

Date:

Bern, july 2010

"Coeliac disease and nutrition in Switzerland – an assessment"

Summary and synthesis of the Federal Commission for Nutrition's (FCN) expert report

1. Introduction

Coeliac disease is a chronic inflammation of the small intestine caused by the immune system in cases of genetic susceptibility. The genetic factors are crucial. There is a familial predisposition for coeliac disease and an 85 percent concordance in identical twins. The condition is triggered by gluten, which is contained in the grain types wheat, rye and barley.

Coeliac disease may manifest itself at any age, and its clinical presentation may vary considerably, particularly during adolescence and adulthood – a fact which often complicates and delays diagnosis. Persons affected with coeliac disease may exhibit intestinal as well as extraintestinal symptoms.

Data from large-scale screening studies have revealed that a majority of coeliac disease patients are oligo-, mono- or even asymptomatic (silent).

Studies report a prevalence of about 1 percent in many European countries and the United States. Of particular note is the fact that coeliac disease may be associated with various other conditions, such as type 1 diabetes mellitus, other autoimmune disorders or Down syndrome.

2. Diagnosis

The diagnosis can be presumed based on classic symptoms and the serological proof of serum antibodies against tissue transglutaminase, endomysium and gliadin. In accordance with existing diagnostic recommendations, a positive antibody test still requires corroboration through a biopsy of the small intestinal mucosa.

It is an important principle in everyday clinical practice to even consider the possibility of coeliac disease and to include the condition in the differential diagnostic considerations. This applies to various medical specialities.

3. Treatment

Treatment of coeliac disease consists of a lifelong gluten-free diet, which represents a substantial challenge for those affected. Patients face a variety of issues in everyday life that make keeping a

Further information:

gluten-free diet difficult. Those issues include, amongst other things, a limited food selection, the lower nutritional value and the special flavour of gluten-free speciality products, not to mention the higher cost of gluten-free food and the limitations in terms of eating out.

Strict adherence to a gluten-free diet is not easy. In addition to accidental dietary errors due to a lack of declaration or false information, coeliac disease patients may intentionally risk errors, e.g. if they don't want to attract attention at social events, if no gluten-free products are available or if the products are too expensive.

Ensuring a quantitatively and qualitatively optimised diet is a daily challenge for coeliac disease patients. The carbohydrate intake tends to be lower than recommended and is compensated energetically through an increased proportion of fat. The generally low share of dietary fibre and the risk of micronutrient deficiencies are also noteworthy. Deficiency symptoms (e.g. iron deficiency) must be actively sought out and, where appropriate, treated in therapeutic doses or supplemented individually for the long term.

4. Food law

A certain level of expertise in food law is a central prerequisite for the implementation of a glutenfree diet. Labelling of allergenic ingredients is mandatory in Switzerland as well as in all EU countries. Grains containing gluten and products derived from them must be declared. The list of ingredients on the packaging will, therefore, indicate whether the recipe for the manufacture of a product included ingredients containing gluten. Additionally, Switzerland – unlike the EU – mandates labelling for accidental mixtures. A corresponding notice (e.g. "May contain gluten") does not release the manufacturer from the obligation to take all necessary measures mandated by good manufacturing practice to minimise the accidental mixing of ingredients containing gluten. Affected persons have to be aware that in many enterprises accidental mixtures are difficult to avoid and that not even the best laws and ordinances can guarantee complete accuracy regarding the absence of gluten.

A solid knowledge of food law, imparted practically during basic training as well as continuing and advanced technical education, is fundamental for all professionals involved in treatment and care.

5. Long-term care

Based on our medical standards, treatment and care of this chronic condition must be provided by experts familiar with the condition who have gained sufficient experience (number of cases) in everyday practice. For the purposes of the bio-psycho-socio-therapeutic approach, care and treatment shall be conducted multi-professionally. In addition to medical and nutritional counselling, in special cases this approach also includes qualified personnel that are trained in psychology and competent in social counselling.

Further information:

Federal Office of Public Health, Consumer Protection Directorate, Food Safety Division, phone +41 31 322 95 86, Lebensmittelsicherheit@bag.admin.ch "Coeliac disease and nutrition in Switzerland – an assessment" Summary and synthesis of the Federal Commission for Nutrition's (FCN) expert report This factsheet is also available in French, German and Italian. Bern, july 2010

6. Patient organisations

Furthermore, all persons affected by coeliac disease should take advantage of patient organisations such as the IG Zöliakie (Coeliac Disease Syndicates) in various parts of Switzerland. The IG Zöliakie provide valuable advice and information on specialists in their respective regions. They work with food manufacturers, restaurateurs and insurance underwriter such as those of the Federal Invalidity Insurance (IV) or the health insurance companies. They provide assistance and support with financial (e.g. taxes) or social (e.g. military) issues.

7. Research, basic training, continuing and advanced education

Even though coeliac disease is a very well-studied condition and substantial knowledge about its pathogenesis and pathophysiology exists, there is still a significant research deficit – even in Switzerland – regarding epidemiology and treatment quality. In this context, the IG Zöliakie supported the Switzerland-wide "Task Force Epidemiology of Chronic Diseases", which promoted the creation of a corresponding national research programme. Unfortunately, in 2010 this proposed research topic was not declared a federal research priority. There nevertheless remains a need for action, and the authorities in charge of health policy are called upon to support (also financially) research initiatives on these issues.