

# Celiac Disease

## Information for women who have celiac disease during pregnancy or breastfeeding

The information provided below is for readers based in the United States of America. Readers outside of the United States of America should seek the information from local sources.

### What is celiac disease?

Celiac disease, also called celiac sprue, is a condition that produces effects throughout the body, and results from disruption mostly within the small intestine, due to the immune system responding inappropriately to the ingestion of gluten, a group of proteins present in wheat, rye, and barley.

### How common is celiac disease?

The prevalence of celiac disease varies among countries and ethnic groups. In North America, it occurs in 0.71 percent of people (about 1 case per 141 people) overall, and 1 case per 100 Caucasian people. One in 100 people are affected in Europe, but the prevalence in Finland is higher, at 2.4 percent. India, North Africa, and the Middle East also have a fairly high prevalence of celiac disease, but the condition is very rare in Japan, China, Southeast Asia, the Caribbean, and sub-Saharan Africa.

While proportions in the range of 1 to 2.4 percent of the population makes celiac disease extremely common, evidence both from food marketing and public health study is mounting that much larger numbers of people in developed countries - many times the number who have celiac disease - are consciously avoiding gluten in their diets, believing (incorrectly) that gluten causes them harm. Most such people actually have much more manageable conditions, namely [irritable bowel syndrome](#) or an [intolerance to lactose](#), the kind of sugar that's in milk. The practice of adopting (or encouraging by alternative health care practitioners) gluten-free diets in the absence of celiac disease amounts to very bad medicine, as the exclusion of gluten also usually means the exclusion of fiber and other benefits of whole-grain foods. But the practice is promoted by a gluten-free food industry that has emerged over the past couple of decades and that is driven by market forces.

Celiac disease is typically diagnosed during one's 40s, but it affects women more often than men, and women with celiac disease tend to be diagnosed at a younger age. Consequently, it is fairly common

for celiac disease to co-exist with pregnancy.

### **How is celiac disease diagnosed?**

First, your doctor must conduct a thorough history and physical examination. This may hint that you might have celiac disease, due to a combination of any of the following: a long history of [diarrhea](#), bloating, tummy pain, sores in the mouth, often with weight loss, bleeding or bruising, and sometimes [bone fractures](#) that can be the result of [vitamin D deficiency](#). Next, there is immunological testing, which involves tests for levels of types of antibodies (specific families of antibodies called IgA and IgG) against a component of gluten called gliadin and against an enzyme present in the intestine called tissue transglutaminase (tTG). Immunological testing also looks for the presence of special proteins on the outside of your cells called HLA-DQ2 and HLA-DQ8, which are sometimes associated with celiac disease. You also may have genetic testing to see if you are genetically prone to produce these and other proteins.

In some cases, immunological testing, plus your history can be enough for a doctor to make a working diagnosis of celiac disease, but confirmation of the diagnosis requires a procedure called upper endoscopy with duodenal biopsy. In this procedure, which should be postponed until after you deliver, a flexible scope with a tiny camera is manipulated through your stomach and part of your small intestine. From the duodenum, the part of your small intestine closest to your stomach, a small sample of tissue is taken during the endoscopy through a tube that moves through your intestine with the camera. The biopsy provides samples of your gut that is tested for the damage and immune effects that are characteristic of celiac disease. Sometimes this biopsy is performed on somebody who is undergoing duodenal biopsy for other reasons since celiac is such a common condition and thus there is a reasonable chance that the individual may have it. If the endoscopy is ordered specifically as part of testing for celiac disease, however, often it will be done after you consume gluten in the diet intentionally for a while. This will be uncomfortable if celiac disease is the reason for your symptoms, but its the only way that doctors can be sure that dietary gluten and the symptoms are connected.

### **Does celiac disease cause problems during pregnancy?**

By affecting the immune system in certain ways, pregnancy can trigger the onset of celiac disease symptoms and can cause an exacerbation of celiac symptoms into a state called celiac crisis. This is characterized by very severe diarrhea and changes in the chemistry of the blood that are life-threatening.

### **Does celiac disease during pregnancy cause problems for the baby?**

Yes. Celiac disease can lead to [spontaneous abortion](#) (miscarriage) as well as a condition called intrauterine growth restriction, during which the developing baby does not grow as well as usual. Additionally, celiac disease can disrupt your fertility making it difficult to become pregnant in the first place.

### **What to consider about taking medications when you are pregnant or breastfeeding:**

- The risks to yourself and your baby if you do not treat the celiac disease
- The risks and benefits of each medication you use when you are pregnant
- The risks and benefits of each medication you use when you are breastfeeding

### **What should I know about using medication to treat celiac disease during pregnancy?**

Elimination of dietary gluten is the treatment of choice for celiac disease. However, in cases when a woman is already sick, either because celiac disease is first being recognized, or because pregnancy has set off a celiac crisis, she may require medications that suppress the immune system. Usually, the choice for this is a group of drugs called [corticosteroids](#), specifically a steroid called prednisolone, which is considered relatively safe in pregnancy. There also are drugs called antimetabolites, the most common example is a drug called [methotrexate](#), but this is harmful during pregnancy, and so corticosteroids are the treatment of choice.

### **Who should NOT stop taking medication for celiac disease during pregnancy?**

In most cases, a gluten-free diet, managed by a licensed dietician who makes sure that you receive all of the needed nutrients, is all that is needed. If your condition is exacerbated, however, you will need corticosteroid treatment.

### **What should I know about choosing a medication for my celiac disease during pregnancy?**

The corticosteroid drug called prednisolone is considered relatively safe in pregnancy.

You may find Pregistrys expert reports about the individual medications used to treat celiac disease [here](#). Additional information can also be found in the sources listed at the end of this report.

### **What should I know about taking a medication for my celiac disease when I am breastfeeding?**

The steroid prednisolone builds up in breastmilk mostly during the first four hours after a dose is given. Consequently, some doctors will suggest that a lactating mother wait four hours after receiving each dose, then pump out her milk and discard it, then wait for new milk to accumulate and nurse the infant from that new milk. Some options for what to do about

that missed feeding include: pumping earlier in the day and saving the milk to feed in place of the discarded milk, feeding formula for that one meal a day, or simply using formula for all feedings. A lactation consultant can help you if you would like to keep breastfeeding. It is true that many studies suggest that there are benefits to breastfeeding both to the child and the mother; its also true that in most such studies it has been difficult to separate the true benefits of breastfeeding from various socioeconomic factors that also relate to whether women chose to breastfeed over formula.

### **What alternative therapies besides medications can I use to treat my celiac disease during pregnancy?**

The main treatment for celiac disease is a special diet that eliminates gluten. It is very important that you choose foods that are both nutritious and also truly free of gluten. Because the gluten-free food industry is aware that most of the people who seek products with a gluten-free label dont actually need gluten removed from their diets, because such labels are now appearing on products that would not contain gluten anyway, such as bottled water and salt, the mere presence of the term gluten-free on a package of processed food is not a serious thing. This also applies to restaurants, particularly when they claim that a food item is gluten-free when the item is obviously made with flour. Consequently, if you are pregnant with celiac disease, your diet should be managed by a professional dietician in consultation with a gastroenterologist.

### **What can I do for myself and my baby when I have celiac disease during pregnancy?**

Work with your doctor and dietician to stick to your special diet.

### **Resources for celiac disease in pregnancy:**

For more information about **celiac disease** during and after pregnancy, contact

<http://www.womenshealth.gov/> (800-994-9662 [TDD: 888-220-5446] or check the following links:

- Celiac Disease Foundation: [How Celiac Disease Affects Pregnancy](#)
- Beyond Celiac: [Maximizing Nutrition for Pregnancy](#)

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## General information

It is very common for women to worry about having a miscarriage or giving birth to a child with a birth defect while they are pregnant. Many decisions that women make about their health during pregnancy are made with these concerns in mind.

For many women these concerns are very real. As many as 1 in 5 pregnancies end in a miscarriage, and 1 in 33 babies are born with a birth defect. These rates are considered the background population risk, which means they do not take into consideration anything about the health of the mom, the medications she is taking, or the family history of the mom or the baby's dad. A number of different things can increase these risks, including taking certain medications during pregnancy.

It is known that most medications, including over-the-counter medications, taken during pregnancy do get passed on to the baby. Fortunately, most medicines are not harmful to the baby and can be safely taken during pregnancy. But there are some that are known to be harmful to a baby's normal development and growth, especially when they are taken during certain times of the pregnancy. Because of this, it is important to talk with your doctor or midwife about any medications you are taking, ideally before you even try to get pregnant.

If a doctor other than the one caring for your pregnancy recommends that you start a new medicine while you are pregnant, it is important that you let them know you are pregnant.

If you do need to take a new medication while pregnant, it is important to discuss the possible risks the medicine may pose on your pregnancy with your doctor or midwife. They can help you understand the benefits and the risks of taking the medicine.

Ultimately, the decision to start, stop, or change medications during pregnancy is up to you to make, along with input from your doctor or midwife. If you do take medications during pregnancy, be sure to keep track of all the medications you are taking.