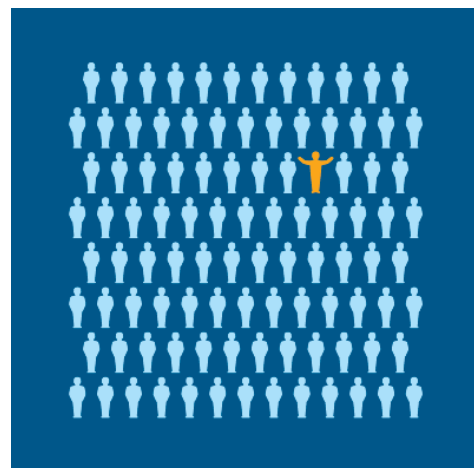


## CELIAC DISEASE

# What Is Celiac Disease?

- ▶ People with celiac disease cannot eat gluten.
- ▶ Gluten is a protein found mainly in wheat, barley and rye, but may also be in products you use each day, such as soy sauce and salad dressing, as well as some medicines, vitamins and even some lipsticks.
- ▶ **When a person with celiac disease eats gluten, the immune system, which is supposed to help protect the body against disease, reacts by harming the cells of the lining of the small intestine and may also harm other parts of the body such as the skin, bones or brain (nervous system).**
- ▶ Patients with celiac disease who do not take gluten out of their diet will keep harming the small intestine. This can cause malabsorption, lower vitamins and minerals in their bodies, and more serious long-term problems, among other things.
- ▶ Celiac disease is a health condition of the small intestine that happens in **1 out of 100** people. Both dietary and genetic factors cause the disease.



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- ▶ Celiac disease is a lifelong health problem.
- ▶ While the disease can be tricky to diagnose, the symptoms of diarrhea (loose stool) and belly pain often ease within weeks of eating a gluten-free diet.
- ▶ If you think you may have celiac disease, do not stop eating gluten until you have been tested and the tests show that you have celiac disease. Getting rid of gluten before testing will change the results.



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## CELIAC DISEASE

# Symptoms

There are many different symptoms of celiac disease. Below are a few more common symptoms, though there are many more.

**People with celiac disease may have one, some or none of these symptoms.** Having the symptoms below does not mean you have celiac disease, just as **some patients with the disease may not show any symptoms.**

- Gas, belly bloating and pain that doesn't go away.
- Diarrhea (loose stool) or constipation (hard stool or trouble passing stool) that doesn't go away.
- Pale, foul-smelling or fatty stool.
- Weight loss or weight gain.
- Tiredness or low energy levels.
- Changes in behavior; irritability in children.
- Tingling or numbness in the legs (from nerve damage).
- Bone or joint pain.
- Muscle cramps.
- Delayed growth in children.
- Pale sores inside the mouth.
- Itchy skin rash.
- Brain fog.

**If you think you may have celiac disease, do not get rid of gluten from your diet until your doctor has tested you.** It is important to talk with your doctor about options and discover the cause of your symptoms.



## CELIAC DISEASE

# Getting Tested

After talking about your symptoms with your doctor, tests for celiac disease may be performed. As celiac disease is a lifelong health issue, a correct diagnosis is very important.

**If you think you may have celiac disease, do not get rid of gluten from your diet until your doctor has tested you.**

### Blood Test

- A blood test is the most common test, as it is easy and can give a clear answer.
- Results often take about a week.
- A blood test to see if you have celiac disease can only work if you are eating gluten, so be sure to keep gluten in your diet before testing is done. (Only limit gluten from your diet if your doctor tells you to do so.)
- Based on the results, your gastroenterologist may wish to do an **endoscopy**.

### Endoscopy

- An endoscopy is done to get a small piece of the tissue (biopsy) from your small intestine to see if there is damage stopping your body from taking in nutrients, caused by celiac disease.
- You will be given medicine to block pain and make you feel relaxed and sleepy, so you won't feel much during the test.
- During the endoscopy, your gastroenterologist will use a long, thin (about the width of your little finger), flexible tube with a camera on the end to look inside.
- The tube is passed through the mouth into the small intestine as your gastroenterologist does a careful exam to check for damage.



- Getting a biopsy before starting a gluten-free diet gives you and your doctor proper baseline data to be used if issues come up in the future, so be sure to keep gluten in your diet before testing is done. (Only go gluten-free if your doctor tells you to do so.)
- Endoscopy is the best way to show that you have celiac disease and the best way to make sure your intestine heals the right way.
- To learn more about endoscopy, **visit [gastro.org/Patient-Care](http://gastro.org/Patient-Care)**.

*While other types of tests, such as saliva and stool tests, may be offered, these are not accurate and should not replace the blood test and endoscopy.*

## Next Steps

- ▶ *If your blood tests and endoscopy say that you have celiac disease:*
  - Your gastroenterologist will give you information on the **gluten-free diet (GFD)** to care for (and hopefully get rid of) your symptoms.
  - Your doctor will also talk with you about **testing for vitamin deficiencies** or other problems linked to celiac disease. Many celiac disease patients do not have gastrointestinal (GI) symptoms, but may have thyroid disease, anemia (too little iron in the blood), osteoporosis (weakened bones), liver disease, or females may have gynecologic issues (irregular periods and infertility).
  - Your gastroenterologist should put you in touch with a **registered dietitian (RD) to help you learn more about the GFD as you start the change in diet.**
    - Ask your doctor to suggest a dietitian skilled in celiac disease.
    - Reach out to your health insurance provider to find an RD that is covered by your plan.
    - Perform an Internet search using these helpful Google search terms to find an RD in your area:
      - “Registered dietitian”
      - “Celiac disease”
      - Your ZIP code



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- ▶ *If your tests **do not** show celiac disease, some choices your doctor may give you are:*
  - Taking a gluten challenge to look for gluten intolerance. Your doctor can give you more information on how to do this and if it would be helpful.
  - Tracking your diet, which can help find other possible food allergies and intolerances, such as to lactose or fructose.

## Celiac Disease – What to Know:

- ▶ Celiac disease is a health issue in which people cannot handle a protein called gluten.
- ▶ Celiac disease causes many GI issues, among other things.
- ▶ The treatment for celiac disease is to cut out gluten and eat a gluten-free diet (GFD).
- ▶ Do not get rid of gluten in your diet until you have been tested by a doctor and then only if he or she tells you to.
- ▶ If you still have celiac symptoms after going gluten-free or would like more information, talk to your gastroenterologist.



## CELIAC DISEASE

# Newly Diagnosed

- ▶ *For some, hearing that they have celiac disease is a relief, a reason for symptoms and a light at the end of the tunnel. For others, it can be scary and daunting. Many will have a mix of feelings. All of this is completely normal.*
- ▶ *No matter what you may be feeling upon hearing you have celiac disease, you are not alone. Many places have support groups for people with celiac disease, both in-person and online, that can be very helpful.*
- ▶ *If you are overwhelmed by your new diagnosis, don't wait to reach out to a mental health expert to talk through the changes.*
- ▶ *Relaxation techniques, such as yoga, meditation or mindfulness may be very helpful.*
- ▶ *Working together with your health-care team, you can make a treatment and nutrition plan just for you, to help control your symptoms and put you in charge of celiac disease.*





## With Your New Celiac Disease Diagnosis, Keep in Mind:

- You must **follow a gluten-free diet (GFD)** to get rid of your symptoms, allow the small intestine to heal and stop future damage.
- **Talk with a dietitian**, as well as your gastroenterologist, until you feel you grasp the new changes.
- **Speak up!** If you have questions, concerns or still have symptoms, share them with you doctor as soon as possible.
- **See your doctor regularly.** Your doctor may do check-up tests (like blood tests or an endoscopy) to see your progress.
- Even being exposed to **small amounts of gluten may make your symptoms worse.** This is often not planned and may come from unexpected sources of gluten, such as cookware (if it has been used to cook food that has gluten), lipsticks and certain medications. Your doctor or dietitian can help you find and learn about these hidden sources of gluten.
- While you may be tempted to cheat and may not notice much of a problem when you do, it is important to keep in mind that your intestine will still be harmed by gluten, it will not heal, and you may run the risk of long-term problems.
- **There are patient-oriented celiac disease support groups.** Check out Additional Resources for more information or talk to your doctor about groups in your community.



### Questions to Ask Your Doctor

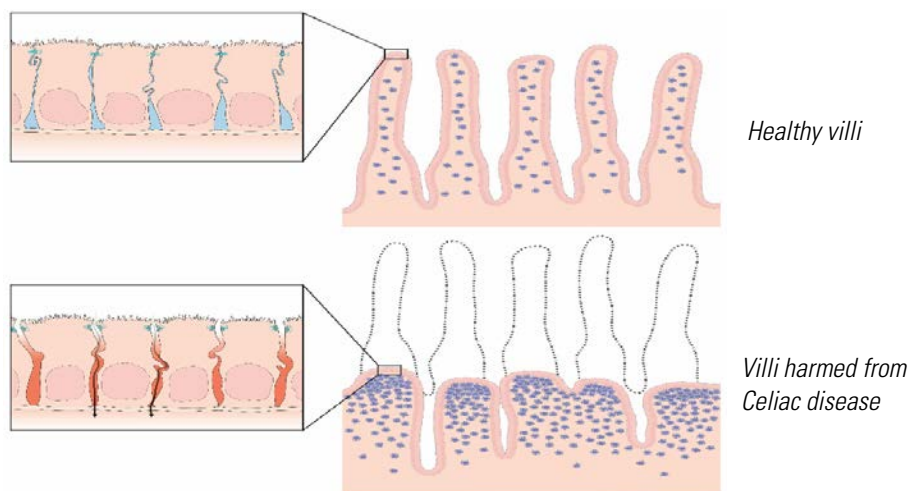
- How often should I get exams for my celiac disease?
- How often will I need blood tests or an endoscopy?
- Are there symptoms that should cause worry? If so, what are they?
- If you don't know something at any point, ask for more (or clearer) information!





## Facts About Celiac Disease:

- **Celiac disease is not a rare disease.** Recent research has shown that as many as 3 million people in the U.S. (about 1 percent of the population) may have celiac disease.
- It is very **common among first-degree family members** of people who have celiac disease, such as brothers, sisters, parents and children.
- Celiac disease can be **found in both children and adults** and people may live for years without knowing they have it.
- In some patients, the disease shows itself after an event such as surgery, pregnancy, viral infections or severe emotional stress.
- **The small intestine**, which is about 20 feet long, finishes the process of digestion, **takes in the nutrients** and passes the leftover material on to the large intestine for elimination. **The small intestine is lined by tiny, fingerlike protrusions, called villi.** Villi absorb nutrients from food. Celiac disease hurts the villi. **Without healthy villi, nutrients will pass through the small intestine without being absorbed** and you may become malnourished and become deficient in some vitamins and minerals.
- **Celiac disease is both an autoimmune health issue**, because the body is hurt by its own immune system, **and a disease of malabsorption**, since your body cannot absorb enough nutrients, vitamins and minerals.



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## CELIAC DISEASE

# Treatment

- ▶ *The gluten-free diet (GFD) is the only treatment for celiac disease.*
- ▶ *In many patients with celiac disease, even a small amount of gluten is enough to cause harm, even though they may not feel symptoms.*
- ▶ *A lifelong GFD will help protect your small intestine, and may be able to undo damage that has already happened.*

**Good news! You should start feeling better within weeks of changing your diet.**

## The gluten-free diet (GFD)

Taking on the gluten-free diet may feel like a lot at first. Don't be afraid to reach out for help and support from your gastroenterologist, dietitian or local support group. Educating yourself and knowing what foods you can have will be the key to staying gluten-free and feeling healthy.

Here are a few tips as you take on your gluten-free diet:

- **The main offenders**
  - These items have gluten and are used in many common food items, even as thickeners or fillers for sauces, condiments and more. These should always be avoided:
    - Wheat.
    - Barley.
    - Rye.
    - Malt (unless a gluten-free grain, such as corn, is named as a source).
    - Brewer's yeast.
    - Oats (unless they are pure, uncontaminated, labeled gluten-free oats and your doctor has said you are able to eat them).



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- **Eat balanced!**

- Fruits and veggies (fresh, frozen or canned without sauces or flavors); plain meat, fish, and poultry; plain nuts and seeds; oils; and most milk products are all naturally gluten-free.
- Stock up on these for snacks and meals to make sure you are getting all the nutrients you need.
- Just like a diet without any limits, eating a balance of each food group will help to keep you healthy.



- **No need to skip the starch**

- There are plenty of gluten-free grains and starches you can eat. Remember, whole grains are part of a balanced diet, too. These can be consumed on a GFD:
  - Rice.
  - Potatoes.
  - Sweet potatoes.
  - Corn.

- **Gluten-free replacements**

- If it is labeled “gluten-free,” it is safe to eat.
- There are many gluten-free replacements for common snacks and foods like crackers, cereal, pasta, baking mixes and more.

## What Successful Treatment Looks Like

Being healed from celiac disease means that your small intestine starts to work as it should again and **can start taking in nutrients the right way**; but, *it does not mean that you are able to eat gluten.*

While you will never be fully cured of celiac disease, meaning you will always have the disease, **after eating a GFD, your small intestine should heal** within two years for adults and within a few months in children and young adults.



Your gastroenterologist may want to take another biopsy (taking a small piece of tissue to look at under a microscope) about one to two years after you start to make sure your new diet is helping.

*The National Institutes of Health suggests these points to keep in mind as you care for your celiac disease:*

## **C - Consultation with a skilled registered dietitian (RD)**

- Ask your GI doctor for a recommendation.
- Perform a Google search for registered dietitians in your area who specialize in celiac disease.

## **E - Education about celiac disease**

- Get and stay informed! Trusted websites, like government sites, can give you great information.

## **L - Lifelong adherence to a GFD**

- Even a little bit of gluten can go a long way in terms of harming your gut. Learn the best ways to eat gluten-free while still keeping up your daily routines.

## **I - Identification and treatment of nutritional deficiencies**

- This means having routine health exams so your doctor can check blood levels of certain vitamins, minerals and nutrients.

## **A - Access to a support group**

- There are plenty of community groups that focus on celiac disease. Reach out and get connected!

## **C - Continuous long-term follow-up by a multidisciplinary team**

- Since celiac disease stays with you your whole life, you need to create a good, long-term relationship with your doctor and dietitian. Be open with them about symptoms, questions or concerns.



## Still Having Symptoms?

It can be scary to keep having symptoms, even after changing to a GFD. There are a few courses of action to think over when this is the case:

- Are you still eating gluten while on the gluten-free diet? **Remember, even a little bit of gluten can have a harmful impact.**
- Are you possibly consuming hidden gluten?
  - **A dietitian can help you find out if you are unintentionally consuming gluten** through such things as medications, supplements or other sources.

*If the answer is no to these questions and you have been on a GFD for at least six months, it is time to meet again with your gastroenterologist to find out if more tests or treatment options are needed.*

Try a symptom tracker, like the MyGIHealth® app, to note your symptoms and when they occur.

### Celiac Disease – What to Know:

- ▶ Celiac disease is a health issue in which people cannot handle a protein called gluten.
- ▶ Celiac disease causes many GI issues, among other things.
- ▶ The treatment for celiac disease is to cut out gluten and eat a gluten-free diet (GFD).
- ▶ Do not get rid of gluten in your diet until you have been tested by a doctor and then only if he or she tells you to.
- ▶ If you still have celiac symptoms after going gluten-free or would like more information, talk to your gastroenterologist.



## CELIAC DISEASE

# Things to be Aware of with Untreated Celiac Disease

If you stick to a gluten-free diet (GFD), you greatly lower the chance of future health problems:

- ▶ People with **untreated celiac disease** are at a greater risk of **not getting enough nutrients, like vitamin D and iron.**
- ▶ Patients with untreated celiac disease may have weak or brittle bones; children may be short for their age.
- ▶ Some patients with celiac disease may have other autoimmune problems, such as Type 1 diabetes, thyroid disease and liver disease, among others.
- ▶ Symptoms that do not get better on the GFD or return after going away can have many causes. Thankfully, most of these are simply treated, but rarely this may be due to refractory celiac disease, which would need treatment with medications along with the GFD.
- ▶ Patients not being treated may have a slightly greater risk of lymphoma and intestinal cancers.
- ▶ Some patients may gain weight with celiac disease and also on the GFD.
- ▶ Some patients may have constipation, which means they have hard stool or trouble passing stool.



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- ▶ **Patients may go through depression (low mood) or anxiety (worry),** or have trouble coping with celiac disease. These are all normal responses to finding out you have celiac disease. If you are having any of these feelings, **reach out to a mental-health expert right away.**

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## CELIAC DISEASE

# Additional Support

### Dining Out Gluten-Free

Celiac disease should not stop you from eating out. There are more new gluten-free choices each day, so start exploring! Here are a few tips to keep in mind when eating out:

- **Know the gluten-free diet (GFD)!**
  - Be sure you have solid knowledge of labels and what you can safely eat.
    - Don't forget about hidden gluten in salad dressings, soups and marinades.
- **Let your server (or host) know about your allergy.**
  - Speak up! Make sure they know you cannot have items with gluten or that have been contaminated with gluten.
- **Ask questions.**
  - Not sure how a menu item is made? Ask your server to ask the kitchen staff. Better safe than sorry!
  - Don't see a gluten-free menu right away? Try asking! They may have one that you need to request.
- **Send it back (if you need to).**
  - Mistakes happen and that is OK. However, if the staff makes a mistake and adds gluten to your dish (such as putting croutons in your salad), you need to ask for it to be fixed.
- **Say thank you.**
  - Needing to change something is nothing to feel guilty about. Showing your thanks and kindness goes a long way.
- **Do your research.**
  - With so many restaurants having gluten-free menus, try a quick Internet search to find new places.



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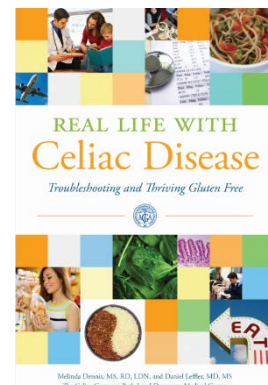
## Religious Practices

There are a few religious customs that call for products with gluten. Below is a table of the most common customs and solutions if you have celiac disease.

Religion	Practice	Gluten-Free Solution
Catholicism	Holy Communion (or Eucharist)	<ul style="list-style-type: none"> <li>• Ask for a <b>gluten-free or low-gluten host</b> (they are a golden color).</li> <li>• Receive <b>wine only</b>.</li> <li>• Take care to use a separate paten or pyx and chalice to avoid cross contamination.</li> <li>• <b>Discuss these options with your local clergy.</b></li> </ul>
Judaism	Eating matzah on Passover or Shabbat	<ul style="list-style-type: none"> <li>• Use <b>gluten-free oat matzah</b> instead.</li> <li>• Check with your doctor that you are able to eat oats first.</li> <li>• If you are unable to eat oats, <b>check with your rabbi</b> to be excused temporarily.</li> </ul>

## Books

*Real Life with Celiac Disease: Troubleshooting and Thriving Gluten Free*  
by Daniel A. Leffler and Melinda Dennis



## Support Groups

There are a number of support groups for caregivers and patients with celiac disease. Reach out to your gastroenterologist, dietitian, local hospital or community center for more details.



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## Trusted Websites

[celiacnow.org](http://celiacnow.org)

[celiac.org](http://celiac.org)

[celiaccentral.org](http://celiaccentral.org)

[gluten.org](http://gluten.org)

[glutenfreedietitian.com](http://glutenfreedietitian.com)

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