

JUST GO – GLUTEN-FREE ABROAD

Information Guide for organizations

You are confronted with a youngster having coeliac disease and don't know anything about coeliacs and you need help? In this guide you will find information about coeliac disease, the gluten-free diet and how to cope with it.

WHAT IS COELIAC YOUTH OF EUROPE?

Coeliac Youth of Europe (CYE) is an umbrella organization of European coeliac youth groups and works within the Association of European Coeliac Societies (AOECS).

CYE was founded in 1995. CYE representatives meet in the annual CYE conference according to the rules & regulations. A Youth Committee, consisting of three persons (General Coordinator, Project Manager, Financial Manager), is leading the CYE. They are elected for a two-year term.

CYE is an international forum for raising awareness, exchanging knowledge and working together to improve life conditions for young coeliacs.

WHAT IS COELIAC DISEASE?

Coeliac disease (pronounced see-liac) is not an allergy or a food intolerance. In fact, it's an autoimmune disease, a small bowel disorder caused by proteins in the cereals wheat, rye, barley, and spelt. These proteins are called "gluten". Because of some genetic factors, the small bowel of a coeliac does not tolerate gluten, upon which an immunological inflammation occurs, damaging the villi in the small bowel. Due to the damaged villi, the bowel of a coeliac patient cannot utilize nutrients normally. This may lead to a wide variety of symptoms or signs of malabsorption.

The only treatment in coeliac disease is a gluten-free diet, where wheat, rye and barley are strictly excluded. The gluten-free oats (oats, which have been produced without gluten contamination) can be included in a gluten-free diet. When a coeliac starts the gluten-free diet, the small bowel villi recover fast, and the function of the bowel and the utilisation of nutrients normalise. This does not mean, however, that coeliac disease is cured. To avoid symptoms a coeliac needs a life-long, strict gluten-free diet. Thus the condition of the small bowel remains normal.

WHAT COELIACS CAN EAT

Coeliacs can eat for example the following products: rice, corn, potatoes, buckwheat, fruits, vegetables, meat, milk products and so on.

WHAT COELIACS CANNOT EAT

Coeliacs cannot eat anything with wheat, barley, rye and spelt. For example normal bread, pasta and pizza all have gluten. Gluten can also be hidden in many products which you wouldn't believe to contain gluten; for example chocolate and candies, soups, chips, sauces and juice or even teeth pasta.

A certain notion is needed to avoid the cross-contamination, the mixing of the gluten containing products and gluten-free products; a coeliac needs his own butter, toaster, cutting boards and so on.

SUBSTITUTIVE GLUTEN-FREE PRODUCTS

It's possible to find gluten-free substitutes for all kinds of products, which normally contain gluten. There are all kinds of bread, biscuits, cakes and pasta, ice cream waffels, croissants, chocolate bars, soups, beer, hamburgers, cereals, corn flakes, muesli, chips, gluten-free flour, cakes, pizza, lasagna, soy and worcester sauces.

WHAT HAPPENS IMMEDIATELY IF THE COELIAC DESPITE ALL THE PRECAUTIONS EATS GLUTEN?

The usual symptoms are for example swelling, stomach ache and diarrhoea. Usually the symptoms ease in a few hours to in a day depending on the person, the amount of gluten eaten, etc. But it's not just the stomach ache: the most harmful effect of gluten cannot be seen, as it damages the villi in the small bowel.

WHY IT MIGHT BE CHALLENGING TO GO ABROAD AS A YOUNG COELIAC?

Coeliacs' everyday life, conducting the gluten-free diet, is usually easy at home. It's not a problem to find gluten-free products or to ensure the safety of the food when cooking yourself. In the local restaurant the waitress or the kitchen staff at school might know the coeliac youngster and the gluten-free diet already very well.

Every day life of a coeliac youngster includes a lot of checking and double-checking: for example reading the ingredients lists of the products in the supermarket and asking the waitress in the restaurant "what is this course made of, does it contain gluten?".

If the coeliac youngster has just got diagnosed, he doesn't have a lot of travelling experience as a coeliac. After diagnose coeliacs get used to coping with the diet at home and learn how to find information. However, the insecurity and doubts "How will I survive there with my gluten-free diet?" might hinder a coeliac going abroad.

When travelling or moving to another country, the coeliac youngster does need to get to know the "gluten-free surroundings". The information coeliac needs, is for example

- where to find gluten-free products,
- what is "coeliac", "gluten", "wheat", "barley" etc. in the local language, to be able to pick the safe products in the supermarkets and to explain the diet to new friends and in restaurants

HOW TO PREPARE THE YOUNG COELIAC FOR GOING ABROAD?

How is it to live as a coeliac in another country?

That varies a lot; gluten-free living might be easier as at home, or it might require more effort. There are coeliacs everywhere in the world. In some countries coeliac condition is better known and gluten-free products are easier to get. How well known coeliac disease is and how easy it is to find gluten-free products, varies from country to country.

Where to find information:

There is a lot of information available concerning the coeliac life in other countries, and preplanning is useful. Where do I find gluten-free products in Germany? Information is available in the Internet! How to explain coeliac disease and gluten-free in Spanish? There are ready translations available!

- Check the Coeliac Youth of Europe website www.cyeweb.eu.
- Travel Net: information about gluten-free living in European countries, for example:
- how get gluten-free hamburgers in Finland?
- know your rights in Italy; according to the law all state owned universities have to serve gluten-free meals
- how to explain coeliac disease in Swedish?
- search for a local contact person in the destination country?

Check "Links" at www.cyeweb.eu to the national coeliac associations all over the world. There is a national coeliac association in almost every European country and in many other countries as well. Check their website, send an email and ask the questions which you wondering about. The local people know the gluten-free surroundings the best.

If there's an organization to receive the youngster in the destination country?

It's worth informing the organization in beforehand, so they are able to prepare gluten-free food for the coeliac youngster. If there will be a host family, they are in need of diet information. The coeliac himself is a good information source, but the local coeliac organizations offer usually a lot of information.

HOW COELIACS SHOULD NOT BE HANDLED?



Coeliac must not prevent a youngster going abroad!

Tina is now 20 years old and had coeliac disease for 6 years. When she was 16 years old, she wanted to attend a language course in Scotland. She contacted a language course organizer, who told her, that they once had a coeliac participating in the language course, but it was not that easy to conduct the gluten-free diet there and they didn't recommend the course for her. Tina had no traveling experience abroad as a coeliac as she had been just diagnosed, so she didn't participate at all. She remembers how she was crying when she realized the coeliac disease would stop her doing the normal things in life.

WHAT KIND OF AN ATTITUDE WE RECOMMEND FOR THE ORGANIZATIONS?

There are coeliacs everywhere in the world. It's true, in some places it's more difficult to cope with the diet than in some others, there are not that many gluten-free products available and coeliac disease is not well known. But there are always naturally gluten-free ingredients available, there's always something to eat. It's easy to take bread, biscuits and pasta with when traveling; the internet stores selling gluten-free products are within reach also abroad.

The decision whether to go or not, depends on the coeliac youngster himself. Encourage him to find out information about the local gluten-free conditions and let him decide, whether he is able to cope with the diet in new circumstances.

Try to encourage the spirit of "Just go!" – don't over think it, you will survive!

HOW AN ACTIVE COELIAC GETS THE MOST OUT OF PERIOD ABROAD?



Libertad came from Catalonia, Spain to do her Erasmus exchange studies in Finland. She visited the website of the Catalan coeliac youth group and found a link to the CYE Facebook group. There she found a local contact person, Mira, and with her help she got to know the local gluten-free surroundings very well.

Through Mira, she also got to know another young coeliac, Riina.

"I could eat chocolate for the first time since I was diagnosed (for 6 months). Because Mira told me what chocolate I was able to eat!"

"I consider myself very lucky for having the possibility of meeting and spending time with two Finnish people. For me, before coming to Finland being gluten-free was a handicap because I thought I would have many problems finding things, etc. But finally it has become an advantage because I've met the Finnish culture in a way that my Erasmus friends haven't had the possibility to experience."

Mira, Libertad, Riina (from left to right on the picture)

CONTACT DETAILS FOR FEEDBACK

In case you have any further questions, please don't hesitate to contact the local societies or check our website www.cyeweb.eu or send an email to cye.board@gmail.com. Any kind of feedback is appreciated!