

Celiacs and College: Tips for Parents and Prospective Students

An NFCA Original Article By Rebecca Panzer, RD, LD

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College is an exciting time—it's a chance to assert your independence and show the world who's boss. However, it's a pseudo-state of independence: You're on your own in respect to your schedule but often, meals and housing are governed by the college. This can be a challenge, but with a little preparation and foresight it's a piece of cake (gluten free of course).

As a dietitian, I frequently have celiac patients enter my office seeking advice on the gluten free (GF) diet. So when I was approached with an idea for a research project about celiac disease (CD) on college campuses, I jumped at the opportunity. As part of my master's degree in Health Communication at Emerson College, I created the study with educational guidance from Dr. Daniel Leffler and other CD experts at Beth Israel Deaconess Center and Children's Hospital in Boston, Massachusetts. In the past few months, I've heard from young adults around the country who shared their experiences and words of wisdom. While the research is on going, I've summarized some of the preliminary feedback to help you ask the right questions and be prepared for the college admissions process.

CD and the **GF** diet do not define me. Most respondents advise that if you have a certain school you're dying to attend, don't let CD stop you. As one young lady from California said:

"...you can make the gluten free diet work anywhere. Just because you have celiac disease doesn't mean your education should suffer. It might take a bit more work if the school can't accommodate you but if you plan ahead and make a few sacrifices, it's definitely possible...but be realistic about how much time, work, and money you want to put in."

Many who responded did not factor in dining services when applying to colleges. However, when acceptance letters rolled in, some used the school's ability to accommodate the GF diet to narrow their decision. In the end, students overall advise that academics should come first.

College tours. New students and parents need to ask questions from the very start. When you visit prospective schools, tour the dining hall that you'll be using. Keep in mind larger campuses may have multiple dining halls and still others limit which dining facility your meal plan is good at...be sure to ask the tour guide how the system works.

Analyzing the dining hall should begin at the tour. Ask the guide how the college accommodates allergies but don't stop there. When you're in the facility ask the staff serving, "What food is gluten free?" If they can't answer you, that's a sign you'll need to be your own advocate in numerous ways.

Every college student I talked to expressed the need to regularly communicate your needs with the staff. No employee at the college is intentionally trying to make you sick; rather they may need a little help understanding the GF diet—especially cross contamination.

Campus dining. Most people make the mistake of only talking with the head chef, dietitian, or dining services manager. While they oversee the operation, the managers are *not* the ones preparing and serving your food. Managers/head chefs are an excellent resource on ingredients and on things *should* be done, but when it comes down to it, it's the individuals on the front lines that will be your greatest day-to-day ally. Questions you need to ask all dining staff include:

• How was it prepared? As one student from Pennsylvania said, "Just because the food Mom made was ok to eat, doesn't mean dining services prepares it the same way." He quickly discovered that

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even vegetables need to investigated after he found out the staff steamed them using leftover pasta water. Another student in Connecticut discovered the eggs she had been eating every morning were the culprit for her sickness. She realized the advertised "gluten free eggs" were being cooked *after* a batch of pancakes... Be sure to double-check *everything* because you never know how it was prepared.

- Have you changed your gloves? Watch the staff. Do they change gloves between serving the breaded chicken and the grilled? Do they use the same tongs for multiple types of food? Don't hesitate to ask for them to accommodate you.
- What are the ingredients? Check if the school labels the food it serves- and look closely. Do they label every ingredient? Allergens? One student from Massachusetts grew frustrated after she realized the dining hall was being inconsistent, *"They would label that a food had soy but they never explicitly stated they were using 'soy sauce' which has gluten..."* Other students expressed the need to look beyond the label. As one young man said, *"The ingredient list would say it has BBQ sauce in it...well what's in the BBQ sauce...?"*
- *How* will they accommodate you? Students expressed a desire by the food staff to accommodate the GF diet; however the accommodations varied and were not always realistic to the student's preferred, spontaneous lifestyle. Be sure to ask the manager how they make dining services work for you:
 - Will they make you a meal in the back? (**NOTE**: This may take an extra 20 minutes).
 - Do you need to supply your own GF food or do they have food on hand?
 - Do you have to call ahead?
- **Talk to other students.** If you want to know how things really work, ask the head chef, dietitian, manager, or head of residential life to put you in touch with other celiac or food allergy students on campus. They can provide you with information about how they live day-to-day on campus and what you can expect as a student.

Administration. Having a discussion with administration can be very helpful in numerous ways when it comes to CD. Students and professionals advise a few things to consider in these discussions:

- **Registering with disability services.** Some students advise incoming freshman with CD to register with disability services since it's covered by <u>Section 504 of the Rehabilitation Act of 1973</u>. However since the Act is not limited to celiac disease, the benefits can be hit or miss. Many students who did were able to get larger rooms or "exceptions" to the normal rules that govern students. It's a worthwhile conversation exploring with administration at prospective colleges.
- Is the meal plan "required?" Or can I get an abbreviated plan? This is a crucial question when exploring colleges. Some institutions claim to be able to accommodate the GF diet but fail to understand cross contamination. Sometimes there is limited variety of GF foods on a day-to-day basis. Be sure to fully understand your meal plan options; otherwise you may have to pay for a meal plan and still doing grocery shopping to have enough food.
- Allowable appliances. Don't assume you can bring a full kitchen with you. Check with the school about which tools you can bring and which you'll have to share with other students. Celiac students swear by the micro-fridge but it was hit or miss if toasters, foreman grills, and rice makers were allowed.

Be consistent. Don't forget your new friends at college most likely will have no idea what "gluten" is. It will take some patience and explaining on your part. The students I spoke with highly advise that incoming students be very consistent in what they do and don't eat. As several student expressed, "If you intentionally slip and eat bread one day, your friends will be more likely to pressure you later to stray from the diet saying, 'well you ate it yesterday and you're still here...what does it matter?'" If you want your diet to be taken seriously, it's crucial that you are your own advocate and that you speak up to insist upon GF

foods—with everyone you encounter. It doesn't need to be the center of your life, but it should play a role in how you live.

While it may seem that navigating college with CD is a mind-boggling challenge, every student I spoke with was extremely happy—regardless of how many tough times they encountered starting out. They all admitted it becomes second nature in a matter of months and within weeks, the staff knew them by name (in a *good* way). So put in the effort early and don't be afraid to be-friend the administration...they're only there to help. I wish each and every one of you the very best of luck!!

To learn more about Rebecca's study, visit:

http://www.celiaccentral.org/News/Survey-Says/Survey-Says/345/vobId_2507/