

your guide to navigating college with celiac disease



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# INTRODUCTION: A MESSAGE FROM ALICE



## ALICE BAST, BEYOND CELIAC FOUNDER & CEO

There are times when having celiac disease or gluten sensitivity is particularly annoying. College is one of those times. Let's admit that. Let's accept that. And now, let's do something about it. The fact is, living glutenfree on campus means you're going to face some challenges. Many of these challenges will be out of your control. But you're here, and you're not going anywhere until you get that degree, so what you can control is how you respond.

Welcome to the Beyond Celiac College Toolkit. This guide offers important background information and advice to help you feel more confident about eating gluten-free on campus—whether it's at the dining hall or in your dorm. By the time you finish reading this guide, you'll know who to contact on campus, what rights you have in requesting gluten-free meals and how to protect your gluten-free stash from hungry roommates.

This toolkit is just one of the many free resources that Beyond Celiac offers to our community. We know that the challenges go beyond the actual food—that you also worry about explaining why you can't have beer at a party or how to handle studying abroad. We're tackling those issues, too—with input from students like you.

Find more resources for gluten-free students at beyondceliac.org/college. ]If you have suggestions for a resource or topic that you'd like us to cover related to life as a gluten-free college student, let us know by emailing info@beyondceliac.org or tweeting @BeyondCeliac.

To living life Beyond Celiac, Alice

## KEY STEPS

First: you are not alone. That's one of the most important things to know about living gluten-free at college. Even at a small school where you may be one of a few students with celiac disease or gluten sensitivity, there are people ready and eager to help you fully enjoy your time on campus.

While every school is different, here are the key steps to follow at each university you visit.

## **Communicating with Dining Services**

Communication is your best asset when it comes to finding a celiac-friendly university.

Long before you make your college decision, reaching out and having conversations with dining services will provide you with a solid understanding of the options available to you, and which options could be made available.

While most large universities have a full-time dietitian, other members of dining services such as the foodservice director, executive chef, or dining hall managers may also be able to answer your questions.

By meeting, you'll also get a sense of how well the dining services team understands gluten-free needs.

## QUESTIONS FOR DINING DIRECTORS

## Some questions to consider asking a dining representative include:

- What are your protocols for safely feeding students with celiac disease?
- What precautions do you take to ensure the safety of gluten free meals (i.e. cross-contact training, separate areas, ingredient labeling, etc)?
- Where is the best place to go for gluten-free food?
- Do any of the dining halls have a gluten-free section?
- Are there other students eating gluten-free on campus?
- Are you able to share the ingredients of dishes served?
- Do the kitchens have a dedicated section for gluten-free food prep?
- How else do you prevent cross-contact in your kitchen?
- Do you use symbols to indicate dishes that are gluten-free or can be made gluten-free?



## COMMUNICATING WITH DINING REPRESENTATIVES

It's crucial to have conversations with each university's dining reps prior to your college decision. Since most dining halls are buffet-style, safe gluten-free meals will have to come from some alternative format, such as a dedicated ordering program, a gluten-free station or other accommodations. In most cases, access to these alternative options requires registering with disability or dining services, so knowing your options and having plans in place before your arrival on campus is key to ensuring the safety of your meals from day one!

An additional benefit to communication is the potential for connection with other gluten-free students. Often, the university dietitian or other dining representative may be able to put you in contact. This is a great resource that will allow you to ask questions about their experience on campus as a student with celiac—a perspective that dining reps simply can't provide you. Some colleges also have gluten-free clubs.

Remember that knowledge is power, and doing the work upfront will save you a lot of stress down the road! Your first weeks of college should be about meeting new people and adjusting to campus life, not worrying about the safety of your meals. Don't be afraid to ask questions, and make sure you get the info you need in order to make an informed decision.

"Before attending
Vanderbilt, I met
with dining services
three times! This
allowed me to begin
my college
experience fully
confident in the
safety of my meals."
—Valerie, Vanderbilt
University

# THE ACCOMMODATIONS PROCESS

Many schools require that you register through the Office of Disability Services before you can be eligible for special dietary accommodations. You will most likely need a note from your physician indicating that you have celiac disease or gluten sensitivity and require a gluten-free diet. Each school has a different policy and procedure for registering with the Office of Disability Services. These steps can help guide you through the registration process.

## Step 1: Contact your school's Office of Disability Services.

You can easily find the contact information for your school's disability office through the school website. Much of the information you are looking for regarding registration may already be available on the website. The office staff will best be able to guide you through the registration process. Don't be afraid to make the call and explain your needs! That's what they are there for.

## Step 2: Obtain a note from your primary care doctor or gastroenterologist indicating that you have celiac disease or gluten sensitivity.

Most likely, your school will require some form of written evidence of a diagnosis in order to process your registration request. If you received gluten-free school lunches in high school, this will be similar to the diet prescription needed for your 504 Plan. The Office of Disability Services staff will be able to tell you exactly what you'll need to provide. Be sure to contact your doctor well in advance of any deadlines.

### Step 3: Fill out all necessary forms and pay attention to deadlines.

Along with medical records or a note from your doctor, you will most likely need to fill out required paperwork. There may or may not be deadlines for completing these forms, so be sure to ask the staff or read all the paperwork to ensure you are finishing the forms on time. If it seems like a lot to do, don't be discouraged! Ask for help and stick with it. You'll not only be helping yourself; you'll also add to the collective voice of other gluten-free students living on campus.

# THE ACCOMMODATIONS PROCESS, CONTINUED

## A Word about the Word "Disability"

You may be hesitant to register with the Office of Disability Services, but it's important to know that they're there to help anyone needing accommodations! Registering does not take accommodations away from anyone else—you are simply opening the door to having the accommodations you need (and are legally entitled to). Look at your registration as being proactive in managing your health!

### **Additional Accommodations**

Some students request accommodations beyond special dietary ones, including:

- Single room to avoid having a roommate who brings gluten into the room
- Having a car on campus to drive to stores and medical appointments
- Access to a community kitchen
- Ability to bring a microwave, fridge, toaster, hot plate, etc. to prep gluten-free meals in your dorm
- · Academic accommodations in case of glutening
- Dorm with a community kitchen or close to a gluten-free dining hall

If you plan on requesting any of these, be sure to have your doctor explicitly mention them in your letter for the Office of Disability Services. "Don't be afraid to speak up! If you don't educate people about your needs, they'll never be able to accommodate them. So, advocate for your own health and I think you'll be pleasantly surprised by the results!"

—Teresa,
Muhlenberg College

## CAMPUS LIFE

Once you decide on a college or university and square away your accommodations and dining options, the fun part begins!

Now's the time to integrate into campus, make new friends and start your college journey.

While students with celiac disease have some additional considerations to keep in mind, don't let your diet stop you from experiencing college life to its fullest potential!



## CELIAC DISEASE AND SOCIAL LIFE

## **Going Out to Eat**

Going to restaurants is often a point of concern for people with celiac disease, but planning ahead can help tremendously! Create a list of restaurants in your area to suggest when friends want to go out. You can research restaurant options near your school by consulting Find Me Gluten Free, which provides reviews and contact info for nearby restaurants.

### **Educating Friends and Roommates**

Talking about celiac disease with friends and roommates may feel daunting, but most friends are willing to listen and learn, and you may even find that some of your friends have dietary restrictions too. If no one knows, they won't be able to help, so remember that advocating for yourself is critical. Take steps to ensure your health, such as drafting a plan with your roommate for preventing cross-contact in your dorm room.

### For 21+ Students

For students of legal drinking age, being informed about the presence of gluten in alcoholic drinks is crucial. With the exception of beer (excluding glutenfree varieties), most alcohol, including wine, is safe to consume on a gluten-free diet. Always be sure to ask about the ingredients in your drink, and when in doubt, don't take the risk! For more info visit beyondceliac.org/liquor.

"Upon diagnosis, I
learned that
socializing and
eating with friends
could be a struggle.
I'm thankful that the
people around me
have been so
supportive through
this transition."
—Ben, Kent State
University

## EATING GLUTEN-FREE ON A BUDGET

Like most students, you may be concerned about stocking up on glutenfree food without breaking the bank.

## **Consider these cost-saving tips:**

- Buy fresh food as you need it so it doesn't go to waste, and freeze whatever you can to make it last longer
- · Coupons are your best friend!
  - Sign up for your local grocery store's savings card
  - Sign up to receive coupons from your favorite gluten-free food manufacturers' websites
- Shop online and compare prices with your local store.
- Buy your food in bulk (if it makes economic sense to do so)
- Set up a weekly food budget for yourself and stick to it!
- If your meal plan includes flex spending, find out if your card can be used off campus as well
- Work with your roommate to split the cost of foods you both enjoy



## LEARNING FROM OTHERS

You're far from the first celiac college student! Here is some advice from past celiac graduates to get your started on your college journey.

## **Hayley Johnston, University of Illinois**

"It's completely possible to live a normal college life while adhering to a gluten-free lifestyle. There are always going to be bumps along the road no matter the journey you're on. This diagnosis is something I never imagined was going to happen to me, but I am lucky to be surrounded by the love and support that I have to help me get through the toughest days. I've learned through everything that I have to stand up for my disease and myself so that I can stay healthy and happy in all aspects of my life."

## **Candice Clifford, University of Scranton**

"I learned that if you are comfortable with being gluten-free, it will only make others more comfortable. For example, I recently went on a school retreat. I was concerned about my dietary needs, so I brought my own food. Yes, this takes a little extra planning, but it's the best thing for me. Taking these steps allowed me to fully enjoy the experience and prevented me from worrying about the food situation. Some people even wondered where I got my food because it looked so good!"

### **Shelby Kaho, Wittenberg University**

"To current or future gluten-free students, ASK QUESTIONS! It may be easier to just eat things you believe are safe, but it isn't worth putting your health at risk. The most important thing is to make sure your needs are met. If your dining hall doesn't have a plan set up, work with them to create one! It will not only be beneficial to you, but it will help others if you take initiative and make changes."

### **Alex Shimalla, Stetson University**

"Just be organized and prepared. Make lists! Write down all the foods you need to buy to stash a mini pantry in your dorm. Plan out your meals, but be flexible. Someone may have used the croutons and spilled them all over the cucumbers in the salad bar. When in doubt, leave it out."

## ADDITIONAL RESOURCES ON BEYONDCELIAC.ORG

If you are...

## **Newly Diagnosed**

- The Getting Started Guide beyondceliac.org/gluten-free-diet/gettingstarted
- The Non-Celiac Gluten Sensitivity Guide beyondceliac.org/celiacdisease/non-celiac-gluten-sensitivity
- Gluten in Medications beyondceliac.org/living-with-celiac-disease/glutenin-medication

## Interested in Learning More about Gluten-Free College Life

- Gluten-free in College beyondceliac.org/college
- Stories and Advice from Gluten-free College Students beyondceliac.org/living-with-celiac-disease/gluten-free-in-college/stories

## **Working to Improve Gluten-Free Options Off Campus**

 GREAT Kitchens (Gluten-free training for schools and restaurants) greatgfkitchens.org

## In Search of New Gluten-Free Products and Recipes

- Gluten-Free Recipes beyondceliac.org/gluten-free-diet
- Is.....Gluten-free? beyondceliac.org/gluten-free-diet/is-it-gluten-free

### **Want to Connect**

- Follow Beyond Celiac on Facebook, Instagram and Twitter
- Reach out to Beyond Celiac about our college ambassador program