluten/kg	e.g. rice, corn (maize), millet, buckwheat, quinoa and products made of them
	Gluten-free products	< 100 mg gluten/kg	Gluten-free flours, gluten-free wheat starch
	Gluten-free products whose gluten content has been reduced to a very low level	< 20 mg gluten/kg <sup>2</sup>	Gluten-free beer, soy sauce <sup>2</sup>
<b>Coeliac UK</b> (Criteria for "Pan-European Crossed Grain Symbol")	Gluten-free products	Check exact criteria from Coeliac UK	

mg gluten/kg is the gluten content in milligrams per kilogramme of product. mg/kg is equal to ppm (parts per million).

<sup>1</sup> Varies between countries. This limit is used in Finland.

<sup>2</sup> This limit is used in Finland for gluten-free products whose gluten content has been reduced to a very low level.

<sup>3</sup> The Codex Stan 118-1979.

In Finland, in addition to gluten-free products oats can also be used if so desired. Many coeliacs tolerate oats as long as the contamination with wheat, barley and rye is excluded. In Finland, 76% of coeliacs have included oats in their diet. Product examples are, e.g., bread, rolls,

biscuits, porridge, muesli, flour, and flakes. An in-house control plan plays an important role and guarantees the safety and purity of oats.

## 4.6 Labelling

### 4.6.1 Source of information

For a coeliac, food labelling is a very important source of information. Careful reading and the correct interpretation of the information on the labelling is part of everyday life.

The facts on the label must be correct, as this assures that the food is gluten-free and suits this special diet. In Finland, the general provisions applying to the labelling of foodstuffs are prescribed in the Decree of the Ministry of Trade and Industry on the Labelling of Foodstuffs and in the labelling Directives.

Careful attention in following a gluten-free diet is needed in practice. The name of the food may be misleading. Potato chips or corn beer may include gluten as wheat or barley may have been used as an ingredient. All ingredients used must be listed on the label and gluten cannot be hidden behind the E-code. Even the smallest possible amounts of ingredients that contain gluten have to be mentioned. Wheat-based glucose syrups, dextrose included, wheat-based maltodextrins and barley-based glucose syrups are exempt from the labelling requirement – the declaration of the ingredient (e.g. wheat, barley) is not mandatory in these cases. This however is not a problem for coeliacs as these ingredients contain only trace amounts of gluten and are thus not harmful to coeliacs. Other food allergens, e.g. milk and milk products, also have to be meticulously labelled. These requirements protect the consumer's health.

At the moment, oats are not classified as gluten-free and it is not allowed to market oats as gluten-free and they cannot get permission to use the Crossed Grain Symbol either. In Finland, it is permitted to use an expression such as "includes oats and gluten-free components" – also "suits a gluten-free diet" is used in practice – on the package of uncontaminated, pure oats products.

## 4.7 Foodstuffs for particular nutritional use

### 4.7.1 Gluten-free products must meet the special dietary needs of coeliacs

Foodstuffs for particular nutritional uses (PARNUT) include, among others, gluten-free foods, low-lactose and lactose-free foods. As gluten-free products are produced for people with special dietary needs, the special food laws are made to ensure the safety of these foodstuffs.

The gluten-free product must meet the requirements laid down for it. When a foodstuff for a particular nutritional use (e.g. a gluten-free product) is placed on the market for the first time in Finland, the manufacturer or the importer has to send a notification of this to the Finnish Food Safety Authority.

## 4.8 In-house control plan

### 4.8.1 Guarantee of high production standard

To ensure the purity of the gluten-free products the production chain has to be carefully controlled. In Finland, an in-house control plan is required by the authorities. The in-house control plan ensures that the product has not been contaminated with wheat, rye and/or barley at any stage of the production chain. In the plan all possible contamination risks and problems in the chain are thoroughly considered and solved. The plan is also required if the product claims to be "gluten-free" or that it "includes oats and gluten-free components"; "suits a gluten-free diet" is used also in practice. Gluten-free products are definitely not contaminated with gluten. Should a mistake occur, the food business operator is obliged to withdraw the product from the market and inform the consumers for the reason of the withdrawal.

In Finland an in-house control plan plays an important role in gluten-free production and many companies have close links with the Finnish Coeliac Society regarding safety issues.

In practice, every stage of the gluten-free products production has to be controlled, from the field to the market shelves.

An example of the stages from the field to the market shelves (cereal products)

Stage 1: Cultivation and harvest

- For example, all foreign crops are removed from the field, the machinery is used only for gluten-free cereals

Stage 2: Mill

- For example, mills are used only for gluten-free cereals, washing of the production line is very carefully done, separate storage

Stage 3: Delivery and storage of raw materials

- For example, bakeries and restaurants co-operate only with reliable companies. The gluten-free status and purity of the product is ensured by analyses and certification.

Stage 4: Production

- For example, a separate room, production line and equipment

Stage 5: Storage and packaging

- For example, closed containers, proper labelling

Stage 6: Transport and storage

- For example, a clean room, proper labelling

Stage 7: Market

- For example, proper packaging and labelling, separate or upper shelves

# 5. FINNISH SPECIALITIES FOR COELIACS

## 5.1 Pure oats

Pure oats are 100% oats and have not been contaminated with gluten-containing cereals (wheat, barley or rye) at any stage in the production chain. The purity of the product makes it suitable for coeliacs and gives the product added value.

### 5.1.1 Clinical evidence shows that oats are suitable for a gluten-free diet

Over recent years several studies have been carried out on using oats in a gluten-free diet. Many researchers have come to the conclusion that oats are non-toxic to people with coeliac disease.

Because of the strong clinical evidence regarding the suitability of oats to a gluten-free diet, they have been permitted for adult coeliacs in Finland since 1997. Since 2000, oats have also been a part of the gluten-free diet of coeliac children and people with dermatitis herpetiformis (skin disease). Finland already has ten years of good experience regarding the suitability of oats to a gluten-free diet and a proper healing process.

In Finland, all people with coeliac disease can include oats in their gluten-free diet if they so desire. This is possible immediately after the diagnosis. The clinical evidence shows that pure oats are safe and that they promote the recovery process. However, the contamination with wheat, barley and rye have to be excluded by the careful manufacturing process or the safety of the final product ensured.

### 5.1.2 Daily amounts of pure oats

In Finland, there is no limitation on the daily amounts used. It is recommended to start using oats in small amounts mostly because of the high fibre content as it takes time for stomach to become accustomed to the fibre. In Finland people with coeliac disease use approximately 30 g of oats per day. Some people use higher amounts. About 76% of coeliacs in Finland have included oats in their diet.

### 5.1.3 Pure oats provide flexibility and may promote motivation

Since oats are part of the traditional Finnish diet, pure oats provide flexibility in a gluten-free diet without harming the recovery process and there is one item less to avoid after diagnosis. Sometimes an oats-containing gluten-free diet may cause more symptoms such as stomach pain and/or diarrhoea than a diet without oats. Nevertheless, oats usually do not provoke the inflammation process.

Oats have many advantages. They make home cooking easier and the selection of cereal products wider. Variety and flavour, much desired in the diet, and lower costs are obtained. In addition, oats are of good nutritional value.

The impact of the nutritional value of oats on a gluten-free diet is important. Oats are rich in fibre. Low fibre intake is one of the greatest problems in a gluten-free diet. Fibre improves the

stomach function and helps to control the appetite. It also helps to keep blood sugar in balance and to lower blood cholesterol levels.

Products made of so called pure oats (whose production is carefully controlled to avoid contamination with wheat, barley or rye) are becoming more and more familiar and popular. There are already on the Finnish market breads, crisp breads, rolls, biscuits, porridges, mueslis, flours, and flakes made of pure oats that can be used by coeliacs.

These facts about oats may have a substantial impact on the motivation to follow a gluten-free diet. Oats may therefore also play an important role in Finland's high compliance for gluten-free diet.

In Europe, for example in Finland, Sweden, Norway and Denmark, oats are considered to be a suitable part of a gluten-free diet. In the UK suitability is considered on an individual basis and it is recommended that one discusses fully with a doctor or a dietician before including oats in the diet.

#### 5.1.4 Contamination risk

It is very important that oats included in a gluten-free diet are not contaminated with any gluten-containing cereals: wheat, rye and/or barley. So called pure oats, whose processing has been carefully designed to avoid any contamination with wheat, barley or rye, literally include only 100% oats. Oats are well tolerated by many coeliacs and can be included in a gluten-free diet if so desired.

When oats are used as an animal feed it is not beyond doubt that they may include 1-2% barley or other grains. However, the amount of other grains is much smaller for human food use. This is due to the selected harvest and milling technology. The purity of oats for coeliacs is ensured at every stage of the production chain (fields, machinery, etc.) and the in-house control plan is carefully followed. The certificate and gluten-free analyses are used to guarantee that the product is free from wheat, barley and rye gluten.

Methods to analyse the gluten content have been developed but more reliable methods are still needed. The methods should be able to measure the possible gluten content and gluten contamination of all cereals and cereal products. At the moment there still seems to be challenges on how to measure the gluten content which includes also the possible cross-contamination of oats with gluten-containing cereals (wheat, barley and/or rye).

#### 5.1.5 In-house control plan plays a central role

In Finland, there are companies that specialise in pure oats products. To ensure the purity of the oats every stage of the production chain from the field to the market shelves is carefully examined and the in-house control plan is carefully followed.

In practice, e.g., pure oats fields are regularly checked to exclude the possibility of any other grains. Also, special machinery and factories are used. These procedures ensure that gluten contamination is definitely excluded and that these so called pure oats products are very safe for coeliacs.

## 5.1.6 Not all products made of oats are suitable for coeliacs

The name of the food may be misleading. Even if the name of the product is "oat bread" or "oat biscuits" it is very important to carefully check all ingredients on the list. It cannot be assumed that wheat, barley and/or rye might not have been used too. Gluten cannot be hidden behind the E-code and even the smallest possible amounts of ingredients that contain gluten have to be mentioned.

## 5.2 Gluten-free beer

### 5.2.1 Safe gluten-free beer made of barley

Barley malt is the natural raw material for beer production and it contains gluten proteins. Some Finnish breweries have a unique processing method and by using it, the amount of gluten can be regulated when brewing the beer.

By using this special brewing method it is possible to control the process and the gluten content. The beers made from malted barley can repeatedly show gluten levels below the 20 mg gluten/kg level. If the beer fulfils the criteria listed below, it is considered to be safe and suitable for coeliacs. A license for the gluten-free Crossed Grain Symbol, which gives added value, can also be obtained.

Criteria for beers whose gluten content is reduced to a very low level (Finnish Coeliac Society):

- Gluten levels are below 20 mg gluten/kg; this is the same level as used with naturally gluten-free products
- At least five production lots are examined when applying for the licence for the first time
- Gluten analyses are then required twice a year and the documentation is sent to the Finnish Coeliac Society
- The in-house control plan is properly drawn up, including adequate actions to ensure that the product is gluten-free

In addition coeliacs are guided to limit their use to a maximum of two gluten-free beers a day, in total 660 ml/day. This is to ensure that the cumulative amount of gluten will not become too high and harmful. If the patient is very sensitive to gluten, it is recommended to consult a doctor before starting to use the gluten-free beer.

A coeliac has to be aware of what are the gluten-free beers as the name of the beer may be misleading. Rice beer and corn beer usually include barley and they may, therefore, contain gluten. Such beers are not suitable for people with coeliac disease. Again the Crossed Grain Symbol helps to identify the safe alternative.

In earlier years, nearly all alcoholic drinks, except beer, were suitable for coeliacs. Gluten-free beers can offer flexibility to a gluten-free diet and can make for the enjoyment of life. As beer is often part of a social life gluten-free beer may help in these situations. In Finland, gluten-free Finnish beers are sold in grocery stores, liquor stores and in many pubs and restaurants. In addition, they are also exported. Good availability of gluten-free products makes gluten-free life easier and more enjoyable.

## 5.3 Rapid Test Kit for the diagnosis of coeliac disease

### 5.3.1 The Rapid Test simplifies the diagnosis of coeliac disease – quick and easy

The Rapid Test Kit detects coeliac disease. It is a Finnish-Hungarian innovation and development. The Test Kit is commercially available and can be used at home and in a doctor's surgery. In Finland Test Kits are sold in pharmacies.

The Rapid Test makes the investigation of coeliac disease quick and easy. It takes only 1-5 minutes to get the result. Only a small amount, a drop, of whole blood is needed from the fingertip. The new method is revolutionary in comparison to traditional laboratory tests. So far blood tests (serum antibody tests) have demanded health professionals, expensive laboratories and 1–3 weeks for analysis. The Rapid Test can be done by anyone, anywhere and in a few minutes, inexpensively. The test is suitable for all, including children below school age.

When a person with coeliac disease has eaten wheat, barley or rye gluten proteins, the test result is positive. The test shows up IgA antibodies associated with coeliac disease after eating toxic gluten. The test result is negative for people who do not have coeliac disease. A positive result requires referral to a doctor who performs a biopsy to confirm the possible coeliac disease diagnosis. A biopsy is always needed to obtain a proper final diagnosis.

The Rapid Test can be used by a doctor also if coeliac disease is suspected. The procedure is very fast and the result is available in minutes.

The Rapid Test hastens the detection of coeliac disease and the correct treatment can thus be started immediately after the biopsy has confirmed the coeliac disease diagnosis. Fast diagnosis and adequate treatment help to avoid inconvenient symptoms and to prevent possible further complications.

A negative test result, however, does not totally exclude the possibility of coeliac disease even if the test is very reliable. The test is comparable to laboratory tests in sensitivity and specificity. If one has an IgA deficiency the test kit is not useful as it shows up only IgA antibodies. A version of the test for doctor's surgeries (for professional use only) includes also total IgA measurement and thus incorrect results can be avoided.

### 5.3.2 The Rapid Test is useful in follow-up

The correct treatment of coeliac disease is a strict gluten-free diet. A negative test result is obtained when a gluten-free diet is followed. This happens approximately 6 months after the gluten-free diet has been started. If the test result is still positive, despite the gluten-free diet, the diet should be carefully checked by a dietician to find possible sources of gluten.

The Rapid Test provides immediate feedback and to be more careful about maintaining his or her diet. Occasional dietary lapses may not be detected by the Rapid Test but a frequent intake of gluten can be.

## 5.4 The Finnish Current Care guidelines

### 5.4.1 Guidelines are used to achieve a high quality and consistency in health care

The Finnish Current Care guidelines are standardised treatment practices. These evidence-based Finnish Current Care guidelines have been available since 1994. The guidelines for coeliac disease was first written in 1997 and afterwards updated twice. The latest update was done in 2005.

The work is organised and managed by the Finnish Medical Society, Duodecim. The development group consists of relevant clinical experts, and always includes a general practitioner, and allied health professionals when appropriate. Based on the evidence and consensus, the development group writes the final guidelines.

Abstracts of many guidelines are available in English. Some of the guidelines will be translated into English and Swedish in the near future.

### 5.4.2 The Current Care guidelines are a model for health professionals in Finland

The model defines what is done by whom and when and why.

In coeliac disease, the target is early diagnosis and the pursuit of consistent practices to treat the disease. The target benefit to treatment is a symptom-free and better quality of life including a recovered gut. Possible malabsorption and complications are attempted to prevent (e.g. bone loss, possible infertility and risk of cancer).

The first step is to diagnose people with typical symptoms and those belonging to risk groups. Tests include laboratory blood tests (transglutaminase antibodies (tTGA), or endomysial antibodies (EMA)). Positive tests indicate possible coeliac disease; however, a negative result does not exclude the possibility of coeliac disease. The final diagnosis is always based on a biopsy both for coeliac disease and for dermatitis herpetiformis (skin disease).

The second step is to provide good care. This includes proper guidance regarding a gluten-free diet. In dermatitis herpetiformis medication can also be used. A dietician will advise on a gluten-free diet. The patient will meet the dietician at least twice: immediately after the diagnosis and 1-6 months later in a follow-up. In practice, in a potentially acute situation after diagnosis, a nurse specialised in coeliac disease may also help in dietary counselling.

The dietician explains the basic facts about coeliac disease and what it means in everyday life. Safe (permitted) and prohibited foods are discussed. Food packages, leaflets, recommended websites and other useful information are used, and information about the Coeliac Society is also given.

In Finland, when a gluten-free diet is started, a wide selection of foods classified as being suitable for coeliacs is included in the diet. This includes all gluten-free foods, foods with a very low gluten content (e.g. wheat starch and other special products that meet the requirements set for gluten-free products) and oats. The oats included in a diet suitable for coeliacs should be processed in the way that gluten contamination of them can definitely be excluded.

The third step is the follow-up about one year after the diagnosis. The aim of the follow-up is to assess how well the gut has recovered and the degree of compliance with the gluten-free diet. If in the follow-up it emerges that the coeliac disease is not properly controlled, the diet is further considered to ensure that it is adequately strict. The follow-up is important for motivational reasons too.

A control biopsy is performed as part of the follow-up, except in the case of dermatitis herpetiformis in which the condition of the skin itself is a good indication. If the gut has healed and the patient's health status is good, the next follow-up is about 2-3 years later. If there are problems with the healing process an appointment with a dietician is booked. The dietician checks the gluten-free diet (including its strictness, food and drinks consumed, motivation, etc.). Adequate advice and supporting material (e.g. leaflets) are given.

In Finland the state financially supports coeliac patients. The role of the Coeliac Society is important in supporting everyday life. The Coeliac Society provides, e.g., information (e.g. magazine, leaflets, websites), courses and education for patients, families, retailers, restaurants, health-care professionals, etc.

## 5.5 Finnish Coeliac Society

### 5.5.1 First-class expertise, activities and co-operation

The primary interest of the Finnish Coeliac Society is to improve the well-being of Finnish coeliac patients in their daily life. The Finnish Coeliac Society has almost 19 000 members (2008) and the number is growing rapidly, approximately 1 400 new members per year. In Finland, diagnosed coeliac patients total about 27 000 (2008). It is estimated, however, that the actual number could be as high as 100 000 (2% of the population).

The Finnish Coeliac Society provides wide services to its members. In addition, the Society actively collaborates with many partners including health-care professionals, researchers, companies, retailers, authorities, etc.

Examples of the activities of the Finnish Coeliac Society:

- Provides a supportive society for people with coeliac disease: regional associations, support person, nutritional advice, etc.
- Organises courses for members, e.g. for recently diagnosed patients and patients who need guidance on how to manage the disease
- Clubs for youngsters and children
- Informs its members and other interested parties on current news in coeliac life
- Publishes the Keliakia magazine (in Finnish), a catalogue of gluten-free products, cookbooks for gluten-free cooking and baking, guidebooks, leaflets, web pages, etc.
- Co-operates with researchers, health professionals, retailers, industry, etc., interested in coeliac disease
- Co-operates with the authorities
- Organises the coeliac fair
- Organises National Coeliac Week and International Coeliac Day
- Rewards The Best Gluten-Free Product of the year
- Grants the Crossed-Grain Symbol
- Provides education for health-care professionals, food companies, retailers, restaurants, etc.

- Maintains a register of coeliac professionals in Finland providing, e.g., special training courses
- Its Scientific Advisory Board provides reports and recommendations concerning coeliac disease
- Is a member of the AOECS (The Association of European Coeliac Societies)

## 5.6 The secret of Finnish success in coeliac disease treatment

In Finland compliance with coeliac disease treatment is high. It is considered that active collaboration over many years between scientists, patients, health-care professionals, industry, retailers, restaurants, authorities and the Finnish Coeliac Society has been the key to success.

Active and innovative work in all sectors enables high-quality care. The result is a better quality gluten-free and symptom-free life.

## 6. SUMMARY

Coeliac disease is a lifelong intolerance to gluten. Gluten is toxic for people with the coeliac condition. The target of the treatment is a normal, symptom-free life.

The harmful gluten is composed of group of proteins present in wheat, barley and rye. These cereals and all products made from them must be carefully avoided. Oats, which have been ensured to contain no contamination with wheat, barley or rye, are usually well tolerated and they can be used as part of the diet suitable for coeliacs if so desired.

In Western countries, about 1% of the population has coeliac disease. It is assumed, however, that the disease is under-diagnosed. Where wheat plays a central role in the daily diet, the disease is common.

Coeliac disease runs in families. Its appearance is due to a complex interplay of "coeliac genes" and gluten. Both must be present for the disease to be activated although not all those with genetic factors related to coeliac disease will have it.

There is no medication for coeliac disease – at least not yet – and the only cure is a gluten-free diet for life. In a gluten-free diet, all gluten is totally excluded and gluten-free alternatives are used. Some people follow a diet that includes only gluten-free cereals (e.g. rice, corn, millet, quinoa, buckwheat) and products made of them. Others also use products that have been specially processed to reduce gluten content to a very low level (e.g. gluten-free wheat starch and gluten-free beer).

In Finland, most coeliacs use in addition to gluten-free products so-called pure oats. Pure oats are 100% oats that have no gluten contamination from wheat, barley or rye. They are usually well tolerated and can be used if so desired. They make a diet more flexible as the number of choices increases. This makes the diet easier to follow.

Fortunately the selection of gluten-free and other suitable products for coeliacs is increasing day by day. In the grocery store, these safe alternatives are usually easily recognised by the international gluten-free symbol, the Crossed Grain Symbol, used on food packages, and by the phrase "gluten-free" or, e.g., "includes oats and gluten-free components" in products made from pure oats.

The inflammation of the gut will occur if a gluten-free diet is not followed. The microscopic fingers in the gut (villi) will be destroyed, the internal surface of the gut becomes flat (villous atrophy) and the absorption area is dramatically reduced. The common symptoms are diarrhoea, bloating, flatulence and vomiting. Other symptoms are fatigue due to anaemia and bone loss (osteoporosis). These are usually due to malabsorption of nutrients and therefore nutrient deficiency (e.g. iron, calcium). It is also possible that no "visible" symptoms occur (clinically silent). If nothing is done, the complications will get more and more severe; at its worst the disease may be life threatening.

The final diagnosis is always based on a biopsy (a little piece of the gut is removed and examined in a laboratory). When coeliac disease is being investigated a blood test often speeds up the correct diagnosis.

A dietician counsels the coeliac patient on how to follow a gluten-free diet. The nutritional quality of a gluten-free diet should be the same as that of a regular diet. The daily food recommendations are the same too. No nutritional supplementation is needed when the condition is under control. The Finnish Coeliac Society also gives considerable help and guidance on how to cope in everyday life.

In Finland compliance with coeliac disease treatment is high. The reason for the great success in managing the disease may be explained by the active collaboration between scientists, patients, health-care professionals, industry, retailers, restaurants, and the Finnish Coeliac Society among others. In addition, there are standardised treatment practices in use (the Finnish Current Care guidelines).

At first, life with coeliac disease may feel restrictive and cumbersome. Later on the condition becomes part of one's normal life. Life with coeliac disease may be as enjoyable, tasty and high in quality as that of anybody else's. It is basically a matter of choosing a new, gluten-free lifestyle.

## 7. MORE INFORMATION

### Web sites

<http://www.aoecs.org>

[http://www.codexalimentarius.net/web/standard\\_list.jsp](http://www.codexalimentarius.net/web/standard_list.jsp) (The list of Codex standards)

<http://www.coeliac.ie/coeliacdisease.htm>

<http://www.coeliac.uk>

<http://www.coeliaki.dk>

<http://www.eatwell.gov.uk/healthissues/foodintolerance/foodintolerancetypes/coeliacdisease/>

<http://www.keliakialiitto.fi>

<http://www.keliakialiitto.fi/pdf/Tuoteluettelo07.pdf> (catalogue of products suitable for coeliacs on the Finnish market published by the Finnish Coeliac Society, in Finnish)

<http://www.kaypahoito.fi/>

<http://www.kaypahoito.fi/kh/kaypahoito?suositus=hoi08001> (The Finnish Current Care guidelines, in Finnish)

<http://www.ncf.no/>

<http://www.scuf.se/>

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# APPENDIX I: MEDICAL VIEW OF COELIAC DISEASE

## What is coeliac disease?

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## Introduction

Coeliac disease is an autoimmune condition where the ingestion of cereal prolamins gluten in wheat, rye and barley results in small-intestinal mucosal damage in genetically susceptible individuals. Its diagnosis is based on small-bowel mucosal inflammation and villous atrophy: the finger-like villi become shorter (partial villous atrophy) and broader, and in advanced cases of the disease the villi are absent (subtotal/total villous atrophy). In overt cases the detection of the condition is easy, but in borderline cases diagnostic difficulties are evident.

The mucosal lesions recover once the patient switches to a gluten-free diet where the harmful cereals are withdrawn. The diet must, however, be strict and lifelong, since the lesions recur on the reintroduction of gluten.

Coeliac disease appears also outside the gut. The best-known extra-intestinal manifestation is dermatitis herpetiformis which is an itching blistering skin disease. The intestinal damage tends to be milder in dermatitis herpetiformis than in the classic coeliac disease, and villous atrophy is demonstrable in two-thirds of the patients; mucosal inflammation is present in virtually all patients, however.

Aphthous stomatitis (painful erosions in the mouth), dental enamel defects of permanent teeth; osteoporosis, liver involvement, brain atrophy and joint inflammation are some other manifestations appearing outside the gut.

In some, fortunately rare, cases coeliac disease is problematic to treat (refractory coeliac disease). Despite a strict gluten-free diet, the intestinal lesions do not heal. In these patients, the risk of small-intestinal lymphoma is increased.

Coeliac disease is much more common than previously thought. At least 1% of the population has the disease. The number of detected cases is much lower throughout the world. One apparent reason is that some patients often suffer from subtle if any symptoms. Serological antibody tests offer a powerful tool for improving the diagnostics.

## Coeliac disease and gluten intolerance

### Definition

The diagnosis of coeliac disease is based on small-intestinal mucosal inflammation, villous atrophy, and elongation of the mucosal 'pits' (crypts). The mucosal biopsy specimens are nowadays taken usually by endoscopy (gastroscopy). The confirmation of the diagnosis requires that the symptoms are healed by treatment, and in symptom-free patients, the healing of the mucosa

should be demonstrated. A common practice is to always perform a second biopsy when the patients have adhered to a gluten-free diet for, for instance, one year. In this way it can be ensured that the diet of the respective patient is adequate and there are no signs of refractory coeliac disease.

The diagnosis of dermatitis herpetiformis is based on a biopsy performed on skin taken from an area outside the blisters. The demonstration of the so-called IgA deposits by immunofluorescence staining is diagnostic. The eruptions arising from dermatitis herpetiformis are also gluten sensitive, the clearance of the rash is slower than the healing of an intestinal lesion. Similarly, the IgA deposits disappear slowly on a gluten free diet, but a follow-up skin biopsy is not required here.

## Gluten

It is generally agreed that the prolamins in wheat (gliadin), barley (hordein) and rye (secalin) are harmful for coeliac disease patients. These prolamins contain peptide sequences that are considered to be the toxic fragments. Oat prolamins, avenin, proved to have no detrimental effect on small-intestinal mucosa: the majority of both patients in remission and newly detected disease can use oats as a part of their otherwise gluten-free diet.

A unanimous view is that gluten-free dieting should be as strict as possible. However, a diet completely devoid of gluten would be difficult if not impossible to maintain. The products on the market are either naturally gluten-free or are rendered gluten-free. Wheat-starch-derived gluten-free products may, after purification, still contain trace amounts of gluten. They have been allowed for decades for coeliac disease patients in Northern Europe and the United Kingdom, and complete intestinal mucosal recovery has been evident both in children and adults. Dietary compliance has also been good and the rates of coeliac complications such as malignancy development are low in patients adhering to such a diet. Of note is the fact that even naturally gluten-free products are not necessarily free of gluten contamination. There has been a debate on the safe amount of daily ingestion of contaminated gluten; it seems that 20-50 mg of gluten is well tolerated by most coeliac patients. Nevertheless, good compliance is more important in the management of coeliac disease than tiny amounts of contaminated gluten.

## Cause of the disease

Both coeliac disease and dermatitis herpetiformis are associated with HLA DQ2 (90% of patients) and DQ8 (almost 10%) in chromosome 6; individuals negative for both HLA DQ2 and DQ8 are unlikely to suffer from these diseases. Coeliac disease and dermatitis herpetiformis may occur in the same families, and even identical twins may have a different clinical manifestation. As many as 15% of first-degree relatives of coeliac disease (and dermatitis herpetiformis) patients suffer from undetected coeliac disease.

HLA DQ2 or DQ8 are present in 25-30% of the Finnish population. Thus, only a minority of individuals with this genetic involvement develop coeliac disease. There has been an extensive search for additional genes that might predispose an individual to coeliac disease. Despite promising results, the contribution of other loci outside HLA DQ has not been yet identified. Apart from dietary gluten, no environmental factors have been clearly shown to be involved in the aetiology of coeliac disease. Against this background it is intriguing that, as in type I diabetes, coeliac disease is much less common in Northern Karelia in Russia than on this side of the border. Hygienic factors may be implicated here. Some studies have shown an inverse relationship between cigarette smoking and coeliac disease, but the issue is still controversial.

## Symptoms

Coeliac disease should always be considered in patients suffering from a deficiency of iron, folic acid, calcium or any nutrients. Steatorrhoea (fatty diarrhoea) is nowadays relatively uncommon. Whilst coeliac disease is a common disorder, it should be suspected even when the symptoms are mild; otherwise the level of diagnosis of the disease remains low.

Atypical symptoms and symptoms occurring outside the gut are not uncommon. In addition, there are many conditions where the risk of coeliac disease is four to five times higher than in the population in general. Symptoms and associated disorders are summarised in Table 1 a-d.

### **Table 1a Classic symptoms of coeliac disease**

- Steatorrhoea
- Growth retardation, failure to thrive
- Anaemia due to iron or folic acid deficiency
- Muscle wasting, reduced bone mineral density

### **Table 1b Intestinal symptoms where coeliac disease should be considered**

- Loose stools, occasional diarrhoea
- Flatulence, abdominal distension
- Secondary lactose intolerance, which alleviates on gluten-free diet

### **Table 1c. Extra-intestinal manifestations of coeliac disease**

- Dermatitis herpetiformis
- Dental enamel defects of permanent teeth
- Aphthous stomatitis
- Nervous system involvement
  - Ataxia (non-alcoholic)
  - Polyneuropathy
  - Brain atrophy and dementia
- Psychic symptoms
  - Depression
- Liver diseases
  - Elevated liver enzymes
- Gynaecologic problems
  - Infertility
  - Recurrent spontaneous abortion
  - Delay of puberty

### **Table 1d Associated disorders reported to occur concomitantly with coeliac disease**

- Family history of coeliac disease
- Type I diabetes
- Thyroid diseases
- Sjögren's syndrome
- Down's syndrome

## How to detect coeliac disease

The symptoms of coeliac disease are diverse, and many, if not most patients, remain symptom-free. Serological tests offer a good method for screening and identifying cases of the disease. The conventional gliadin antibody test has been replaced by more effective tests. IgA class endomysium antibodies offer a high specificity (almost 100%) for coeliac disease; in other words false-positive results are highly uncommon. The sensitivity (=how many cases the test will pick up) of the test is 86-100%. The tissue transglutaminase antibody test offers a sensitivity and specificity of 95-99%; it has replaced the endomysial antibody test in many places, because it is easier to perform. Equal percentages have been achieved by new gliadin antibody tests, where deamidated gliadin peptides are used as a substrate; we will see in the future whether this test will replace endomysial and tissue transglutaminase antibody tests.

When a serologic test turns out to be positive, the diagnosis must always be confirmed by a small-intestinal mucosal biopsy. However, the high specificity of these tests means that one should be careful in case of a 'false'-positive test: these may occur, but it should be ensured that the quality of biopsy samples is adequate. Moreover, some false-positive cases may develop coeliac disease in time. The definition of latent coeliac disease comprises normal mucosal villous architecture and a subsequent development of villous atrophy when gluten ingestion is continued. It has been seen that some patients may suffer from gluten-dependent symptoms even before the manifest mucosal lesion has developed. The diagnostics of these patients should be made in specialised clinics.

It must be remembered that some coeliac disease patients remain negative for antibody tests, and a small-bowel biopsy is indicated in seronegative cases when suspicion of the disease is high. Screening the whole population is still debatable, and more studies, especially cost-benefit analyses are warranted. An alternative approach is to concentrate on risk groups of coeliac disease. A high index of suspicion and recognition of risk groups (Table 1) of coeliac disease are the essential elements. The liberal use of serological tests is essential in this context.

## Occurrence

Serological screening studies have shown that the frequency of coeliac disease in Western countries is roughly 1%. In many countries, only one of 10-15 coeliac disease patients will be detected. In Finland the detection rate is relatively high: 0.5% of the population has a diagnosis of coeliac disease – in some regions 0.7%. Fifteen per cent of these have dermatitis herpetiformis. Two-thirds are female, but in dermatitis herpetiformis there is a slight male predominance. Coeliac disease may appear at any age after the start of gluten ingestion, the peak incidence is in young adulthood, but the variation is high. Dermatitis herpetiformis is uncommon in childhood.

The frequency of malignant lymphoma is less than previously thought, but clearly higher than in the population in general. According to the literature, 2.10% of coeliac disease patients develop small-intestinal lymphoma, which is in general a very rare malignancy. At risk are coeliac patients who do not adhere to a gluten-free diet, and those whose diagnosis is made at an advanced age after a long diagnostic delay. An early diagnosis and good dietary compliance are essential for the prevention of lymphoma.

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