

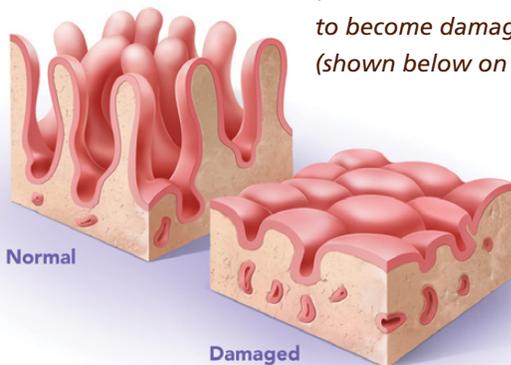


## Understanding **CELIAC DISEASE**

### *What is celiac disease?*

Celiac disease is a bowel disorder caused by a reaction to ingested gluten, a protein found in wheat, rye and barley and contaminating all commercial-grade oats. If you have celiac disease, eating gluten damages the villi (small finger-like structures) that make up the lining of your small bowel. This injury prevents nutrients from being properly absorbed.

*For those living with celiac disease, gluten causes normal villi in the small intestine (shown below on left) to become damaged (shown below on right).*



Celiac disease is considered an autoimmune disorder because it results in the body damaging its own tissues. It is the only autoimmune disease in which the trigger is known. Celiac disease is not a food allergy. If you have the disease, your body's response to gluten differs from the immune response caused by a food allergy.

Rates of celiac disease have nearly doubled in the last 25 years in western countries. In Canada, about 110,000 people have been diagnosed with the disease. It is suspected that up to an additional 220,000 Canadians are living with the disease but have not yet been diagnosed. The disease can occur at any stage of life, including childhood. It may be slightly more common in women than in men, though the higher rate of diagnosis in women could be due to women getting more regularly scheduled health care.

### *Celiac or sensitive?*

Some people test negative for celiac disease and show no signs of the intestinal damage. However, they still react badly to eating wheat with symptoms such as abdominal pain, fatigue, and headache. Such people are said to be gluten-sensitive or intolerant. Gluten sensitivity exists on a spectrum of severity, so not all people react to the same amounts or types of gluten-containing foods in the same way. Recent evidence suggests that people with gluten sensitivity may react to other proteins or carbohydrates in wheat, so "wheat sensitivity" or "wheat intolerance" may be more fitting terms for the condition.

It is suspected that as many as **330,000** Canadians are living with celiac disease with only about 1/3 having been diagnosed.

# CELIAC DISEASE

## What causes celiac disease?

Celiac disease often runs in families. If you have a first-degree relative (parent, sibling, or child) with the disease, you have an 8 to 15% chance of getting it, and a 5% chance of getting it if one of your second-degree relatives is affected. A few medical conditions can also put you at higher risk, such as:

Condition	Celiac risk
Type 1 diabetes	4 to 15%
Other autoimmune diseases (thyroiditis, rheumatoid arthritis, multiple sclerosis, primary biliary cirrhosis)	3 to 5%
Down, Turner or Williams Syndrome	4 to 8%
Osteoporosis (weak bones that fracture easily)	2 to 4%
Deficiency in immunoglobulin A (IgA)	10 to 30%
Irritable bowel syndrome	2 to 5%

Not all people with a genetic vulnerability to celiac disease develop the condition. An additional “trigger” is needed, such as stress, infection, surgery or pregnancy. In children, recurrent gastrointestinal infections can bring on the disease.

## What are the symptoms of celiac disease?

Symptoms vary greatly from person to person and some people – especially those with associated conditions – have no symptoms at all. Many adults with celiac disease do not suffer from classic digestive symptoms. Instead, they may experience such symptoms as unexplained fatigue, mouth cankers or joint pain, making diagnosis all the more challenging. Not all affected individuals lose weight; in fact, about 30% are overweight. About 10% have a skin condition called dermatitis herpetiformis, an intensely itchy rash usually found on the elbows, knees and buttocks. It may appear initially as groups of blisters that form small red lesions from being scratched. In children, common additional symptoms include dental enamel defects, irritability, poor growth or failure to thrive, and delayed puberty.

Some people first come to their doctor’s attention because of unexplained lab test results such as a low red blood cell count (anemia) or elevated liver enzymes. In other cases, celiac disease is diagnosed when a patient undergoes an upper endoscopy for other reasons (e.g., gastroesophageal reflux disease). If you have celiac-type symptoms and have

an upper endoscopy, ask your physician to obtain tissue to help diagnose (or rule out) celiac disease.

## Symptoms associated with celiac disease

As shown in the table below, symptoms extend beyond the gastrointestinal (GI) tract to all parts of the body and even the mind.

GI symptoms
<ul style="list-style-type: none"> <li>• Abdominal pain</li> <li>• Nausea and vomiting</li> <li>• Bloating</li> <li>• Gas, flatulence</li> <li>• Diarrhea, foul-smelling stools</li> <li>• Constipation</li> <li>• Mouth ulcers</li> <li>• Dental enamel abnormalities</li> <li>• Lactose intolerance</li> </ul>
Other bodily symptoms
<ul style="list-style-type: none"> <li>• Unhealthy pale appearance</li> <li>• Weight loss (though 30% of affected people are overweight)</li> <li>• Fluid retention</li> <li>• Bone and joint pain</li> <li>• Muscle cramps, weakness and wasting</li> <li>• Headache</li> <li>• Easy bruising</li> <li>• Skin rash</li> <li>• Infertility and recurrent miscarriages</li> <li>• Poor growth, delayed puberty in children</li> </ul>
Perceptual/psychological symptoms
<ul style="list-style-type: none"> <li>• General weakness and fatigue</li> <li>• Tingling in legs and feet (from nerve damage)</li> <li>• Persistent hunger (due to malnutrition)</li> <li>• Vertigo (dizziness)</li> <li>• Anxiety, Depression</li> <li>• “Foggy mind”</li> </ul>

# CELIAC DISEASE

## How do I know if I have celiac disease?

Many people go years without knowing they have celiac disease, while others believe they have it when they actually don't. Identifying celiac disease can be tricky (if you're not looking for it), because symptoms may be general, vague or entirely absent. If you think you may have celiac disease and your doctor doesn't raise the possibility, don't be afraid to bring it up yourself. In Canada, the average time from the start of symptoms to diagnosis is 12 years for adults and 1 year for children. This should not be the case.

Fortunately, new blood screening tests are improving the speed and accuracy of diagnosis. The most effective of these tests are:

- IgA anti-transglutaminase antibody test (tTG)
- IgA anti-endomysial antibody test (EMA).

If you have a positive blood test for celiac disease, you'll need an upper endoscopy and intestinal biopsies (tissue samples) to know for sure whether you have the disease. This safe outpatient or day procedure is performed under sedation. If you want, you can reduce the gluten in your diet to the equivalent of 1-2 slices of bread per day without affecting the biopsy results but **do not** cut out gluten altogether as a gluten-free diet before the biopsy may reduce damage which makes it very difficult to confirm the diagnosis.

**Identifying celiac disease can be tricky because symptoms may be general, vague or entirely absent.**

## How is celiac disease treated?

Treatment for celiac disease is both simple and challenging. Those with the disease must maintain a strict gluten-free diet for life. By avoiding gluten, you allow your intestine to heal. Your other symptoms should gradually subside and your risk of developing serious complications of untreated celiac disease will be reduced.

Going gluten-free can be challenging because it requires you to educate yourself about foods that contain gluten, to watch for "hidden" gluten in food products and medications, and to give up a number of common foods you may enjoy. Here's a partial list of where gluten can be found:

- Most breads and baked goods (e.g., muffins, donuts, cakes)
- Many other grains, including spelt and kamut
- Most breakfast cereals
- Most pasta
- Some soups, sauces and salad dressings
- Some processed meats and fish (e.g., wieners, imitation seafood)
- Most beer (which contains barley)
- Some cosmetic products
- Some condiments.

Fortunately, the world has become a much friendlier place for people who can't eat gluten. In fact, in 2009 the gluten-free diet became the # 1 "speciality diet" in North America. Grocery stores stock an increasing number and variety of gluten-free products, including gluten-free versions of pasta, bagels, crackers, pretzels, and other baked goods. Be sure that these products are nutritionally sound before using them. Gluten-free options are also gaining ground in restaurants, cookbooks and cooking websites.

## Alarm symptoms

Some alarm symptoms are not unique to celiac disease. These symptoms may signal other, possibly more serious health issues. Consult your doctor if you experience any of the following:

- Rectal bleeding with dark red blood mixed in with the stool
- Unintended weight loss
- Fever
- Nausea
- Vomiting
- Persistent diarrhea
- Abdominal pain that is not relieved by a bowel movement or that wakes you up at night.

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Once you've been diagnosed with celiac disease, ask your doctor to refer you to a registered dietitian with expertise in celiac disease for nutritional counselling. Your local chapter or the national office of the Canadian Celiac Association or [www.celiac.ca](http://www.celiac.ca) can also provide excellent resources about diagnosis and management. You will most likely need to start Vitamin D and may also require extra iron and multivitamins until your intestine heals.

You should get follow-up blood testing to verify that your intestines are healing. This will be done ideally 3-6 months after you've started a gluten-free diet and every 1-2 years after that. Some, but not all people, require a repeat intestinal biopsy.

Adults living with celiac disease who have symptoms of malabsorption (such as diarrhea, weight loss, or anemia) or bone pain need a bone mineral density (BMD) test at diagnosis and annually afterwards until the problem is resolved. You should also request BMD testing if you are a woman at menopause or a man over age 50. Children's bones heal rapidly and most do not require a BMD.

## Are there any complications of untreated celiac disease?

If you have celiac disease, living a gluten-free life is imperative to your good health. Over a period of time, untreated celiac disease can lead to such medical problems as:

- **Lactose intolerance:** This means you're unable to digest the milk sugar (lactose) found in dairy products. While not dangerous, lactose intolerance can lead to uncomfortable GI symptoms.
- **Osteoporosis:** Celiac disease interferes with the absorption of bone-strengthening substances like calcium and vitamin D and may also damage bones directly.
- **General malnutrition:** If you're malnourished, you feel weak and tired and you're unable to recover properly from infections and injuries.

Those with Celiac disease **must maintain a strict gluten-free diet for life.**

- **Auto-immune diseases** such as type 1 diabetes and inflammation of the thyroid, joints, nerves or liver.
- **Cancer:** Untreated celiac disease slightly increases the risk of colon cancer and lymphoma (cancer of the lymphatic system). Whether or not you have celiac disease, it's important to be aware of colon cancer symptoms, which include blood in stools, unexplained weight loss, and changes in bowel habits lasting more than 4 weeks.
- **Infertility and miscarriages**
- **Failure to thrive,** poor growth or delayed puberty (in children).

To reduce your chances of developing these complications, ensure you follow an entirely gluten-free diet for life. Multiple studies have shown that your risk of getting almost all these complications falls quickly to the risk in the general population – as long as you maintain a gluten-free diet. Remember that even tiny amounts of gluten can trigger symptoms that increase your risk of complications over time. As an example, as little as 1/60 of a slice of bread can cause intestinal injury.

## Living positively with celiac disease

There is no reason to restrict your social activities if you have celiac disease. As previously noted, many restaurants now offer gluten-free options. You don't need to be shy to ask waiters about modifying dishes to meet your health requirements.

You can also prepare for restaurant outings by checking out their online menus. If you know that

gluten-free choices won't be available, you can eat before going out, bring gluten-free snacks with you or choose a more appropriate restaurant.

Keeping tabs on your overall health, especially the possible complications of celiac disease, can help put your mind at rest and manage problems before they get serious. For example, it's a good idea to have regular screening tests for osteoporosis. If a test shows you have strong bones, it's one less thing for you to worry about. If your bones show signs of weakening, you and your doctor can begin a treatment

**Remember: For those with celiac disease, even tiny amounts of gluten can cause intestinal injury.**

## CELIAC DISEASE

plan, which could include calcium, vitamin D supplements, and possibly prescription medications.

Celiac disease has a strong presence in the digital world. Take advantage of discussion forums, support groups, and gluten-free apps for smart phones and tablets. Some of them have food databases you can search to find gluten-free products and menu options.

Finally, being open with family and friends can help them accommodate your dietary needs. If you feel uncomfortable divulging details about your personal health, you can give people this guide to read.

### Gluten-free cooking

The following tips can make your life easier in the kitchen.

- Start with recipes that include very little flour or other gluten-containing ingredients. Then omit those ingredients or use gluten-free substitutes instead.
- Choose old-fashioned recipes that involve preparing dishes “from scratch” rather than using convenience foods.
- Learn to make basic sauces and gravies used in soups and casseroles.
- Use herbs and spices for flavouring. In Canada, spices are gluten-free but seasonings may contain gluten.
- Invest in a gluten-free cookbook.
- Use gluten-free macaroni, bread, and corn tortillas.
- Serve lean protein (e.g., chicken breast, fish, eggs, low-fat cheese), vegetables and fruits while developing your celiac-friendly cooking skills.



### Preparing for health care professional appointments

Good communication with your doctor is an important part of managing your digestive health, regardless of your diagnosis. To ensure that all doctors have the most accurate information about you, it's a good idea to keep a journal in which you:

- Write down the symptoms that are bothering you, and for how long you have had them.
- Write down key personal and medical information, including any recent changes or stressful events in your life.
- Jot down triggers (such as food, stress, activity, or menstrual cycle) that seem to make your symptoms worse.
- Make a list of medications you are taking, including the conditions you take them for. Also note if any of your medications seem to affect your symptoms.
- Create a list of 3-6 questions to ask your doctor during your appointment.

If you have an iPhone or Android smartphone, you can easily track your symptoms and create reports for your doctor using Gi BodyGuard from the CDHF (see page 6).

### Learning more about celiac disease

The Canadian Digestive Health Foundation provides information, tools and support to help you take control your digestive health with confidence and optimism. Visit [www.CDHF.ca](http://www.CDHF.ca) to view free recorded on-line seminars, read personal stories and access other helpful resources.

Watch our information videos on celiac disease:

#### Celiac Disease is not an Allergy

This session helps you understand the medical differences between food intolerance, food allergy, and Celiac disease. Dr. Connie Switzer reviews each of these conditions, common misconceptions, detection and treatment, and how these conditions impact the individuals who must deal with them on a daily basis.

[www.CDHF.ca/en/videos/video/74](http://www.CDHF.ca/en/videos/video/74)

# CELIAC DISEASE

## Celiac Disease 101 : A General Introduction

At the 2012 CDHF Digestive Health Public Education Forum, Dr. Sanjay Murthy explained Celiac Disease to a capacity crowd. Watch and listen as he explains the disease, how it is diagnosed, how it is treated, who is at risk and how you can protect yourself.

[www.CDHF.ca/en/videos/video/65](http://www.CDHF.ca/en/videos/video/65)

Read a Personal Story About Celiac Disease:

## Small Sacrifices, Big Gains

Marc Legel began to experience gas, bloating, rumbling, general discomfort in his stomach, and worst of all, extreme fatigue, at a time when he was trying to go to school, establish his career, and enjoy a normal social life. Read how he successfully manages his life as a happy, healthy person with celiac disease.

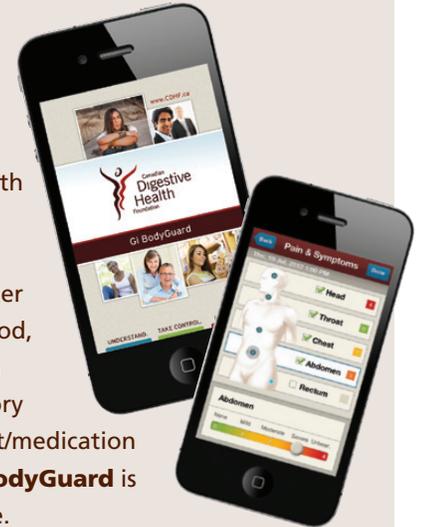
[www.CDHF.ca/en/disorders/details/id/6](http://www.CDHF.ca/en/disorders/details/id/6)

## CDHF App helps track information

The CDHF has developed a smart phone app for iPhone and Android called

**Gi BodyGuard** to help you quickly, easily and privately track and share your digestive symptoms with your physician.

**Gi BodyGuard** has a built-in symptom tracker (stool, pain, blood), food, fitness and medication trackers, a health history form and appointment/medication reminders. Using **Gi BodyGuard** is quick, easy and private.



As well, **Gi BodyGuard** lets you produce comprehensive reports so you can share important information with your physician during your next appointment. You can download **Gi BodyGuard** for free at:

[www.CDHF.ca/GIbodyguard](http://www.CDHF.ca/GIbodyguard)

**Please note:** The information contained in this digestive disorder guide is not a substitute for medical care and the advice of your physician. There may be variations in treatment that your physician may recommend based on your individual facts and circumstances. Always consult with your physician when you have concerns about your health.

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TAKE CONTROL.

LIVE BETTER.

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- I have enclosed a cheque for \$ \_\_\_\_\_
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- Please send me information about protecting and improving my digestive health.

Over 20 million Canadians suffer from digestive disorders every year. The Canadian Digestive Health Foundation believes this is unnecessary and unacceptable.

We reduce suffering and improve quality of life by empowering Canadians with trusted, up to date, science-based information about digestive health and disease.

As the Foundation of the Canadian Association of Gastroenterology, we work directly with leading physicians, scientists, and other health care professionals to help you understand and take control of your digestive health with confidence and optimism.

Through research and public education, we aim to:

 **REDUCE**  
the incidence and prevalence of digestive disorders

 **IMPROVE**  
understanding of digestive health issues

 **SUPPORT**  
those suffering from digestive disorders

 **ENHANCE**  
quality of life for those living with digestive disorders

## Request for support

The Canadian Digestive Health Foundation is a national charity governed by a volunteer board of directors. We rely on donations from the public and the generosity of our partners to develop and deliver our programs. Please consider including our Foundation as one of your chosen charities.

## Contact us/Donate to

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