

# TEMPLATE

## Output factsheet: Tools

Version 1

<b>Project index number and acronym</b>	CE111 Focus IN CD
<b>Lead partner</b>	Municipality of Maribor
<b>Output number and title</b>	O.T2.1 E-learning tool for HCPs
<b>Responsible partner (PP name and number)</b>	Ludwig-Maximilian's University Medical Center KUM (PP8)
<b>Project website</b>	<a href="http://www.interreg-central.eu/Content.Node/Focus-IN-CD.html">http://www.interreg-central.eu/Content.Node/Focus-IN-CD.html</a>
<b>Delivery date</b>	5/2019

**Summary description of the key features of the tool (developed and/or implemented)**

## **Background of Celiac Disease**

Celiac disease (CD) is one of the most common lifelong autoimmune disorders which mostly develops in early childhood but may also be diagnosed in adults. The overall prevalence reaches 1% in the general European population. However, only 10 to 20% of affected individuals are actually being diagnosed.

The autoimmune reaction is triggered in genetically susceptible people by the protein gluten which is present in wheat, rye, barley and their hybrids, leading to an inflammatory reaction which mainly occurs in the small bowel, but can also affect other organ systems. Consequently, CD may present with a variety of symptoms not only restricted to the gastrointestinal tract. Still the only but very efficient treatment is to keep a strict lifelong gluten-free diet. This usually resolves or at least substantially improves the symptoms and also reduces the risk for long-term health consequences. However, the strict diet has an impact on the patients' daily and social life, the eating habits and the overall quality of life.

Early detection of CD patients can prevent many negative manifestations of the disease and reduce costs in the health care system. When following the available evidence-based guidelines, the diagnosis is usually straight forward. However, many physicians have an insufficient knowledge about celiac disease, its huge variety of symptoms and the risk groups which makes case-finding difficult. Furthermore, both false-negative and false-positive diagnoses are frequent as physicians are not aware of the updated guidelines and the potential pitfalls in the diagnostic process. In addition, dietitians are often not specialised in the gluten-free diet, although they have an important function in giving a reliable and comprehensive dietary counselling and advice to the patients, considering the patient's individual situation.

### **Rational and Key Features for Output D.T2.1**

To improve the knowledge about CD, an e-learning (online course) for Health Care Professionals (HCPs, mainly physicians and dietitians) has been developed within the Focus IN CD project. The e-learning is mainly based on previously available evidence-based literature and we have also made the effort to update the content according to the most updated guidelines of the European Society of Pediatric Gastroenterology, Hepatology & Nutrition (ESPGHAN) to diagnose celiac disease in children which are being published in May /June 2019. However, as four of the project partners were involved in the guideline group we were able to already include the final version. The content was mainly developed and written by the expert physicians and scientific writers within the project partnership, reviewed and revised by all project partners as well as by external reviewers (physicians with expertise in celiac disease). Stakeholders as the German Celiac Disease Society (DZG) gave valuable input. The course was tested by physicians and dietitians with basic or no experience with celiac disease.

The e-learning consists of 2 Units, each offering a self-assessment and several lessons including interactive elements as "image hotspots", for example to explore the variety of symptoms of celiac disease. Users can access the course without need to register.

### **Summary of Results of Analyses Report of Usefulness (Evaluation)**

In our evaluation of the e-learning for HCPs we did not only find a very high user satisfaction with an average of 8.6 (on a scale from 1 to 10), but also could show significant knowledge gains. This means the improvement of knowledge about celiac disease among HCPs who have been using this e-learning will also be beneficial for the patient management and care in Central Europe and likely will reduce costs for unnecessary expenses related to celiac disease in the health care system.

**NUTS region(s) where the tool has been developed and/or implemented (relevant NUTS level)**

HCPs from different institutions and regions were and are being reached via several channels and media: advertisement in newsletters or on websites of medical societies, advertisement of medical and patient societies, presentations at conferences and via personal contact at meetings and seminars.

List of regions reached is as follows:

**DE11** Stuttgart  
**DE12** Karlsruhe  
**DE13** Freiburg  
**DE14** Tübingen  
**DE21** Oberbayern  
**DE22** Niederbayern  
**DE23** Oberpfalz  
**DE24** Oberfranken  
**DE25** Mittelfranken  
**DE26** Unterfranken  
**DE27** Schwaben  
**DE30** Berlin  
**DE40** Brandenburg  
**DE80** Mecklenburg-Vorpommern  
**DED2** Dresden  
**DED4** Chemnitz  
**DED5** Leipzig  
**DEE0** Sachsen-Anhalt  
**DEG0** Thüringen  
**HU10** Közép-Magyarország  
**HU21** Közép-Dunántúl  
**HU22** Nyugat-Dunántúl  
**HU23** Dél-Dunántúl  
**HU31** Észak-Magyarország  
**HU32** Észak-Alföld  
**HU33** Dél-Alföld  
**HR03** Jadranska Hrvatska  
**HR04** Kontinentalna Hrvatska  
**ITC1** Piemonte  
**ITC2** Valle d'Aosta/Vallée d'Aoste  
**ITC3** Liguria  
**ITC4** Lombardia  
**ITH1** Provincia Autonoma Bolzano/Bozen  
**ITH2** Provincia Autonoma Trento  
**ITH3** Veneto  
**ITH4** Friuli-Venezia Giulia  
**ITH5** Emilia-Romagna  
**SI03** Vzhodna Slovenija  
**SI04** Zahodna Slovenija

## Expected impact and benefits of the tool for the concerned territories and target groups

With the now available e-learning for HCPs, we expect that the knowledge about CD will substantially improve among the users. As we had already before and during the project established a huge network within the pediatric, gastroenterology and celiac community, we have and still can take advantage of it to disseminate and advertise the online course in order to reach a high number of participants in the target group. Dissemination will even be further pushed after at the end of the project in parallel to the publication of the new ESPGHAN guidelines (June 2019), which is already awaited in the community.

Consequently, HCPs who are well educated in CD due to participation in our e-learning will be able to correctly identify, diagnose and treat the patients. This will reduce the number of false positive and false negative diagnoses decrease the previously unacceptable diagnostic delay and the overall management of patients with CD. The risk for long-term health consequences - usually caused by long diagnostic delays or insufficient treatment and monitoring of the patients - will be reduced. When HCPs are aware about the psychosocial aspects of the strict gluten-free diet, they will also have more understanding and likely give more support to affected patients, making it easier for them to communicate with their HCPs.

Overall, the e-learning for HCPs will not only improve the overall management of celiac disease patients and therefore their well-being and health but also decrease the costs in the health-care system, which are often wasted as patients do not receive the correct diagnosis or suffer from long-term health consequences of undiagnosed CD.

## Sustainability of the tool and its transferability to other territories and stakeholders

Already during the project duration, many stakeholders as the Association of European Coeliac Societies (AOECS) and other national CD societies as the German Celiac Disease Society (Deutsche Zöliakie-Gesellschaft e.V. DZG) have shown interest to contribute to the continuation of this output.

Furthermore, medical societies can be involved to further finance the running costs and potential updates and improvements in the future.

Moreover, celiac experts and societies outside the Central European region, for example member of the ESPGHAN Celiac Disease Interest group are considering to collaborate with us to implement the HCP course in their own language (e.g. into Spanish). This will of course substantially increase the target groups we can reach with this tool.

When the new ESPGHAN guidelines will have been published (approximately June 2019), we will also accredit the course for European educational credits points 8 (EACCME) which will make it even more attractive for stakeholder as the very well established ESPGHAN and the United European Gastroenterology (UEG) association.

Lessons learned from the development/implementation process of the tool and added value of transnational cooperation

1) The development of the contents of the HCP course was initially done by a subgroup of celiac experts within the project's partnership as we had learned from the e-learning for patients that this allows a more efficient writing and harmonisation. However, it was extremely important to involve all project partners with different backgrounds and expertises to review and adapt the contents and get their input which was also related to some country-specific requirements. This input was very valuable and important to consider for the finalization of the e-learning as it should be feasible for use in all countries.

**Lesson:** The collaboration among the project partners from the different countries was extremely important to further improve the e-learning and shape it according to allow its use in different health-care systems of all involved partners and maybe even beyond.

2) As four of the Focus IN CD project partners were involved in the ESPGHAN guideline group to update the existing evidence-based guidelines (Husby et al 2012), we aimed of course to build our e-learning on this new knowledge. The guideline group consists of 18 experts in the field of pediatric celiac disease from Europe. All members of the group volunteered to fulfil this task to the best of their knowledge and efforts, without being paid. Although the group was working hard, lots of discussions and re-investigations, revisions of the manuscript and further literature research lead to a substantial delay. The initially scheduled date for the publication of these guidelines was actually October 2017, but although the project partners being members in the group tried to push the progress, the guideline will finally be published only in June 2019. Nevertheless, as four project partners were members of the group, the content of the e-learning had already been developed according to what was clear earlier, but the final content (confirmed by voting) was only available by end of March 2019. The existing e-learning content was therefore updated were needed and the output needed to be finalized short-termed.

**Lesson:** Dependence of external outputs which are not in the hands of project partners but which are important for the quality and timeliness of the project output is detrimental for the finalization according to the given framework of the project. However, in our case it was worth to wait as an e-learning based on old guidelines would not be attractive.

3) The e-learning was initially implemented on the Moodle e-learning platform of the Early Nutrition eAcademy (ENeA), which had already been established many years ago by the project partner Child Health Foundation. As the platform was almost free to use and hosted by the public university-related data processing center (Leibniz-Rechenzentrum LRZ, Munich), it seemed to be a good choice and sustainable due to very low running costs. However, it became evident that an e-learning Platform which is specialised on Early Nutrition, mainly addressed to experts working in this field is not the perfect setting. Furthermore, there were structural limitations on the platform e.g. not allowing us to develop our own corporate identity or improve the navigation et cetera. Unfortunately the LRZ did not allow us to establish an own additional platform for our Focus IN CD project and the e-learning due to license issues.

In addition, the technical support to solve any technical problems (e.g. which arised e.g. when using the H5P-Plugin to include interactive elements) was not given. Finally at a late stage of the project we decided to move our e-learning to a new platform, which now provides much more possibilities and will finally allow a sustainable future of our e-learning.

*Lesson: Many web tools are available, and expert analysis of their functionality by IT personnel is important in selecting appropriate tool for defined purpose.*

References to relevant deliverables and web-links  
If applicable, pictures or images to be provided as annex

This output is related to deliverables D.T2.1.1 and D.T2.1.2

The e-learning (online course) for HCPs can be accessed via the following domains:

[www.celiacfacts.eu](http://www.celiacfacts.eu) (Englisch)

[www.zoeliakie-verstehen.de](http://www.zoeliakie-verstehen.de) (German)

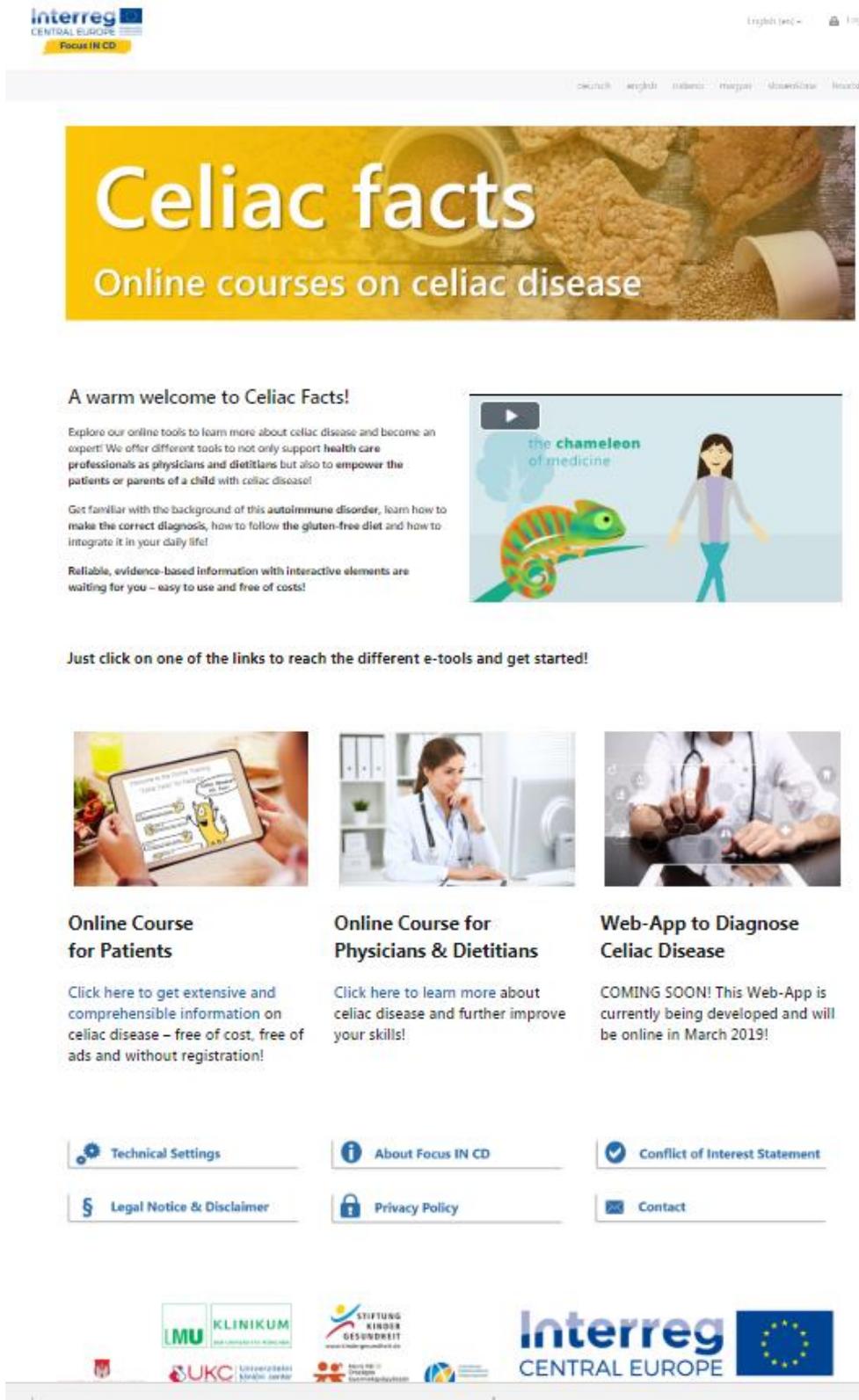
[www.poznam-celiakijo.com](http://www.poznam-celiakijo.com) (Slovenian)

[www.coeliakia.info](http://www.coeliakia.info) (Hungarian)

[www.sveocelijakiji.hr](http://www.sveocelijakiji.hr)

[www.celiachia-info.it](http://www.celiachia-info.it) (Italian)

Annex: Screenshots - Examples from the e-learning for HCPs



The screenshot shows the 'Celiac facts' website. At the top left is the Interreg Central Europe logo with the text 'Focus IN CD'. At the top right, there is a language selector set to 'English (en)' and a user profile icon. Below the header is a navigation bar with links for 'czech', 'english', 'italian', 'magyar', 'slovenčina', and 'hrvatski'. The main banner features the title 'Celiac facts' and the subtitle 'Online courses on celiac disease' over a background image of bread and a bowl of flour. Below the banner, there is a section titled 'A warm welcome to Celiac Facts!' with introductory text and a video player showing a woman and a chameleon. Further down, there is a call to action: 'Just click on one of the links to reach the different e-tools and get started!'. Three main content cards are displayed: 'Online Course for Patients', 'Online Course for Physicians & Dietitians', and 'Web-App to Diagnose Celiac Disease'. At the bottom, there is a footer with navigation links: 'Technical Settings', 'About Focus IN CD', 'Conflict of Interest Statement', 'Legal Notice & Disclaimer', 'Privacy Policy', and 'Contact'. The footer also contains logos for partner institutions: LMU Klinikum, Stiftung Kinder Gesundheit, and others, along with the Interreg Central Europe logo and the European Union flag.



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## Online Course "Celiac Facts" for Physicians & Dietitians

Introduction

**Unit 1**

**Background, Clinical Manifestation and Diagnosis**

Unit 2

Therapy and Monitoring of Celiac Disease

Self-Assessment

Lesson 1 - Definition

Lesson 2 - Clinical presentation

Lesson 3 - Diagnosis

### Welcome to Unit 1: Background, Clinical Manifestation & Diagnosis of Celiac Disease



In Unit 1 you will learn about the **prevalence of CeD** in the general population and in risk groups. You will understand the **impact of the genetic predisposition and potential environmental factors** which may be involved in the CeD development.

As CeD can present with a **huge variety of symptoms** which are not restricted to the gastrointestinal tract, it's important to know these symptoms in order to identify patients which should be tested.

Of course you will also **explore the different diagnostic measures** and learn which tests are reliable and where you have to **be aware of pitfalls** which may lead to both false negative or positive diagnoses of CeD.

**The likely duration that the reader will need to engage with the material is 75 minutes.**

**[View here the content and learning aims of Unit 1](#)**

**Self-Assessment Unit 1**

**Lesson 1**

**Celiac Disease: Definition,  
Prevalence & Pathogenesis**

**Lesson 2**

**The Celiac Iceberg:  
Clinical Presentation & Symptoms**

**Lesson 3**

**Diagnosing Celiac Disease**

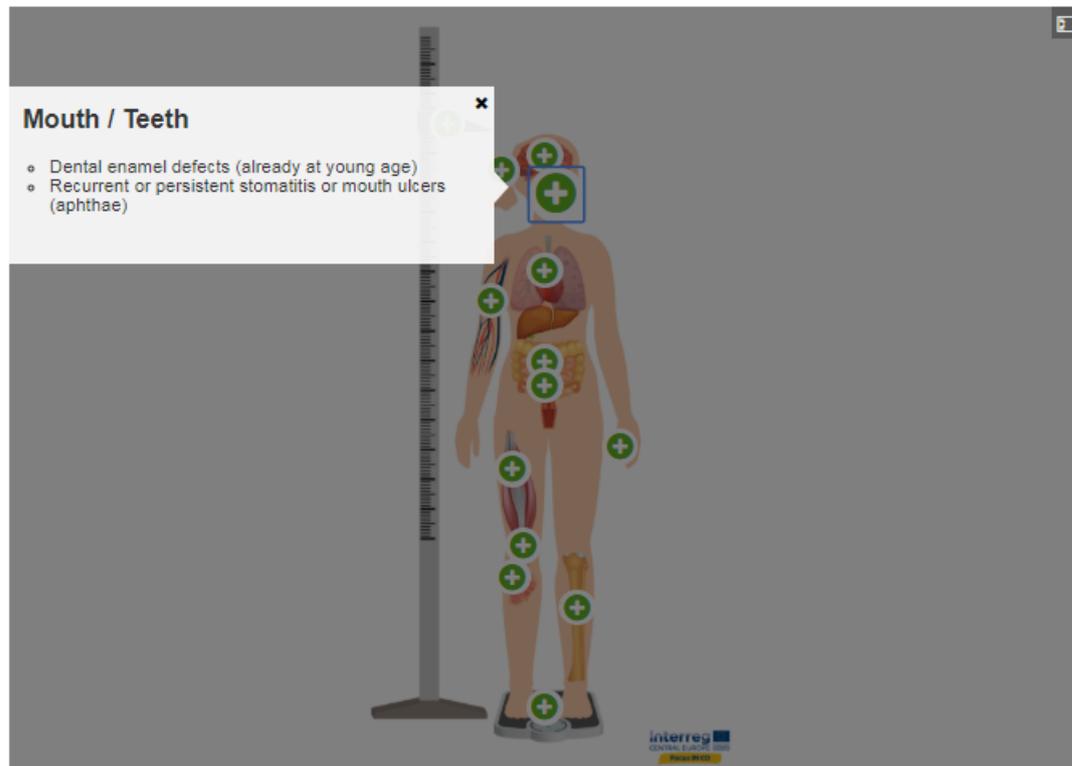
**The presentation of CeD can be classified as follows (Husby et al. 2012; Felber et al. 2014; NICE 2015):**

**“Classic” and symptomatic CeD – gastrointestinal and extra-intestinal complaints**

When CeD was first described as an entity, the symptoms comprised gastrointestinal signs such as abdominal bloating, diarrhea with malabsorption of nutrients resulting in weight loss, iron deficiency anemia and in children growth retardation. This presentation is often referred to as “classic celiac disease” (Ludvigsson et al. 2012).

However, nowadays it is clear that **CeD is not restricted to malabsorption (Green et al. 2015)**, but **may present with less obvious symptoms from the gut** (e.g. constipation or only abdominal pain) **or outside the digestive system**. Consequently CeD can affect any part of the body, e.g. with symptoms of the cardiovascular, musculoskeletal, reproductive or nervous system, and other less specific symptoms such as hair loss, skin rash or dental enamel defect. Since these symptoms do not point to an intestinal disease, many of the patients are not diagnosed to have CeD. Explore the interactive **figure 8** to learn more about the different symptoms of CeD.

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**Figure 8: Possible signs and symptoms of celiac disease. Source: Focus/NCD own**

**Asymptomatic and subclinical CeD**

From systematic screening studies it has been recognized that many affected individuals don't experience any or only very non-specific symptoms. This phenomenon is called “asymptomatic” celiac disease (Ludvigsson et al. 2012). In some of them diagnostic tests may reveal abnormalities such as decreased bone mineral density or elevated transaminases. These persons are considered to have “subclinical” celiac disease (Ludvigsson et al. 2012). Both asymptomatic and subclinical patients will also show raised levels of CeD-specific auto-antibodies (**Unit 1 lesson 3**) and **villous atrophy**. Consequently, they can also develop complications and long-term health consequences of CeD if they are not diagnosed and follow a gluten-free diet.

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Introduction	Unit 1 Background, Clinical Manifestation and Diagnosis	<b>Unit 2 Therapy and Monitoring of Celiac Disease</b>
Self-Assessment	Lesson 1 - Gluten-free Diet	Lesson 2 - Health Risks and Benefits Lesson 3 - Psychosocial Consequences Lesson 4 - Monitoring

## Welcome to Unit 2: Therapy & Monitoring of Celiac Disease

GLUTEN  
FREE

The only available **treatment for celiac disease is a strict and lifelong gluten-free diet**. On a gluten-free diet, symptoms will improve or even completely resolve in most cases; the antibody levels will gradually normalize and the intestine will usually recover.

Since gluten is contained in a wide variety of commonly eaten foods, the **necessary dietary adjustments** after a confirmed diagnosis can be **challenging**. Good knowledge about the gluten-free diet and its implications on daily life are essential to avoid dietary mistakes and involuntary gluten ingestion.

With the gluten-free diet, all nutrient requirements can be met and dietary supplements are usually not necessary. **Although generally healthy, the gluten-free diet requires more careful food choices than a normal diet**, especially when certain co-morbidities or lifestyle choices are present as well.

Besides the medical aspects of celiac disease, including **follow-up examinations and co-morbidities**, healthcare professionals should be aware of the **psychosocial effects** celiac disease can have on patients and their families. Good education and peer support/ mentoring from celiac societies/ organizations and/or psychology support are important factors in helping overcome emotional difficulties after diagnosis.

The likely duration that the reader will need to engage with the material is 75 minutes.

[View here the content and learning aims of Unit 2](#)

**Self-Assessment Unit 2**

**Lesson 1**  
The Gluten-free Diet: What can Patients with Celiac Disease Eat?

**Lesson 2**  
Health Risks & Benefits of the Gluten-free Diet

**Lesson 3**  
Psychosocial Consequences

**Lesson 4**  
Monitoring of Celiac Disease

[potential future therapies](#)

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## Lesson 1 - The Gluten-free Diet: What can Patients with Celiac Disease Eat?

### 1.3 What can patients eat?

A strict and lifelong gluten-free diet is the only effective treatment for CeD. So far, there is no other scientifically proven or effective treatment, although several ongoing clinical trials are investigating the use of drugs (see optional further reading). Although it involves major changes in diet and lifestyle, patients should know that unlike other chronic diseases, this treatment does not require medication with possible adverse effects or other drastic interventions: [\(Niewinski 2008\)](#).

**When is a gluten-free diet initiated?**

It is of utmost importance that the diet is not initiated before all necessary tests for the diagnosis are performed! Otherwise this leads to unnecessary uncertainties and delays in the diagnostic process as test results may be equivocal or false-negative. Consequently, neither the treating physician nor the patient her/himself should decide to reduce or eliminate gluten from the diet prematurely!

The diet should only begin when all diagnostic test results are available and the diagnosis is confirmed without doubt. If possible, the patient should be referred to a dietician with practical experience of the gluten-free diet and knowledge about the current national food regulations.

View this slide show by clicking on the arrows or on the slide show bar (blue) below and learn more about the sources of gluten in the diet and in non-foods which your patients have to be aware of!



### Naturally gluten-free foods

The good news is: there are actually much more naturally gluten-free foods than gluten-containing foods!

They are easily identifiable as gluten-free because they are not related to grains. This group contains **fruits, vegetables, animal products (meat, dairy, eggs), potatoes and roots**.

In addition, there is a wide variety of naturally **gluten-free cereals** such as rice and corn and **pseudo-cereals** such as buckwheat, quinoa and amaranth, which are now becoming more and more popular.

The broad variety of naturally gluten-free cereals, pseudocereals and seeds are used to substitute gluten-containing cereals not only when cooking at home, but also in **products specially designed for the needs of celiacs**, e.g. gluten-free bread or pasta.

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Figure 6: Sources of gluten in the diet and in non-foods  
Source: FocusINCD own

Gluten-containing cereals	Gluten-free (pseudo)cereals and other alternatives
→ wheat	→ rice (all types)