

THE TEEN AGER'S ULTIMATE GUIDE TO LIVING WITH CELIAC DISEASE

AT THE FOREFRONT
UChicago Medicine
Celiac Disease Center
cureceliacdisease.org

Over time, my children and my entire family learned to adapt and adjust, and you will too.

—Dr. Verma

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hello

My name is Ainsley. I am 14 years old and like you, I have celiac disease. Since I was diagnosed five years ago, there are so many more gluten-free options. There is also a lot more awareness for celiac disease. But some days it's still hard.

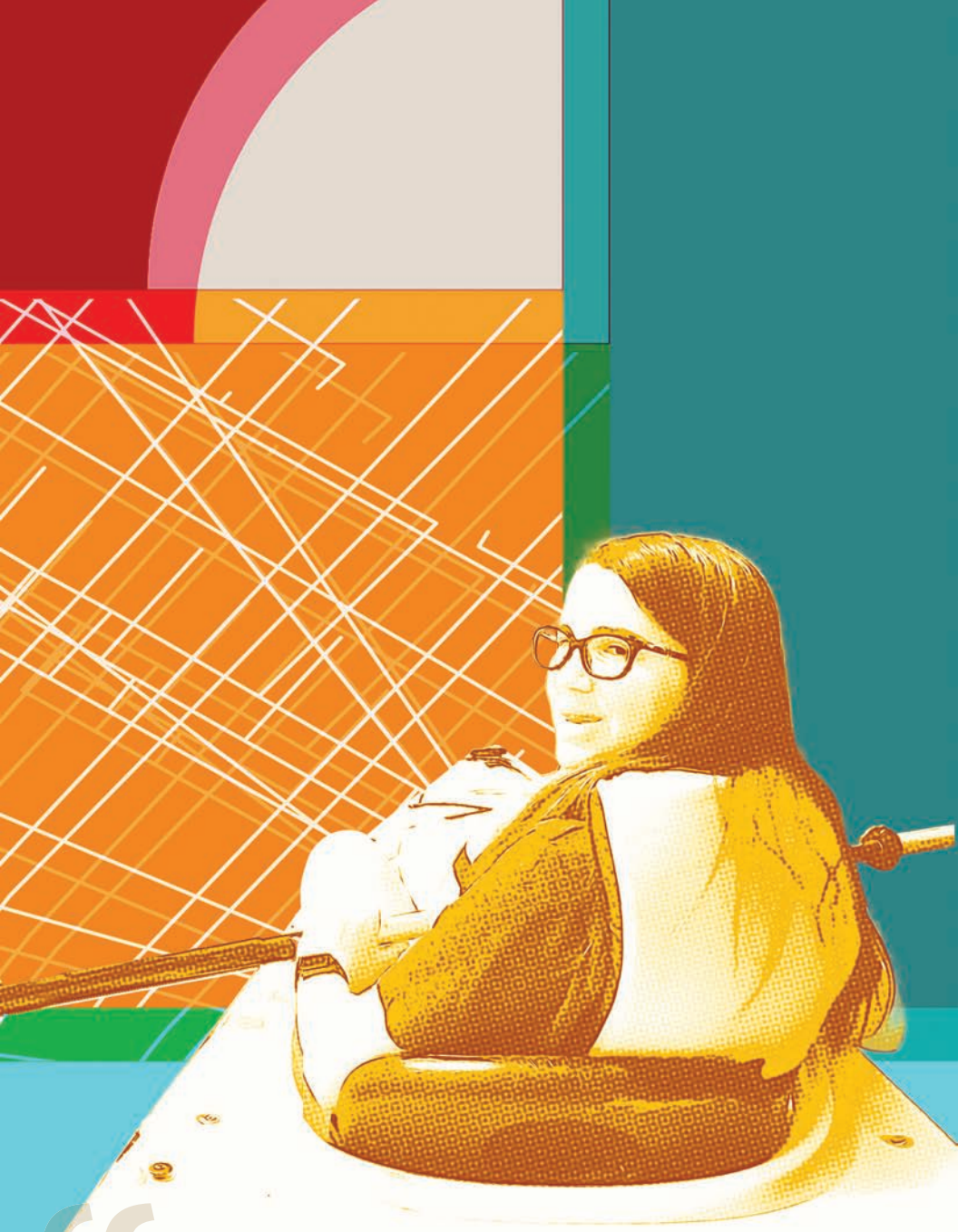
I know what it's like to be a teenager with celiac disease. It can feel overwhelming. No matter how much you plan, mistakes can sometimes happen. I remember one time I went to an overnight camp. My mom had coordinated all the food on-site for me. On the last day of camp, they served pizza. I was told it was gluten-free. Guess what? It wasn't. When my mom picked me up, I was feeling so sick. But even though this happened, it didn't stop me from doing activities I love.

I hope that other teens who read this booklet can get tips and advice to make things a little bit easier. My personal tips are to use the Find Me Gluten Free app to help you find gluten-free options when you're traveling or even in your hometown, and to listen to the Celiac Project Podcast. I get so much great information from that podcast. Oh, and if you're looking for some really awesome gluten-free sweets, try Caramel M&Ms and Tate's cookies! They are my favorites.

Just remember that you are not alone. There are lots of teenagers like me who also have celiac disease. I know it is challenging to have to plan everything in advance, pack your own food, and always have to speak to the chef in restaurants, but no matter how you feel now, just know it will get better in the future. It did for me, and I know it will for you too.

I hope this information will make you feel inspired to become an advocate for yourself and for others with celiac disease and to enjoy a healthy life.

Ainsley



“... no matter how you feel now, just know it will get better in the future. It did for me, and I know it will for you too.”



You have celiac disease...

WHAT NOW?

Does Ainsley's story sound familiar? Have you ever found yourself in a situation where having celiac disease felt overwhelming? Whether it's eating out with friends, going to sleep-away camp or even going on a date, when you have celiac disease, there is a lot to think about.

Having celiac disease means more than just a gluten-free diet. It means learning what questions to ask and how to ask them. Maybe your parents or caregivers did this for you in the past, but now that you're a teenager, you probably have to advocate for yourself more and more.

We know it's not easy. But with **the right information**, the right support, and the right preparation, there is no reason you can't enjoy fulfilling and exciting teenage years.

We hope this guide will provide you with facts and tips to help you along the way.

get the FACTS about Celiac Disease

What exactly is Celiac Disease?

Celiac disease is a medical condition. **It's important for you to understand exactly what it means and how you need to treat it**. If not treated properly, celiac disease can have serious long-term effects.

What is celiac disease? **It's an autoimmune disease**. This means that your body's immune system, which normally protects you against germs like bacteria and viruses, mistakenly attacks your body. More precisely, **it attacks your small intestine**.

It's a food that triggers the attack. **Specifically, it's a protein called gluten, which is found in wheat, barley and rye.** When people with celiac disease eat foods that contain gluten, their immune systems react by creating damage to the lining of the small intestine and to its **tiny hair-like structures called villi.**

These villi have a very important job. They absorb all the nutrients from the foods that you eat. If you put the villi under a microscope, you would see that they normally look like long fingers. But when they are attacked, they can become shortened and weakened and less able to absorb important nutrients.

This means that the body doesn't get properly nourished. As a result, other conditions and diseases can occur that can cause complications and affect the quality of life in people who have not been properly diagnosed with celiac disease, or who do not avoid eating gluten. And it's not just the digestive system that is affected. These conditions can affect the brain, the skin and reproduction as well.



Celiac disease occurs in people who have certain genes and eat food that contains gluten.

How did I get celiac disease?

Celiac disease is genetic. This means that one or both of your parents passed certain genes to you. You may have heard your doctor talking about these genes - HLA-DQ2 and HLA-DQ8.
Some people who inherit these genes end up developing celiac disease, and some people don't.

Experts believe that there is an **environmental trigger** that causes the body to "activate" an autoimmune response to gluten. This isn't completely understood, but many people report experiencing celiac disease symptoms after a stressful event, a bad illness or a surgery. **One thing that is certain, though, is that to develop celiac disease, you must be eating gluten.**

We don't know exactly why some people get celiac disease and some people don't, but we do know that **there is nothing that you or your parents did that caused you to develop celiac disease**. We also know that people can develop celiac disease at any age - from 6 months to 60 years and beyond!

What are the symptoms of celiac disease?

The signs and symptoms of celiac disease can be different for everyone. Some of the most common symptoms include diarrhea, bloating and gas, abdominal pain, nausea, vomiting, and constipation.

What is important to know is that **some people don't have any symptoms at all. Others experience symptoms that are completely unrelated to the digestive system**. Some people with celiac disease develop an itchy rash on their skin and some experience headaches and fatigue. Other symptoms include weight loss, iron deficiency, joint pain, damage to the enamel of the teeth and tingling in the hands and feet. Even delayed puberty, and slow growth and learning disabilities can be symptoms of celiac disease.

If you haven't been diagnosed with celiac disease but you are experiencing these symptoms, **it's important to see a doctor before trying a gluten-free diet.** If you stop, or even reduce the amount of gluten you are eating before you are tested for celiac disease, it can affect the test results.

How gluten-free do I have to be?

For people with celiac disease, **even the tiniest amount of gluten can be harmful**. This means that even something that might have been contaminated with gluten, such as a baking pan or a serving spoon, must be thoroughly cleaned before using it. **When gluten is removed, the small intestine will begin to heal.** However, if left untreated, celiac disease can lead to the development of other serious autoimmune conditions.

There are other gluten-related disorders, such as non-celiac gluten sensitivity, that do not have the same serious complications, even though they may share some of the same symptoms. It's important not to confuse the two. **If you've been diagnosed with celiac disease, any gluten is too much gluten.**

Can I be cured of celiac disease?

The only current treatment for celiac disease is to follow a strict, lifelong gluten-free diet. This means completely eliminating gluten from your diet.

For some patients, the intestines don't completely heal, and they continue to suffer from symptoms. This is usually because they continue to eat gluten, even if it's in very small quantities. Sometimes this is accidental or because something they've eaten has been contaminated with gluten. **Once you have accidentally eaten gluten, there is no way to stop a reaction.** Sometimes, though, what appears to be a reaction to gluten is actually caused by something else. That's why it's important to talk to your medical team if you have any symptoms.

There are several drugs currently being developed and tested that hope to help people with celiac disease be able to tolerate small amounts of gluten. They aren't expected to replace a gluten-free diet, but they could be beneficial in case of cross-contact exposure. So far, none of these medications have been approved.

For people with celiac disease, there is currently no substitute for a gluten-free diet.

LIVING

with celiac disease



It can be hard to explain why you can't have any gluten – even the smallest amount.

And it can be even harder when your friends don't really understand what you're going through. So, how do you handle fun times with friends when food is involved? Here are some tips on handling common social situations with friends.

SLEEPOVERS

The good thing about sleepovers is that you usually know about them ahead of time. This means you can do some planning. Here are a few ideas to help make a sleepover easier:

Talk to your friend(s) ahead of time and remind them about what you can and cannot eat. This way, you can avoid an uncomfortable situation if they offer something you can't eat. Give as much advance notice as possible. It's possible that your friend(s) might want to get gluten-free food to serve and might not already have it in the house.

- You could also bring your own food. This might make it easier for both you and your friend(s). You could even bring enough food to share. Don't forget about breakfast!

- If there is a friend you spend a lot of time with, you could ask to leave some snacks in his/her freezer. That way, you'll always have something to eat when you're at your friend's house.

- You could also try hosting the sleepover yourself.

SLEEPAWAY CAMP

Many teens with celiac disease enjoy sleepaway camp experiences. Even Boy Scout trips where the campers are required to shop for and cook their own food can be successful. The most important thing to know about camp is that you will need to educate others about celiac disease. You will need to explain the restrictions of a gluten-free diet to camp directors and ask a lot of questions. Some camps are very good at taking steps to keep you safe. At others, you may need to ask a lot more questions. This is OK. Frustrating, maybe, but OK. Just be sure that before you go, you feel good about being kept safe while away from home.

You will also need to talk to your fellow campers. It's not easy to talk about celiac disease. And yes, it is tiresome to have to keep saying the same thing over and over every time you meet someone new. But, if they don't understand what you're going through, how can they ever become your supporter/advocate?

PARTIES

Like sleepovers, you can usually plan ahead for celebrations like birthday parties and bar/bat mitzvahs.

- If the event is happening at a restaurant or at a venue where food will be catered, **call ahead.** Find out if there will be any gluten-free options and if so, what they are. We are sure your parent(s) or guardian(s) will be happy to guide you.

- For some parties, you might want to bring your own food. (Ask the restaurant if they will allow you to bring in food. If necessary you can get a letter from your doctor.)

- For others, you might want to eat before you go.

- If you do eat snacks at a party, stick with what you know is safe, maybe some potato chips and a soda. When in doubt, don't eat it.

- Even if you eat beforehand, it's always a good idea to have some snacks with you. You might get hungry!

LAST MINUTE GET TOGETHERS

So, what about things you can't plan ahead for? You know, like when the bell rings and your friends decide to meet up at a local restaurant after school, or when they call you at 5 p.m. to go bowling at 6? For sure, when things happen last minute, it can be more challenging. But it doesn't mean you can't still participate and enjoy time with your friends. If you want to join the activity, don't say "no!"

Here are a few ideas to help you navigate those spontaneous activities.

- **Never ever leave home without a snack**. Grab one when you walk out the door. Keep an energy bar in your pocket or your backpack or in your car. This way, if your friends decide to go to McDonald's, you can still go along, and you will have something with you that you can eat.

- **Keep some of your favorite candy bars in the freezer.** If you grab one in the morning, it should be defrosted by the time school is done. And if not, you can still eat it like a frozen ice cream bar. If you go someplace where a salad is your only choice, it will taste a lot better with a Snickers bar on the side.

- **Suggest a restaurant that you know has gluten-free options.** Sometimes when your friends suggest places where you can't eat, it's simply because they just don't know or aren't thinking about gluten-free choices. You think about it because you have to. For people who don't have celiac disease, sometimes they just forget.

- **Educate your friends.** Share this information with them too!

> I never know when food situations will come up with my friends, so I always have snacks on me just in case. —Liam

DATING

First dates are tough for everyone. You might be nervous about having to talk about celiac disease, but chances are your date is nervous too. The fact is that you're going to have to talk about it. It's probably going to feel awkward at first but telling your date as soon as possible will take the pressure off and make the date more fun for both of you. Read on for some dating tips especially for people with celiac disease.

- **Find out where you are going on your date.** Offer to help plan. If you're going to a restaurant, call ahead and ask about gluten-free meals. Or suggest a place you know has options for you.

- **If you are going someplace other than a restaurant,** such as a driving range or an arcade, you can still call ahead to find out about what snacks they serve.

- **Always bring a snack** with you, just in case.

- **Suggest dates that don't revolve around food.** Some examples might be a bike ride or a hike.

- **When you talk to your date,** mention that people with celiac disease could even get sick from kissing. Your date is probably wondering about this and will be very thankful to know ahead of time. Yes, it may be an uncomfortable conversation. But it will be *way* more uncomfortable if you leave this until the moment a kiss is about to happen. (If your date wears makeup, you also need to mention that some lipsticks contain gluten.)

- **Consider bringing a new travel toothbrush and toothpaste** with you for your date.

- Whether or not your date goes well, remember that **having celiac disease does not define you**. Your strengths and positive attributes are more important than any challenges celiac disease might throw at you. **When you find "the one," they will accept you just the way you are – gluten-free and all.**

If you are under age 21, you shouldn't be drinking alcohol. Period. But it is important to know which alcoholic drinks contain gluten because someday, you may be confronted with a choice, and if you make the wrong one, you definitely don't want it to be doubly negative because you've chosen something that could make you sick.

Just like food, you must read the labels on beverages too, and that includes alcohol.

Most distilled liquors are safe for people with celiac disease. This includes liquors like whiskey, gin, vodka, and rum. **Wine, which is made from grapes, is typically gluten-free, but beer is not**. In fact, anything that contains yeast or malt contains gluten. And it's not just alcohol. Even flavored coffees can contain gluten! Remember to **always read the label**.

> My favorite gluten-free snacks are rice cakes, frozen fruit and Sieta brand chips.
>
> —Libby



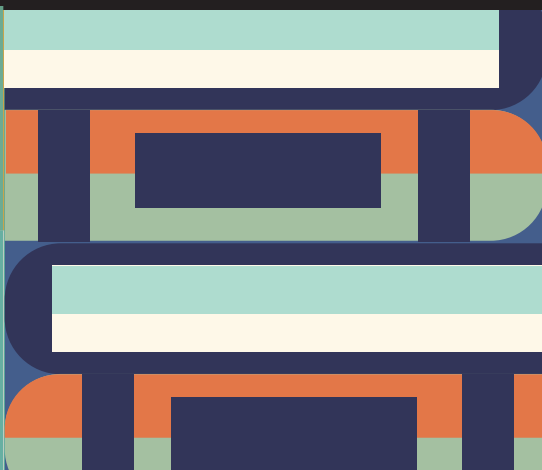




going to

SCHOOL

When you have celiac disease, going to school can seem challenging. From the cafeteria to field trips to school dances, many school activities involve food. You want to "fit in." You want to be "normal." But you also need to be safe. Here are some ways to deal with school that other teens have found helpful.



If you want to eat hot lunch at school, you will need to meet with the food services manager. You might be surprised to learn that your school already knows how to handle a gluten-free diet. But if they don't, you, along with your parent(s) or guardian(s), may need to educate the kitchen staff about what a gluten-free diet is and how to prepare your lunch without cross-contamination. Remember that educating staff will not only help you, but also future students as well! If you attend a public school (or a private school that gets federal funding), you are entitled to a gluten-free lunch. See the section below about the 504 Plan to learn more about this.

Many teens prefer to bring their own lunch to school. This way you know you will have something that you like to eat. Whether it's a gluten-free sandwich or pasta, salads or just a bag of snacks, you can feel comfortable that your lunch is safe if you pack it yourself. And remember to always wash your hands before eating. This is a good idea for everyone, but especially for someone with celiac disease. You may have touched surfaces throughout the day that have been contaminated.



If you have art class, know that some art supplies, such as modeling clay, may contain gluten. **Go ahead and enjoy art. Just remember to wash your hands before you eat.**

FIELD TRIPS

Just like school lunches, if food will be served on a field trip, you are entitled to a gluten-free option. (See the section below about the 504 Plan.) If you will be eating out on your trip, you should call the restaurant or the caterer yourself to be sure that the gluten-free option is being prepared without any cross-contamination.

The easiest solution is to bring your own food on field trips. If you do, you know that you will have food you like to eat and that is gluten-free. Many teens prefer this because it's less hassle and makes them feel most comfortable.

SCHOOL DANCES AND ACTIVITIES

When it comes to school dances and activities like sporting events, you will need to ask questions. You might need permission to bring your own food, especially if the dance is a prom or other formal and is held outside of the school. Or you could call the restaurant or banquet hall ahead of time and find out if there will be any gluten-free options for you. Just like when you're hanging out with friends, make sure you bring at least a snack. If you have celiac disease, one of the best gifts you could give yourself is to always be prepared. Just in case.

If you do bring your own food, bring a mix of things. Maybe something salty, something sweet and something savory. That way, no matter what is being served at the dance, you will have something that satisfies you. If there's a delicious-looking cake being served that you can't eat, a bag of pretzels might not make you happy. But maybe a candy bar will.

When you move from elementary school to middle school or high school, you go from having one or two teachers who know you very well to having six or more teachers who may only see you for a short time each day. All of your teachers will read your 504 Plan, which means that they will have the information they need about your celiac disease. It's easier for them and it's easier for you.

So, what exactly is a 504 Plan?

It's a way to communicate any accommodations you need (and are entitled to) because of your celiac disease. **If you go to a public school (or a private school that gets money from the federal government), a 504 Plan means that your school has to provide you with a safe, gluten-free option at any school activity.** That doesn't just mean in-school activities. Say you're on the soccer team and your team has an end-of-year banquet, or you're on the debate team and you travel to another city to compete and you eat lunch out. Wherever you are, if the activity is sponsored by the school, you can participate. And it has nothing to do with how well you're doing in school. Having a gluten-free option has nothing to do with your grades.

Also, thanks to a law called the Child Nutrition Act, any gluten-free option the school offers you has to meet the same nutrition standards as meals served to other students. So, they can't just give you an apple, for example, while the rest of the school is eating pizza.

If you don't have a 504 Plan, talk to your parent(s) or guardian(s). They may need to contact your school guidance counselor to find out how to get one. If you don't already have the Celiac School Action Guidelines for Education, you can find it here. (Or ask your doctor for a copy). This helpful document includes recommendations for developing a plan to manage celiac disease at school.

EATING OUT

(or ordering in)



When you have celiac disease, you have to be careful about eating in a restaurant or getting food to go. Do your homework before you head out! Searching menus online will help you to know if a restaurant has gluten-free options. It will make dining out easier if you know before you go.

If you've been living with celiac disease for a while now, you've probably heard your parent(s) or guardian(s) ask a lot of questions. If you've been newly diagnosed, or if you're starting to eat out "on your own" with friends, you will need to learn to advocate for yourself. Yes, at first you might feel a little embarrassed or uncomfortable, but the more often you do it, the easier it will get.

WHAT TO ASK

The first thing to know is that you have to let the restaurant know you have celiac disease. The second thing to know is that you should ask politely. Chances are good that your server will be glad you spoke up. After all, if you don't tell them, how will they know? The restaurant does not want you to get sick.

To start, look at the menu and select a few choices that interest you. Many menus today include symbols to show which items are gluten-free or can be made gluten-free. Look out for them. They can be super helpful. Then, tell your server "I have celiac disease. Do you know if this can be made gluten-free?" Or "Can you confirm with the chef that this dish is gluten-free? It's important because I have celiac disease." You could also follow up with, "If I eat anything with gluten, like flour or breadcrumbs or soy sauce, I could get very sick."

When it comes to selecting your meal, always order a safe option. Just know that it might not be exactly what you want. Be prepared to eat something that isn't your first choice. Don't assume that anything is gluten-free. For example, sometimes restaurants will cover baked potatoes in flour to make them crispier. It's always best to order simple dishes without any coatings or sauces (or ones that can be made without coatings or sauces).

If you're unsure about anything, ASK!

If you're not sure how the restaurant prepares gluten-free food, ask questions such as, "Is there a separate prep space for gluten-free food?" or "Do you clean or use separate cookware and utensils for gluten-free food?" If you're ordering fried food, ask "Do you change the oil before making gluten-free food?"

WHAT TO ASK

If you're eating at a "fast-casual" restaurant, for example, Chipotle, be sure to ask them to change their gloves when preparing your meal. To be safe, ask to have a new container opened, for example, a tub of ice cream at an ice cream parlor. Cross-contamination can happen easily. Changing the scoop (or the serving spoon) won't help if the food has already been contaminated. Even if you feel embarrassed and even if there are 10 people behind you in line, ask. It takes practice to get comfortable, but you CAN do it!

These same questions apply to ordering food to go. Ordering through an online app may be convenient, but it's best to call and talk to someone who knows how the food is being prepared.

> If you go to a restaurant that serves bread first, bring your own gluten-free bread and ask for some oil to dip.
>
> —Dr. Verma

WHEN TO ASK

It's true that what you ask is important. But when you ask is also important. If you're eating in, be sure to tell your server right away. If you're calling ahead (or ordering takeout) try to call in the afternoon, before the restaurant gets busy. When the chef has 30 meals to prepare, he/she won't be able to give you the time you need to ask your questions.



If you eat at the same restaurant again, ask for the same manager or chef that you spoke to the first time and thank them! **They will remember this gesture and you will be helping others with celiac disease.**

WHO TO ASK

If you're dining in, start with your server. Make sure they understand how important it is that your food is not only gluten-free but also hasn't been contaminated with gluten accidentally. Your server will probably ask the chef or the manager to come and speak to you. If they don't offer, ask.

If you're calling on the phone, ask to speak to the manager. Inform whoever answers the phone that you have celiac disease and would like to talk to someone about how your food will be prepared.

GROCERY SHOPPING



You've probably been to the grocery store thousands of times with your parent(s) or guardian(s). But someday – maybe in high school, maybe in college – you'll be going by yourself. And when you do, it's important to be prepared.

The first thing to know is don't be in a rush. Go when you have the time to read the list of ingredients on every label. Even if you've bought something many times before, it's important to **read the label every time** because companies can (and do) change their ingredients.

Fortunately, there are many foods that are naturally gluten-free and safe to eat. From fruits and vegetables to steak, chicken, and fish to beans, brown rice, and quinoa, there are many choices. Here is some information to help make grocery shopping a little easier.



Not all brands of soy sauce are gluten-free, and your favorite candy may release a special holiday version that has extra ingredients. **Always check the labels!**

GLUTEN FREE **NOT GLUTEN FREE**

MAKING YOUR WAY AROUND THE STORE

Some parts of the grocery store are easier to shop than others. Take the **produce aisle** for example. Fresh fruits and vegetables are naturally gluten-free. This is a great place to start your shopping adventure. A crispy apple makes a great snack. And a salad is one of the easiest (and healthiest) gluten-free meals to prepare. You can fill it with any fruits and vegetables you like to eat. The more colorful, the better.

The dairy section also has many options. Dairy products like milk and cheese and plain yogurt are naturally gluten-free. Be careful, though, of anything that has something added to it, for example, chocolate-flavored milk or flavored yogurts. Also, be sure to look carefully at anything that says "low-fat" or "fat-free." Sometimes these products have starches in them to make them thicker and these starches contain … you guessed it… gluten!

> Popcorn is a fun gluten free snack.
>
> —Ainsley

Meat is naturally gluten-free but pay special attention to anything you buy from a meat counter. Stuffed chicken breasts, marinated meats, and meatloaf made with breadcrumbs are often sitting right next to the plain meats. It's best to stick with pre-packaged meat when possible. Beware of processed meats such as hotdogs and even rotisserie chickens! Also, be careful at the **deli counter**. **Slicing machines are usually only cleaned once or twice a day and the deli may make sandwiches from gluten-containing bread**. Cross-contamination is a real possibility. Stick with packaged meats that are labeled "gluten-free" (see *How to Read a Label* below) or if you are getting meat sliced, choose a brand that is labeled "gluten-free" and ask the staff to clean the machine first.

There are many naturally gluten-free foods. Check them out!

Meat	Poultry	Fish	Pork
Milk	Cheese	Fruit	Corn
Vegetables	Beans	Nuts	Potatoes
Rice	Quinoa	Amaranth	Buckwheat
Teff	Tapioca	Flax	Arrowroot
Chia	Millet	Soy	Sorghum

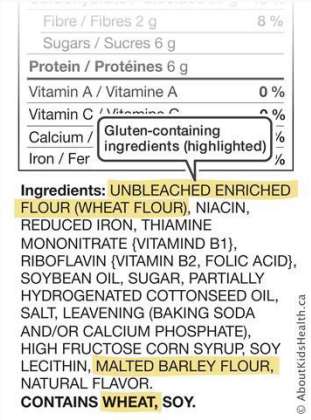


You might think you have to skip the bread aisle, but there are many gluten-free breads available. Sometimes you can find them on the standard bread aisle, and sometimes grocery stores have special gluten-free sections. You may have to try one or more grocery stores, but you should be able to find gluten-free versions of your favorite bread products such as bagels, rolls, and even pizza crusts!

One section you might want to skip is the bulk foods sections. Low prices on items like quinoa and rice are tempting, but bulk bins are often a source of cross-contamination. You never know if someone used the same scoop for wheat flour and then for brown rice. Unless your grocery store has a dedicated gluten-free section, it's best to just walk away. The same goes for the **soup and salad bar**. You never know if say a crouton fell in the dressing. If you must eat at the salad bar, avoid anything that is in a bin next to a gluten-containing item. When it comes to soups, assume they contain gluten unless they are specifically labeled "gluten-free."

So, what about snacks? Unless your snack is naturally gluten-free (say a piece of fruit or raw vegetables) it probably comes in a package. And that package has a label. And you will want to read every label very carefully every time.

HOW TO READ A LABEL



- The top 8 food allergens must be clearly listed in the ingredients section.
- Wheat is one of the top allergens, but barley and rye are not

Even though a food label may not list wheat as an ingredient, the food may still contain gluten!

Celiac Sprue Association®

Certified GF Gluten-Free

THIS PRODUCT IS CERTIFIED GLUTEN FREE

When it comes to packaged foods, it can be hard to tell what is gluten-free and what isn't. You know you need to avoid anything with wheat, rye or barley but there is a lot more to consider. Here are some things to look out for when grocery shopping.

- **Look for a certified gluten-free symbol**. These foods should not be made with any amount of gluten.

- **Wheat-free does not mean gluten-free**. Food manufacturers are required to label the top food allergens and wheat is one of them. But barley and rye are not. You've probably seen allergy statements on labels that say things like "Contains wheat, peanuts, and milk." This can be helpful in weeding out foods you can't eat, but you can't rely on these statements to know if a food is safe for you to eat.

- **Many people with celiac disease can eat oats** but make sure they are certified gluten-free because oats are often cross-contaminated with gluten products.

- **Some foods don't have to be labeled with top allergens.** These include meat, dairy, soup, broth, and chili. Avoid meats that have already been marinated or soups that don't specifically say "gluten-free."

- **Always read the list of ingredients**. If you have any doubt, put it back on the shelf.

- INGREDIENTS: ENRICHED PARBOILED LONG GRAIN RICE RICE, NIACIN, FERRIC ORTHOPHOSPHATE (IRON), THIAMIN MONONITRATE (VITAMIN B1), FOLIC ACID, ENRICHED VERMICELLI WHEAT AND DURUM FLOUR, NIACIN, FERROUS SULFATE (IRON), THIAMIN MONONITRATE (VITAMIN B1), RIBOFLAVIN (VITAMIN B2), FOLIC ACID, CORN STARCH, MALTODEXTRIN, CHICKEN FAT (WITH ROSEMARY EXTRACT TO PROTECT QUALITY), HYDROLYZED SOY PROTEIN, CORN SYRUP*, SALT, CHICKEN POWDER, ONION POWDER, SUGAR, POTASSIUM CHLORIDE, CARROTS*, PARSLEY, YEAST EXTRACT, NATURAL FLAVOR, DISODIUM GUANYLATE, DISODIUM INOSINATE, EXTRACT OF TURMERIC (COLOR), SPICE. *DRIED MAY CONTAIN MILK, SULFITES.



To be advertised as "gluten-free" foods must be tested to have less than 20 ppm of gluten.

- **Some companies will provide "contained labels."** For example, the label may say "may contain wheat" or "made on shared equipment with products containing wheat" or "made in a facility that processes wheat." Unfortunately, there are no federal rules and regulations about "contained labels." Don't rely on these labels.

- There are some common items found on food labels that **ARE gluten-free**!

- sorghum
- maltodextrin
- oils
- modified food starch (on products made in the USA)
- monosodium glutamate (MSG)
- corn gluten
- most vinegars (not malted vinegars)

TIP: Some grocery stores have dieticians! They can help you find gluten-free foods in the store. Call ahead and find out what hours they work.



- There are also common foods and ingredients you may be surprised to know **may contain gluten.**

- broth
- sauces
- autolyzed yeast
- fried foods
- malt vinegar
- marinades
- miso
- teriyaki sauce
- some teas
- fermented foods
- veggie burgers
- bouillon
- gravy
- brewer's yeast
- imitation seafood
- malted beverages
- dressings
- soy sauce
- seitan
- probiotics
- candy
- gluten-removed beer (That's right! "Gluten-removed" means it goes through a cleaning process to remove the gluten. But this is changing the DNA of the product and you can't be sure it's safe.)

COOKING WHAT YOU BOUGHT



Gluten-Free Pasta Feta Bake

INGREDIENTS

2 pt. cherry or grape tomatoes
1 shallot, quartered
1 medium zucchini, chopped
3 cloves garlic, smashed
1/2 c. extra virgin olive oil, divided
½ tsp kosher salt
1 tbsp crushed red pepper flakes
1 tbsp Italian seasoning
1 (8-oz.) block feta
10 oz. chickpea pasta (Banza)

DIRECTIONS

Preheat oven to 400°.

In a large baking dish, combine tomatoes, zucchini, shallot, garlic, and the majority of the olive oil. Season with salt and red pepper flakes and toss to combine.

Place feta into the center of the baking dish surrounded by the tomato and zucchini mixture and drizzle with remaining olive oil. Sprinkle the Italian seasoning on top of the tomato and zucchini mixture.

Bake for 40 to 45 minutes, until tomatoes are bursting and feta is golden on top.

In a separate large pot, boil water and cook the pasta according to package instructions. Reserve ½ cup pasta water before draining.

After removing the tomato, zucchini, and feta mixture from the oven, carefully burst/smash the tomatoes and mix with the now very soft feta to create a creamy sauce. Mix the cheesy sauce and toss to coat the pasta. Use the reserved pasta water to thin out the sauce to desired consistency.

***Tip you can add a variety of different vegetables to this recipe to utilize seasonal options like spinach, asparagus, or winter squash.*



Warm Quinoa and Vegetable Salad

INGREDIENTS

1½ cups water
¾ cup dry quinoa
2 cup cauliflower rice, steamed/ microwaved
1 (15-oz.) can chickpeas, drained, rinsed
2 cups baby spinach
1½ cups cherry tomatoes, quartered
1 large English cucumber, chopped
1 medium orange bell pepper, chopped
1 medium avocado, chopped
½ medium red onion, chopped
3 Tbsp. olive oil
4 Tbsp. fresh lemon juice (approx. 2 lemons, juiced)
Salt and ground black pepper

DIRECTIONS

Bring water and quinoa to a boil over medium-high heat.

Reduce heat to low and gently boil, covered, for 5 to 7 minutes, or until quinoa is tender and most of the liquid has been absorbed.

In a large bowl mix together the cooked quinoa and cooked cauliflower rice.

Add in the chickpeas, spinach, tomatoes, cucumber, bell pepper, avocado, onion, olive oil, and lemon juice.

Season with salt and pepper as desired.

Toss gently to fully combine ingredients.

Gluten-Free Chicken and Sweet Potato Enchiladas

Serves 6-8

By Vicki Gainsberg, RD

4 chicken breasts or use a cooked rotisserie chicken and shred
1 medium onion, cut into 4 large chunks
2 bay leaves
2 large sweet potatoes
1 can black beans, rinsed and drained
1 can diced green chilies, mild
1 15oz jar Siete Red Enchilada sauce
1 -15 oz can tomato sauce, unsalted
1 tsp cumin and chili powder
½ cup cotija cheese
½-1 cup shredded Chihuahua cheese or mozzarella
8-10 Siete Cassava Flour Grain-Free tortillas
Toppings of your choice: salsa, guacamole, radish, shredded cabbage, cilantro

Place chicken in a large pot of water with bay leaves, salt, pepper, and onion. Bring water to a boil, cover, reduce heat and simmer until fork tender and cooked through, about 20 minutes.

While chicken is cooking, wash and clean sweet potato. Dice sweet potato into medium size dices and place on a large baking sheet. Toss with a small amount of olive oil. Add a sprinkle of salt and pepper. Roast in the oven @ 425 degrees for 20-25 minutes.

Combine jar of enchilada sauce and tomato sauce in a small saucepan. Cook on medium heat until simmering. Add a teaspoon of cumin and chili powder to the sauce.

Remove chicken from water and place on cutting board to cool. Shred with 2 forks once cooled down.

Place shredded chicken, cooked sweet potato, black beans, green chilies, and cotija cheese in a large bowl and mix together, add a small amount of sauce to the mixture.

Add a small amount of sauce to the bottom of a large baking pan (9x13). Place a heaping ¼ cup of mixture into each tortilla and roll up. Add to baking pan, keeping the tortillas tightly next to each.

Top with enchilada sauce. Be sure to cover all tortillas. Add shredded cheese on top of the sauce.

Bake in oven uncovered at 375 degrees for about 20 minutes, until cheese is bubbly.

Top with desired toppings, see above. Enjoy!!



When it comes to cooking, beware of using tools that might be contaminated with gluten. Always wash them thoroughly. Some common culprits include:

- sponges
- utensils
- muffin pans
- pots and pans
- cutting boards
- old wooden utensils (Avoid these entirely.)
- toasters (Use a dedicated toaster for only gluten-free breads or try toaster bags!)
- cast iron pans (It's best to avoid these as they are usually washed with water only)

Gluten isn't only in food

Most people with celiac disease can safely touch gluten. **Just remember to wash your hands after handling gluten products.** Surprising items that contain gluten are:

- Play-Doh and modeling clay
- makeup, especially lip products (More research is needed on the effects of cosmetics, but to be safe, keep your makeup bag gluten-free.)
- lotions
- communion wafers (O.K., technically, this one is a food.)

Vitamins and supplements and medications

Similar to food products, when it comes to vitamins, supplements, and medications, be sure to read the labels very carefully. Just because it's a vitamin doesn't mean it's gluten-free. Even herbal supplements may contain gluten. For prescription medications, always ask your pharmacist if they contain gluten.

preparing for COLLEGE

So, you're heading off to college? Congratulations! You might be feeling some mixed emotions. You might be excited, but also a little anxious. On top of the normal uneasiness shared by most incoming college freshmen, if you have celiac disease you may feel as though you have more to be nervous about.



Fortunately, many students with celiac disease have successful and enjoyable college experiences. But it does take some extra preparation.

When deciding which colleges to apply to, make your decision based on where you want to be – not on food options. You've worked hard to get where you are!

Use these checklists at every stage in your journey to college to help you ask the right questions and ensure that your transition is as smooth as possible.

EXPLORING SCHOOLS

First, know that different schools handle meeting the needs of celiac disease in different ways. It will be important for you to ask questions and find out exactly what that means at the schools you are interested in.

- When you schedule a school visit, ask if you can tour dining services with a dining manager and/or a dietician. You will need to schedule this in advance of your visit.
- Talk to someone in Disability Services. Ask about the types of dorms available to you. You may be able to get a suite-style dorm with a kitchen. Also ask about having a microwave and refrigerator in your dorm room. Some schools allow them, and some don't.

TIP Ask your medical team for help if you need it! And ask all your questions no matter how minor they might seem.

> Don't let celiac disease stop you from enrolling in any course or even from studying abroad!.
>
> —Dr. Verma

AFTER YOU'VE COMMITTED

- Register with Disability Services and ask for your dining accommodations to be recognized. (Do this right away! Some schools have deadlines.) **Celiac disease is acknowledged by the Americans with Disabilities Act (ADA).** If your college or university can't guarantee you a safe dining experience, they will usually make arrangements for you to pre-order meals or have access to a kitchen.

- Confirm what types of resources are available to you in terms of dorm accommodations and/or having a microwave and refrigerator in your room.

- Purchase a meal plan. Some colleges require freshmen to purchase the highest plan (the one with the most meals). However, if your college cannot provide you with good gluten-free options, you can ask to purchase different meal plan options.

- **Talk to your roommate(s) and suite mate(s) early** – before you get to campus. Explain that you have celiac disease and that it will be important for you to keep your food, utensils and kitchen equipment separate. It's best to be honest rather than trying to downplay the severity of celiac disease.

It's also important to register with the Disability Office in case you have accidental exposure to gluten, and it affects your academic performance, for example, if you need some time to recover.

> After I filed for dining accommodations, I was able to get a meal plan where I only pay for what I eat. This offers me great flexibility.
>
> —Julia

ARRIVING ON CAMPUS

- Get familiar with the health services your university provides, including mental health. Visit campus health services. Know where it is and how to make an appointment. Sticking to a strict gluten-free diet can be exhausting – mentally, physically and emotionally. **Know where to turn for help before you need it.**

- Get to know the chefs and dieticians and others who work at your dining hall. Educate them about your needs, show them kindness and tell them "thank you." They will look out for you, and it's good to have someone "on your side." Don't be shy about telling the dietician what kinds of food you like. They might be able to order your favorite brands.

- Talk with your roommate(s) and suite mates. Remind them that you have celiac disease and discuss how you will handle keeping food and utensils separated in your dorm room.

- Speak with your resident hall advisors and make sure they are aware of your dietary needs.

If you have a microwave available to you, you can actually make all kinds of things. Here are some ideas for gluten-free foods you can cook in the microwave.

- baked potatoes
- bacon (think gluten-free BLTs!)
- canned soups (certified gluten-free only)
- steamed vegetables and microwave rice packets
- gluten-free quesadillas with salsa
- scrambled eggs

TIP Free food attracts college students, so it's common to find it at recruiting events, social events, etc. Always be prepared as there may not be gluten-free options. Carry snacks in your backpack and avoid going to events hungry. Eat first if you can.

TRAVELING



If you're traveling internationally, there is a fantastic app – Gluten Free Card – that is so helpful. It describes celiac disease in many languages. When I went to Prague and was having trouble communicating, it helped me to describe celiac disease in Czech.

—Julia

You might feel nervous to travel with celiac disease, but there is no reason you can't. From sleepaway camp to international travel and everything in between, there is no place you can't go just because you have celiac disease. Here are some tips to make traveling less stressful.

- **If you're going by plane,** call the airline 24-48 hours ahead of time to order a gluten-free meal.

- However you choose to travel (car, plane, bus, train – even motorcycle!) **pack plenty of gluten-free snacks to bring with you.**

- **If you have emergency medications,** don't forget to pack them.

- **Call ahead to restaurants, theme parks and other attractions** to ask about gluten-free options.

- **For peace of mind,** bring a doctor's note with you stating that you have celiac disease. This could be helpful if you are trying to bring your own food in to someplace that doesn't have gluten-free options and doesn't allow outside food

- **If you're staying in a hotel,** try to find one with a mini-fridge and a microwave.

- **If you're going camping,** bring your own camping grill.

- **If you're leaving the country,** have a card explaining your dietary needs translated into your host country's language.

- **Research grocery stores in the area you will be visiting.** If you can get gluten-free foods easily, you won't have to pack as much with you.

MENTAL HEALTH

Having celiac disease doesn't just affect your body. It also affects your mind. It's completely normal to feel sad or angry or any other feeling you may have after learning you have celiac disease. You're not alone. About 2 million people in the U.S. have celiac disease. The good news is that for most people, it gets easier with time. Here are some things that might help you feel a little better.



TALK TO OTHER PEOPLE

You might find it helpful to meet other people with celiac disease and hear about their experiences and their advice. And talking about your own experiences – the good ones and the bad ones – will help other teens going through the same thing. Knowing you helped someone else, can really make you feel good. A great place to start is with your doctor. He/she might know of resources where you can find other teens just like you. There are groups that meet in person and online.

SET SMALL GOALS

There is so much information coming at you that it's easy to get overwhelmed. Changing your diet all at once can feel like too much to handle. Try making small goals for yourself every week. When you meet one, move on to another. You will be surprised at how quickly you will adapt. No one is perfect, but with practice, it will get easier and easier.

FIND YOUR COMFORTABLE PLACE

You might be feeling scared about gluten exposure or having physical symptoms. You might even be avoiding things like hanging out with your friends or going to restaurants. Don't let fear keep you from enjoying your life. Try taking small steps. Maybe start with eating before you see your friends. Even if they are going to a restaurant, you could join them and order a soda. Over time, you will figure out what makes you comfortable. You might even surprise yourself.

IT'S OK TO FEEL YOUR FEELINGS

There's a lot about having celiac disease that can be frustrating. From planning and shopping to educating your friends and teachers and coaches. And every time you meet a new friend and you have to explain to them about celiac disease, it can feel exhausting. Even dealing with your extended family can be disheartening. Some family members can be very supportive, and others may have a harder time understanding celiac disease. Guilt is also a common feeling, especially if you've eaten something you know you weren't supposed to. However you feel, know that it's OK to feel this way.

ASK FOR HELP

If you are finding it hard to deal with your diagnosis, with your diet, or with your feelings, don't be afraid to get help. Find someone you can talk to. It might be a friend or a parent, or it could be a teacher or counselor, or doctor. The important thing is to not keep it bottled up inside. You might feel very much alone in coping with celiac disease but know that you are not. There are many people who want to help you. You just have to let them.



One of the most empowering moments of managing my celiac disease was going on a school camping trip. I was in charge of dinner and I made a dinner my whole class could eat! —Libby



visiting your DOCTOR

GETTING QUESTIONS ANSWERED

Before you leave your doctor's office, ask him or her, "How can I get in touch with you?" Some doctors will provide you with an email address, or a phone number or a link to an online portal where you can leave a message. Don't be shy about getting in touch.

WHY FOLLOW-UP VISITS ARE IMPORTANT

Once you've been diagnosed, you might think you don't need to see your doctor anymore. But follow-up visits are very important. And it's not just about tests and monitoring your physical condition. **Your doctor sees many other teens with celiac disease and has a lot of helpful information to share with you**. If a specific situation arises that you have a hard time handling, talk about it! If your friends aren't being sensitive to your diet, talk about it! Chances are others have had the same concerns and your doctor has heard them all. He/she can give you great advice. So, don't skip appointments. See your doctor at least once a year.

ADVICE

from other teens



Be really clear with your friends. Let them in and know what is going on. Explain the risks and they won't pressure you. Libby

My best advice is to always have snacks on you just in case. You never know when food situations will come up with your friends. Ben

Don't let celiac disease keep you from doing things you love. My school trip to Montreal is one of my best memories. Emma

Don't be afraid to tell other people about celiac disease. It's not anything to be ashamed of. Taylor

The diet really works. It will make you feel so much better. It's hard when I see someone eating something I want to eat but can't, but then I remember how much my stomach used to hurt before and now it doesn't. Matt



Having a good doctor relationship is one of the biggest things for me. My advice is to find a doctor that really listens to you. A doctor who understands the severity of your symptoms if you have cross contaminations. When you don't have that it makes it much harder. I'm glad I can trust my doctor. It changes the entire situation of managing my celiac disease. I am not alone, and it takes a weight off of my shoulders to not carry it alone.

—Libby, age 15

“I’m glad I can trust my doctor. It changes the entire situation of managing my celiac disease.”





...I discovered it's OK to be different. I don't have to be like everyone else.



In the beginning [after diagnosis] it was hard to not cry or not be angry. My mom got me a punching bag and boxing gloves so I could take my anger out on something. It really helped me. If you are just diagnosed and feeling sad or nervous, I understand. I felt the same way. Sometimes, I would hide behind the pillar at school and cry. But I discovered it's OK to be different. It makes me stand out. I don't have to be like everyone else.

—Alisha, age 10

A few words from Dr. Verma

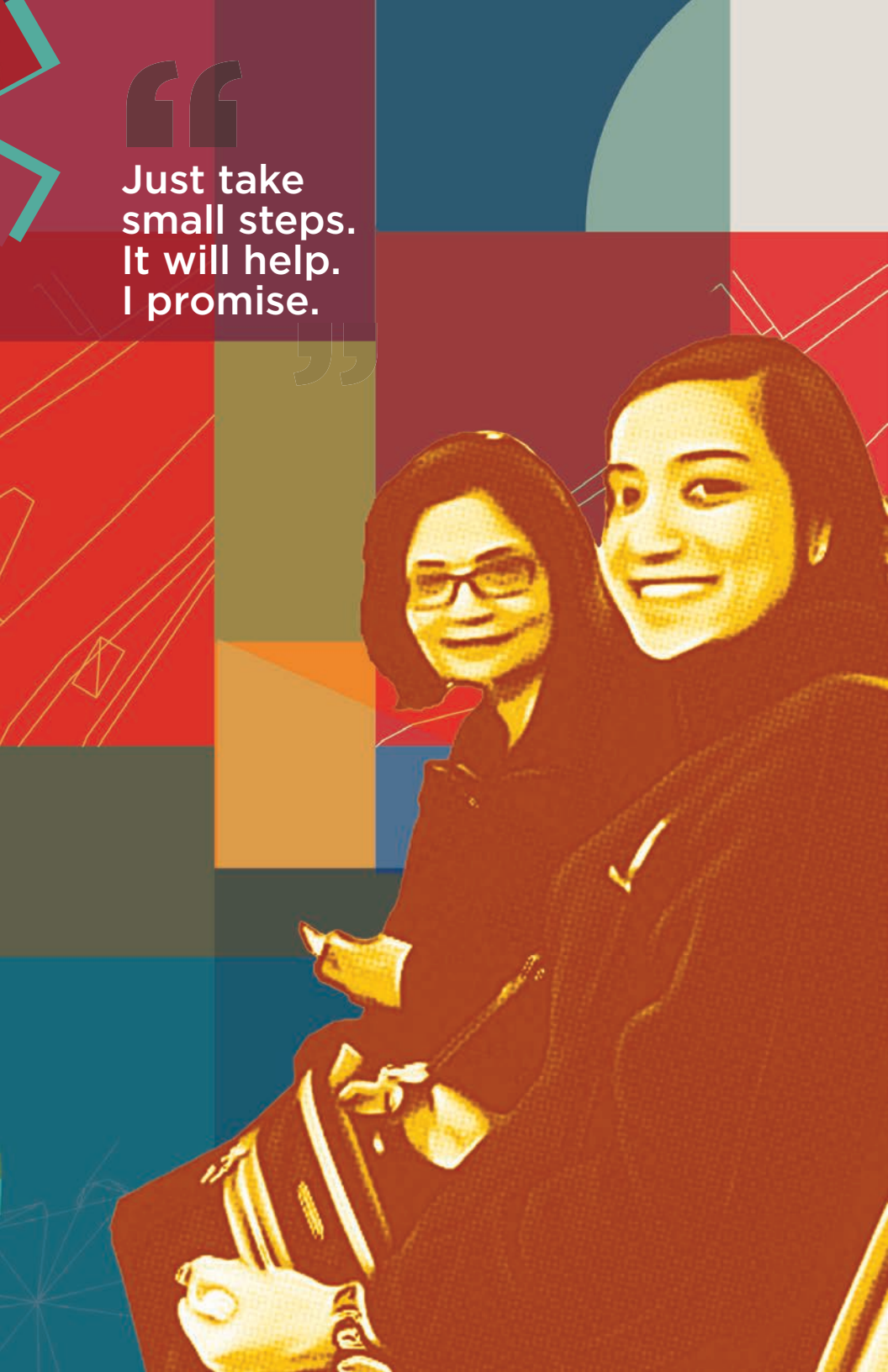
It's true that as a doctor I was trained to help patients with celiac disease, but I am also a parent of three grown children, two of whom have celiac disease.

My experiences with my own children have taught me so much about what teenagers with celiac disease (and their parents) are really going through. I hope that by sharing some of my story with you, you might see a different perspective and be inspired to share your story as well.

When my youngest was diagnosed, he was six years old. Some of the symptoms of celiac disease had been there since he was only a toddler. How could a doctor – a gastroenterologist who treats patients with celiac disease – have not recognized the signs? It's a sneaky disease and sometimes the way it presents is very difficult to recognize. Only by looking back did it become obvious. This happens to a lot of patients. They aren't diagnosed for many years after symptoms first appear. I truly empathize. For some, finally getting a diagnosis comes as a relief. For others, the diagnosis is devastating. It was the latter for my oldest daughter.

As you might know, celiac disease is genetic. When my youngest was diagnosed our entire family was tested. It turned out that my oldest child also had celiac disease and she had zero symptoms. For her, the news was crushing.

Over time, my children and my entire family learned to adapt and adjust, and you will too. I always tell my patients that if God came down and told me I *had* to pick a disease, I would choose celiac disease every time. That's because if you eliminate gluten, you can manage the symptoms and help prevent future complications. Other diseases are much harder to cope with.


Just take
small steps.
It will help.
I promise.

As a parent, I definitely made mistakes. But I learned from them and I can now offer advice to others. One thing I did was to make my entire home gluten-free. That seemed like a good idea at the time, but I had another child - one who did not have celiac disease. I came to realize, after learning from my child's experiences, that our home was her home too and I had excluded her needs when I removed gluten from our home. Eventually, I made a section of our kitchen gluten-free and allowed some non-gluten-free products in the home. I know it's difficult to eat a gluten-free diet, but if you have siblings, consider how they might feel too. You might find that supporting them as well could make a positive difference to your whole family.

When my kids were teens, they felt embarrassed whenever I asked to speak with the chef, or if a mistake happened (and mistakes do happen!) and I asked to speak to the restaurant manager. I remember one time, my daughter ate a delicious dessert and couldn't wait to go back to that restaurant to have it again. The second time, though, our server told us that that dessert contained gluten! She had already eaten it on our previous visit, and we couldn't change that. But by speaking to the manager, we could help someone else with celiac disease to not have that same experience. It may help you to let go of embarrassment to remember that every question you ask and every person you educate could make life a little bit easier for someone else.

My best advice to teens (and all ages) with celiac disease is to learn all you can about the disease. Take ownership. Know exactly why you have to follow a gluten-free diet. When you really understand the *why*, it's easier to take the right action. I also advise my patients to talk about celiac disease. Join a support group, either online or in person. Talk about your experiences and how you overcame them. Maybe you learned the hard way, maybe you learned the easy way, but either way, sharing your lessons with other teens will not only help them, but it will also help you because it will make you feel good. You don't have to give big speeches. Just take small steps. It will help. I promise.

As a doctor, I want you to know that your medical team is here for you. We are your biggest advocates and supporters. Think of us as your partners. Things you may not want to share with your parents, you can always share with us. Chances are we've heard it before, and we know best how to help you through it.



If there is one thing I hope you take away from this book, it's that we are on your team, 100%.

Warm wishes,
Rutu Verma, MD

Professor of Pediatrics and Medical Director, University of Chicago Celiac Disease Center


AT THE FOREFRONT
UChicago Medicine
Celiac Disease Center
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