



A Teenager's Guide to

**THRIVING**  
WITH CELIAC  
DISEASE



**Children's National.**



## WHAT'S INSIDE

<b>Welcome</b> from Chloe.....	3
My <b>Journey as a Teen</b> with Celiac Disease .....	4
Becoming a <b>Proactive Advocate</b> .....	5
<b>Understanding the Basics</b> of this Autoimmune Disease .....	6
The Facts: What is Celiac Disease? .....	6
Why Did I Get Celiac Disease? .....	7
Can I Die from Celiac Disease?.....	7
Is there a Cure for Celiac Disease? .....	8
What's the Difference Between Celiac and Gluten Sensitivity? .....	8
<b>Thriving</b> with Celiac .....	9
Going to <b>School</b> .....	10
<b>Dining Outside</b> of Your House .....	13
Going to a <b>Friend's House</b> and Spending the Night .....	14
<b>Party Time!</b> .....	15
<b>Grocery Shopping</b> .....	16
<b>Sleepaway</b> Camp.....	17
Looking at <b>College</b> .....	18
<b>Talking</b> About Celiac Disease .....	18
Celiac Disease and <b>Mental Health</b> .....	19

# HI ALL!

## My name is Chloe.

I'm here to take you on my journey through celiac disease while giving you some tips and tricks to make your teenage years with celiac easier than they may seem!

Before February of 2015, I was just like every other kid. I may have been the shortest girl in my class my whole life, but it never concerned me or crossed my mind. That all changed at my yearly physical right before my 13th birthday.

My pediatrician told me that I had only grown half an inch and gained no weight since the previous year. At an age where I should have been getting taller and gaining weight, I was stuck at 4'10" and 70 pounds.

One month, one endoscopy, and a few blood tests later, I officially became a kid with celiac and I didn't even know where to start...

My hope is to make sure that no other kid or teenager feels like I did when I was diagnosed. I hope you will read about my journey and feel inspired to become a strong advocate to live a healthy and very normal life.

Let's get started!

Chloe



## My Journey as a Teen with Celiac Disease

Since I was diagnosed with celiac at the beginning stages of middle school, my experience with learning how to be a kid with celiac was very different from those who were diagnosed as babies, toddlers, or even elementary schoolers.

At a time in my life when I was starting to become more independent, it seemed pretty inconvenient to me to be diagnosed with this disease that limited me so much. It was hard for me to wrap my head around the idea that I would have to call restaurants in advance to see if they could accommodate me, and to bring snacks with me everywhere in case I couldn't find something, and to eat before an event in fear that I would be hungry and not be able to eat anything. My middle school brain didn't really know what to do.

# Becoming a **PROACTIVE** ADVOCATE

In learning how to deal with my celiac disease, I was put into a lot of different of situations that served as learning experiences for me in eating gluten-free. It may seem hard, but really, once you know how to be proactive and advocate for yourself, it can be easier to live with celiac than anticipated.

In managing celiac disease, a teen most likely has to think about things like **eating out, going to a friend's house and spending the night out, eating at school, going to parties, buying groceries, going to sleep-away camp, and looking at colleges.** It took me a while to figure out how to handle all of these situations, but now that I know, I'm going to break them all down for you and give you some tips along the way!

But....first we have to talk about some of the stuff that's important from a medical perspective. It won't take long, I promise!



## The Facts: What is Celiac Disease?

It's important to accept that you do have a medical condition and you really need to understand what that means.

Celiac disease is a **genetic, autoimmune disease** where the body targets an attack on the small intestine. The small intestine's function is to absorb all of the nutrients from the food we eat including vitamins and minerals.

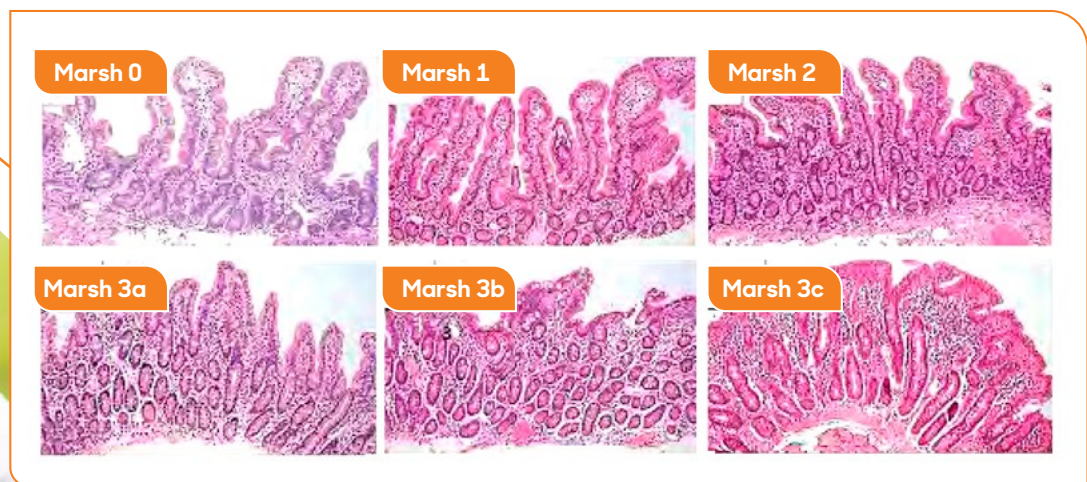
Ironically, in celiac disease, damage to the small intestine is **caused by food – specifically, a protein called gluten, which is found in wheat, barley, and rye.**

When gluten is ingested by those of us with celiac disease, an autoimmune reaction causes inflammation and damage to the nutrient-absorbing villi and the surrounding tissue. Villi are tiny, finger-like projections within the small intestine that become blunted, or

shortened, when a person with celiac disease ingests the protein. As the villi become shortened, less surface area is available and fewer nutrients can be absorbed.

The end result is that when the body isn't being adequately nourished, other conditions and diseases can occur which further degrade and complicate the quality of life for those who remain undiagnosed. Injury can be found in nearly every system of the body: the skeletal, reproductive, neurological, and dermatologic systems to name a few.

Below are some pictures of what the villi in your intestines look like. You want them to be long and look like fingers so they can absorb lots of nutrients (like the first picture below that says "Marsh 0"). The bottom row shows villi that have become damaged. The flatter the villi become, the fewer nutrients they absorb from food.





## Why Did I Get Celiac Disease?

We know that celiac disease is a genetic, hereditary autoimmune disease. This means that your parents have one more genes that they passed on to you during conception. Some people with these genes end up developing celiac disease, while others do not.

It is possible that there is an unknown environmental trigger that activates your body's autoimmune response to gluten. Many people report their "active" celiac disease symptoms arising after an emotional stress on the body—think sickness (like a bad virus or bacterial infection), emotional distress, surgery, etc.

It is important to know, however, that **nothing you or your parents did** caused you to develop celiac disease.



## Is there a Cure for Celiac Disease?

The only treatment for celiac disease is a lifelong gluten-free diet, meaning total elimination of gluten from the diet. There is also **no way to stop a reaction if you accidentally eat gluten.**

There are some drugs in development and some going through the clinical trial process of receiving FDA approval. Some of these drugs are meant to aid in the tolerance of small amounts of gluten in celiac disease patients (think preventing cross-contact), and others are meant to replace the gluten-free diet. Until anything is approved by the FDA, though, the gluten-free diet is our only treatment.

To date, none of these medications under review have been approved. Therefore, no marketed products for better gluten tolerance are recommended by the Children's National Celiac Disease Program.



## Can I Die from Celiac Disease?

Untreated celiac disease can cause a multitude of serious conditions, including malabsorption, cancers, severe vitamin & mineral deficiencies, and secondary conditions like thyroid problems.

The good news is that once the gluten-free diet is in place and your body has had time to heal, many of the underlying symptoms and related conditions can resolve with a change in diet alone.



## Celiac Disease vs Gluten Sensitivity

Celiac disease and gluten intolerance are different conditions and represent part of the spectrum of gluten-related disorders.

With **celiac disease**, gluten sets off an autoimmune reaction in the small intestine. The gluten protein triggers the immune system of a person with celiac disease to attack the patient's small intestine. Left untreated, celiac disease can lead to the development of other autoimmune conditions, as well as osteoporosis, infertility, neurological conditions, and cancer.

In contrast, **non-celiac gluten** sensitivity is not associated development of antibodies, damage to the gut, or the same serious complications. The most common symptoms include abdominal pain, fatigue, headaches, "brain fog," or tingling/numbness in one's hands or feet.



# THRIVING with Celiac Disease!

## Going to School with Celiac Disease

There are lots of parts about going to school that you have to think about with celiac disease. Eating at school took me a while to figure out. I have never been much of a "lunch eater" and I've always been relatively picky with my food. Here are some of my best tips for managing celiac at school.



**SCHOOL LUNCHES:** Before being diagnosed, I would get hot lunch at school. I would have pasta, or pizza, or sandwiches for lunch every day. When I was first diagnosed, I contacted the head of food services at my school and went with my mom to meet with him about my restrictions. Although it was a while ago and people were just becoming more aware about accommodating people with celiac, I was surprised about the reaction that I received from my school. They knew exactly how to handle my gluten-free diet, regarding cross-contact and that kind of stuff, but they really were not very interested in what I wanted to eat. They said that I would have something set out for me to the side and that would be my only safe option.

To me, that wasn't so appealing. I didn't know what kind of food they would give me and whether it would even be good or not, so I decided to start **bringing my own lunch to school**. It was the right choice. I bring gluten-free sandwiches, pasta, salads, and all kinds of snacks. That might not be the right route for everyone, but for me, I like packing my own lunch and knowing that I'll like what I'm going to have to eat.

While the safest and easiest option is to bring your own lunch, if that does not appeal to you or you cannot bring your own lunch, talk with your school's administration and cafeteria staff to look at your options. Be prepared to educate kitchen staff about what the gluten-free diet is and how to prepare your food while limiting cross-contact.



**FIELD TRIPS:** In order to make it as easy as possible on yourself and your school, I think that it is always safer to bring your own food on school field trips. If you do, you'll know that you won't get hungry, you know that you'll like the food you have to eat. You'll also know that it could make it easier on the school too since it would eliminate extra work and coordination in order to get you gluten-free food.



**CELEBRATIONS:** At the beginning of the year, ask your teachers ahead of time about any planned events where food will be served. Depending on your school's resources, you could request a safe option for yourself, or permission to bring your own, safe food. This also applies to activities affiliated with school like prom and winter formal.





## 504 Plans and Celiac Disease

Ok fine, this isn't a fun topic, but it's an important one. Your parents and medical team are probably going to bring up the idea of setting up a 504 plan at school. What does this mean? If you go to a public school or even a private school that receives federal funding, they are required by law to accommodate a gluten-free diet for students with celiac disease.

A 504 plan is helpful for middle and high school students because of the freedom and peace of mind it provides. Students are no longer in a classroom with just one teacher all day. We are often in contact with five or six teachers throughout the day, right?!

A 504 plan provides all of these teachers with information about the student's celiac diagnosis and needs, taking the burden off of the student to keep track of whom they've told. A 504 plan also holds the school accountable for providing accommodations for the student.



Any school that receives state or federal funds is obligated to provide these accommodations. So, any time food is normally provided in a school-sponsored setting like a field trip, school dance, after school activity or sport etc., there should be an accommodation made for gluten-free food to be available.

For more information about 504 plans and getting one in place, please reach out to the Celiac Disease Program at Children's National at [celiac@childrensnational.org](mailto:celiac@childrensnational.org).

Please note that 504 plan services are only available to patients of the Celiac Disease Program at Children's National. You can also review the 2020 Voluntary Recommendations for Managing Celiac Disease in Learning Environments at <https://childrensnational.org/departments/celiac-disease-program/resources-for-families/gluten-free-at-school>



## Dining Outside of Your House

Eating out was probably the hardest thing for me to figure out how to navigate after being diagnosed. I'm here to tell you how to handle eating out and make it as celiac-safe as possible!

#1.

**Tell the restaurant you have celiac disease.** You'd rather say something than get sick, right? Don't be afraid of embarrassing yourself, because you won't. Your server will be glad that you informed them. They'll know to handle your order differently if you tell them, but how would they know if you don't?

#2.

**If you're not sure, ask.** You would rather just ask the question than get sick. It's as simple as saying, "I have celiac disease, do you know if this can be made gluten-free?" If the waiter or waitress doesn't know the answer, then ask for the manager or to speak with the chef directly. It's definitely better than guessing.

#3.

**Keep an eye out for menu symbols.** Restaurants have become a lot more accommodating of gluten-free customers. And now, many restaurants use symbols or other indicators on their menus to show what food is gluten-free, or can be made gluten-free, and what cannot. Always keep an eye out for those because they can be super helpful!

#4.

**Always order the "safe" option.** Of course you should ask if you are curious about a certain option, but if you get an answer you are not confident in, or have a feeling that something might not actually be gluten-free, then stick with something that you know is safe. It's always better to go with the safer option. Of course this is not ideal, but it is more important to be safe with your gluten-free diet.

#5.

**At "fast-casual" style restaurants, ask to change their gloves and use new utensils.** There is a lot of potential for cross-contact at these "fast casual" restaurants. They can be so great for kids with celiac disease in terms of convenience but their inevitable cross-contact can make it hard. So, simply ask the staff to use clean gloves and utensils to make your meal.

Make sure you **advocate for yourself** when eating out! It's not a bad thing to ask about getting gluten-free food or telling your waiter or waitress about your celiac disease!



## Spending the Night at a Friend's House

Just like dining out, it is important to advocate for yourself and plan ahead when going to a friend's house. Here are some pointers for going to a friend's house and sleeping out that I use all of the time!

#1.

**TALK TO YOUR FRIEND BEFOREHAND.** Remind your friends about your celiac and your specific food restrictions before you go to their homes. Make it clear to them what you can and can't eat. You don't want to be put into an uncomfortable position at their homes if you are served something that you can't eat, so make sure that you are clear about eating gluten-free. Make sure to give your friend some time in advance to plan since not everyone has gluten-free food in their homes.

#2.

**PLAN AHEAD.** If you'd rather bring your own food to a friend's house, then make sure to think ahead. If you are sleeping over, bring something for breakfast. If you are going to be at your friend's house for dinner, bring enough for you to eat dinner as well. You can also bring enough gluten-free food for you and your friend! Think about all of the meals you'll be eating in advance and prepare accordingly.

#3.

**BRING SNACKS.** Don't be afraid to bring your own food. You'll never know when you're going to get hungry or whether your friend has snacks for you to eat, so it's always safer to come prepared and bring your own. My go-to snack to bring to a friend's house is usually, a vegetable, like sugar-snap peas or carrots, some sort of protein, like cheese or peanut butter, and a fruit, like sliced apples or bananas.



## Party Time!

Since we go to all different kinds of parties at our age, it's important to think ahead and plan in terms of eating gluten-free. As you may have noticed by now, **planning ahead** is really important for me personally and has proved to be one of the best ways for me to manage my celiac disease. In terms of going to parties, I always do the following:

#1.

**EAT BEFOREHAND.** In order to make sure that I won't get hungry, I always play it on the safe side and eat before going to a party.

#2.

**BRING YOUR OWN FOOD.** It's never a bad idea to bring a little bag of snacks with you. I personally bring snacks with me almost everywhere I go. Especially when going to parties, you could get tired and hungry when you're dancing or relaxing with your friends, so, just bring your own gluten-free snacks in case.

## Grocery Shopping and Gluten-Free

Through my whole diagnosis stage, I had an amazing support system of doctors, family, and friends. Right after I was diagnosed, I was lucky enough to have a family friend, whose daughter has celiac, take me to a few different grocery stores and show me how to find gluten-free food and recommend all of the good brands. I thought that grocery shopping would be one of the harder things to navigate with celiac, but actually, it's pretty simple if you know how to look for the right things!

First of all, I want to make sure you think about naturally gluten-free foods, like fresh fruits and vegetables, brown rice, quinoa, poultry, steak, fish, dairy, etc. There is a huge list of foods that are naturally gluten-free and safe to eat.

Then there are packaged foods....of course it's hard to tell what's gluten-free and what's not if it does not say so on the label explicitly. You want to make sure that you're reading food labels correctly (looking for **wheat, rye, and barley**)....and looking for the "gluten-free" symbols on your packaged food.

Sometimes, you want to know if an item is gluten-free even if it does not have the "gluten-free" symbol directly on it. In that case, you can try and look on the manufacturer's website for more information. Sometimes you might see a statement on the packaging that mentions how the product was processed. You can deduce whether or not a product is safe to eat this way:



**"Made in the same facility as wheat-containing ingredients"**

This is safe for people with celiac disease. Facilities can be miles long, and it doesn't mean that anything comes into contact with the gluten-free food!

**"May contain wheat"**

Put it back on the shelf. It's best not to take a chance with this one.

Just remember: the gluten-free symbol or wording on a product means the product is safe for you, **REGARDLESS** of what the label says about processing procedure!

Give the manufacturer a call and ask them about their cross-contact and cleaning procedures.

**"Processed on the same lines/equipment as wheat-containing ingredients"**

For a more detailed explanation of grocery shopping on a gluten-free diet, please check out the **Grocery Store Guide** from the Celiac Program at Children's National at [childrensnational.org/departments/celiac-disease-program/resources-for-families](http://childrensnational.org/departments/celiac-disease-program/resources-for-families)



## Looking at Colleges

Deciding where you are going to college is a big task in itself, but adding in having to find a celiac-safe environment can make finding the right college for you a little bit more difficult.

When you're doing your college searches, make sure that you ask questions. That's the only way that you are going to figure out whether a college campus is safe for you. A lot of colleges nowadays are more accommodating for kids with all different kinds of food restrictions. Many different college campuses label their food with different allergen information which can be very helpful for kids with celiac.

In addition, there are a lot of resources to inform people about celiac-safe college campuses. Many websites show colleges that accommodate gluten-free students which can be very helpful when looking for the right school for you.

For more information about planning for college, please tune in to the **Celiac Program Webcasts** at: [www.gotostage.com/channel/celiacdiseaseprogram](http://www.gotostage.com/channel/celiacdiseaseprogram)

## Sleepaway Camp with Celiac Disease

Since going into 6th grade, I've been attending a sleepaway camp that has become my second home. Once I was diagnosed with celiac, I had to figure out a way to be in a safe, gluten-free environment at camp. So, what did I do?

I contacted my camp and told them about my celiac diagnosis and all of the restrictions for the gluten-free diet. Surprisingly, they actually made it easier than I expected it to be.

I was lucky enough to attend a camp that knew how to deal with celiac. They had designated cooking staff for kids with celiac, they cooked my food in a separate facility, and allowed me to bring my own snacks from home in case I wanted them.

Not every camp is like mine, so you may need to ask a bunch of questions. This is ok. Just be prepared to educate and make sure you don't go to camp until you feel confident that you will be kept safe. In going to sleepaway camp, it's very important for you to know that you are going to be in a safe environment.

For more information about attending summer camp safely, please tune in to the **Celiac Program Webcasts** at [www.gotostage.com/channel/celiacdiseaseprogram](http://www.gotostage.com/channel/celiacdiseaseprogram)





## Talking about My Celiac Disease

Learning about how to talk about celiac is one of the most important things you can do. If you don't explain it properly to others, then you could end up eating something unsafe. Here are some key ideas that I make sure to talk about when telling people about my celiac to ensure that my food will be safe and that people understand what this condition truly is.

**What Gluten Is:** I make sure to explain that gluten is a protein found in wheat, barley, and rye as well as all other derivatives of these ingredients.

**How I was Diagnosed:** When people understand how I was diagnosed, (the endoscopy and all of the blood work) they realize how serious celiac disease really is.

**What Eating Gluten Does to Me:** Especially at restaurants, in order for people to really understand how serious celiac disease is, I make sure to say that it can make me very sick. I'll say that I can get a really horrible stomachache and sometimes throw up. People will understand better how to handle the disease if they know what it does to you.

**Cross-Contact:** I make sure to explain how to avoid cross-contact by keeping gluten-free foods separate from those that contain gluten. I like to think of it this way: pretend that gluten is raw chicken. If you touch raw chicken, you're going to want to wash your hands before you touch anything else, right?! It's the same for utensils, too. If you can wash raw chicken off of your hands and utensils, you can get rid of gluten, too



Celiac disease doesn't just affect your body... it also affects your mind. Let's talk about it...

# Celiac Disease and MENTAL HEALTH

It is absolutely normal to feel shocked, sad, angry, or just about anything after learning about your diagnosis. Many people find that it feels like a major loss to make this change. For most people, it will get easier with a little time. Here are some suggestions for helping yourself feel better.



**Connect with Others:** Many people find it hard to feel connected to people when adjusting to the gluten-free diet. It may be helpful to meet others with celiac disease to get tips, hear about their experiences, and know you're not alone. Try out our teen meet-up events or join an online community. Just be careful of all the incorrect information that is out there and always factcheck things you hear from others.



**Take Baby Steps:** It is normal to feel overwhelmed by the information needed to successfully follow the gluten-free diet. Most people have trouble making dietary changes all at once because it can be paralyzing. Try to make small, easy changes at first and build from there. Pick short-term goals each week and try to reach them before attempting a new goal. No one is perfect, but with practice, the diet will become easier and easier.

## Ask for Help:

If you're finding it hard to cope with your diagnosis or the diet (or both), reach out for support. This might be a friend, a parent or other family member, or teacher or counselor.



## Build Your Independence:

It's very important (and fun) to become more independent as you get older. Ask your parents how they would be willing to give you more responsibility for your diet, such as being more involved in grocery shopping, meal preparation, and researching the safety of foods. Of course, this is a gradual process and your parents should be helping you make informed decisions to stay healthy. As these skills are built, you can become increasingly self-reliant in following the gluten-free diet. You will feel better being in more control over your diet and knowing what is safe or not.



**Empower Yourself:** You might be surprised by all the foods and snacks you love that are already gluten-free. Work together with your parents to learn ways of finding out what foods are safe or not. Try out some apps and look up restaurant menus and reviews. You will feel empowered knowing how to find out what you can and cannot eat.



## Facing Your Fears:

It is normal to feel nervous about gluten exposures or physical symptoms which can lead to avoiding things that scare us. Look for ways to practice doing things that make you a bit nervous while still keeping the chances of exposure to a minimum. If you have been avoiding going out with friends, try eating ahead of time and going to spend time with them, even if you aren't ready to order at a restaurant yet. Over time, try researching a bit about restaurants that might have options for you or ask a question to a server to find out more. Once you feel at ease, you will find your own level of comfort that will help you live your life the way you want to.



## Stress Relief Techniques



**JOURNALING:** Research has shown that journaling is an effective stress reliever and can even promote longevity. It is a wonderful opportunity to speak your mind without any fear of pushback or judgment. Try finding a journal with writing prompts, or even searching online for ideas. Of course, you can always just write about what you're feeling without any prompts.



**MEDITATION & MINDFULNESS:** Meditation helps to calm the mind through mindfulness. Mindfulness can be thought of as being present, aware, or concentrated on the present moment. For beginners, try listening to guided meditations online.



**BEEP BREATHING:** Deep breathing techniques have been shown to reduce anxiety, relieve pain, improve mood, and improve the function of multiple body systems. If you're a beginner to deep breathing, try "Belly Breathing". You can sit down or lie down for this exercise. Place one hand on your belly (directly below your rib cage) and the other on your chest. Inhale slowly through your nostrils and feel your stomach rise while your chest remains still. Once you have inhaled as deeply as possible with your chest still exhale through pursed lips, like you're blowing through a straw. Repeat this process for 5 minutes.



### **EXERCISE OR GO FOR A WALK:**

Getting your body moving can help unleash frustrations and clear your head. Some people just need some fresh air, and others like to exercise to release anger or hurt.



### **DISTRACT YOURSELF:**

Sometimes your brain needs a break! Turn on a favorite movie or TV show, read a good book or listen to some music. It can help to focus on something else for a bit.



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