# Composition

Food Allergy Survival Guide

By Lily Roth



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## A Letter From The Author

Dear Reader,

Thank you for taking the time to explore our food allergy guide for high school students. My name is Lily Roth and I am the author of this guide, which I have made for high school students and their families. I am a student at the University of Pittsburgh. I am currently studying PreMed and Emergency Medicine and I love it. Not too long ago though, I was navigating high school with food allergies just like you are. I have multiple anaphylactic food allergies and asthma, which often made high school a minefield of allergens. Throughout high school, I had 7 anaphylactic reactions and many asthma attacks. By the end of my senior year, I had learned how to safely get involved and use my outspoken nature to teach others about food allergies and the needs of food allergic people. I know that when I was in high school, I would have loved to have someone with food allergies to offer me some advice, so here it is! I hope this site gives you some encouragement, some wisdom and some of the tools you need to stay safe in high school while still having the best time of your life!

All the best,

Lily Roth

# **Chapter 1: What To Consider When Considering Colleges**

College is an exciting stage of any teenager's life. For many, college marks a new beginning. For many students, college is the first time they will be living away from their parents on their own. While college is an exciting time, it brings a unique set of challenges for food allergic families and their parents. College means eating in dining halls, living in dorms and encountering social situations that may pose health risks for food allergic students.

This chapter has been designed to help you:

- Determine living accommodations you will need in college
- Pinpoint your priorities college location
- Learn the best way to visit colleges while staying safe
- Figure out the right questions to ask to get the answers you want
- Understand the college timetable for food allergic students applying to college
- Realize food allergies stop not stop you from going to the college of your dreams

## **Section 1: Living Options In College**

There are four basic living options when it comes to going to college; freshman dorms, apartment style on campus dorms, apartment/condos off campus and living at home and commuting.

Keep in mind that not all colleges offer all living options. So, if you determine you need to live in an apartment, and the school you are looking at doesn't have apartments, you need to come up with a plan for where you can safely live to attend the school. Also, keep in mind that in order to get any special accommodations for housing because of food allergies, you have to go through the office of Disabilities Services at the school (more on that later).

In this section, we are going to discuss the pros and cons of each living option so you can help decide which option will be best for you.

## Freshman Dorms

Freshman dorms are often small, not air-conditioned, over crowded and usually require you to have at least one roommate, as well as using communal bathrooms. On the bright side though, they are often fun and filled with a lot of social interaction. Lets look at some of the pros and cons of living in a freshman dorm:

## Pros:

- Normalcy- Most freshman going to college live in freshman dorms so living in them your freshman year means you will get to be with kids in your class and who are the same age as you
- RA's- RA's or Resident Assistants are upperclassmen or graduate students who are trained to help make your transition to college smoother. They also plan activities for your floor and

- are trained in first aid. If you have an allergic reaction, they might be able to help you use your epinephrine auto-injector and get emergency assistance. However, they are not usually trained to recognize symptoms of anaphylaxis or administer epinephrine.
- Roommates-Roommates can be lots of fun and like an instant friend. Having a roommate can be great as it ensures someone is living with you. That way you do not have to worry about having a reaction in your room, being alone and no one finding you to help until it is too late. Some schools ask whether you have food allergies on housing forms. Food allergic students are never forced to live together, but it could be an option at some schools.

#### Cons:

- Living Condition- For people with asthma and food allergies, air quality can sometimes be an issue in freshman dorms. Freshman dorms are often the oldest dorms on campus. Thy may not have air conditioning. They may be dusty and moldy leaving lots of allergens in the air which can cause asthma flares.
- RA's- Let us repeat: Most RA's are not trained to deal with food allergy emergencies. This may sound shocking to students and parents who are used to attending K-12 schools where classroom teachers and nurses take pride in their training to administer epinephrine. In 2014 only two states: Indiana and New Jersey have laws that would make it legally feasible for schools to train RA's on food allergy emergencies, and as far as we know, only one college in the United States does that. So unless you have a reaction in the student health building assume university personnel -including housing and dining- is not trained for food allergy emergencies.
- Lack of cooking abilities- Living in a freshman dorm means that you will not have a kitchen and a means to cook food for yourself, leaving you to rely on dining services to prepare you safe food. Many small cooking appliances that you might think you can use to prepare supplemental food are banned in dorms. Depending on your allergies and level of sensitivity, it may be difficult to get a healthy variety of food you can eat from dining services. As much as no one wants a freshman 15, a freshman minus 15 is not healthy either! If you do rely on dining services, have some shelf stable safe food options in your room in case of emergency. If there is an unforeseen event that makes it impossible for dining services to prepare food they will bring in food from outside sources that might not be safe. We know someone who experienced this and went a whole weekend practically without eating.
- Roommates- While roommates can be a big pro, they can also be big cons. Depending on your sensitivity, in order for you to be safe, your roommate may not be able to eat what you are allergic to in the room. This can be a bit hard to ask of someone you have just met, and to trust that they will follow through. We know food allergic college students who had roommates who brought their allergens into their room after agreeing not to. Peanut butter, nuts, yogurt and milk are deadly to some and quick nutrition to others.

## **Apartment Style Dorms**

Apartment style dorms are exactly what they sound like, they are apartments complete with kitchens, living areas and bedrooms but they are owned by the college or university. Like freshman dorms, these dorms also have some pros and cons. Let's check them out!

Pros:

- Kitchen- Having a kitchen can be quite useful. It allows you to control what you eat so that you don't have to worry about entrusting your health to anyone else. Kitchens can be most useful for kids who would not have adequate choices at the dining hall because of the number of food allergies they have, or have a high risk of cross contamination due to allergy to a ubiquitous food or ingredient. If you just have one food allergy, chances are, dining services will be able to accommodate you.
- Better Condition- because apartment style dorms are often meant for older students they
  are often nicer then freshman dorms and often air conditioned and better maintained. If
  you have asthma, this may help reduce flare-ups, which can make a reaction much
  worse.

#### Cons:

- RA's- Because most apartment style dorms are meant for upperclassmen, there usually aren't RA's. This can be a con because in case of a reaction alone in your apartment, there really isn't anyone designated to help you. One option to overcome that safety issue is to purchase an emergency alert system such as First Alert, Mobile Help or Life Alert among others. They can provide both in-home and mobile alert system devices that will call 911 for you. Another con to living in an apartment, you will not have the typical floor activities that freshman dorms will have.
- Age- because most apartment style dorms are meant for upperclassmen, chances are
  your neighbors will not be your age it may be more difficult to make friends at first. But if
  you are an outgoing person, you can meet friends in other places and they will love to
  study and hang out in your apartment.
- Cost-Living in apartment style dorms are often more expensive then regular dorms. In addition, you will need to buy kitchen supplies, dishes, bathroom furnishings and many things that most college freshmen will not need to buy.
- Time- because living in an apartment with a kitchen will mean that you will not have a meal plan, you are going to have to cook your own food. Cooking your own food will take a significant amount of time to prepare since you will have to go shopping as well.
- Social Isolation- because you will most likely be living by yourself, apart from the other freshmen, you will have to work harder to make friends and find your niche.

## Off Campus Living

Living off campus is a major commitment both financially and socially. Off campus living in an apartment or in a condo comes with its own benefits, but can also come with some cons. Let's get right into it, here they are:

#### Pros:

- It is yours for as long as you own or lease it- Your own apartment is nice when it comes to move out day. Because you will have more food prep stuff than students who eat at cafeterias or restaurants, it is nice to not need to move it, and also nice to be able to use it in the summer if you choose to take summer classes or do summer internships.
- No need for disabilities services- Getting special housing accommodations for food allergies will need to go through disabilities services. While K-12 schools are filled with students who have food allergies and staff is used to dealing with requests to accommodate, food allergies are relatively new to disabilities services at colleges and universities. However, it is a growing chronic health condition they will also have to accommodate in greater numbers in years to come. We will explain how to approach Disabilities Services for accommodations in a later section. Having your own place will mean avoiding the disabilities office altogether.

#### Cons:

- Off campus- Being off campus can be a logistical nuisance. If your apartment is not in
  walking distance from campus it may mean getting up earlier to get to class, having to go
  home by yourself late at night and dealing with the logistics and responsibility of having a
  car. Off campus apartment buildings also are not campus secured-but may have their
  own guards or systems.
- RA's- Because most off campus apartments are not university run, there aren't RA's. This can be a con because incase of a reaction there really isn't anyone designated to help you. One option to overcome that safety issue is to purchase an emergency alert system such as First Alert, Mobile Help or Life Alert among others. They can provide both in-home and mobile alert system devices that will call 911 for you. Also, you will not have the typical floor activities that freshman dorms will have.
- Cost-Living in an apartment is much more of a financial commitment then regular dorms. In addition, you will need to buy kitchen supplies, dishes, bathroom furnishings, beds, couches, chairs, desks, and dressers on top of apartment rent.
- Time- because living in an apartment with a kitchen will mean that you will not have a meal plan; you are going to have to cook your own food. Cooking your own food will take a significant amount of time to prepare since you will have to go shopping as well.
- Social Isolation- because you will not be living on campus with your classmates, you will
  have to work harder to make friends and find your niche. This will be a bigger issue the
  farther you are from campus. Some schools have off-campus options that are just as close
  as school-owned housing.

## **Commuting From Home**

Commuting from home can be an option for students who go to college within commuting distance from their homes. This option probably has the most cons of all of the living arrangements. Lets check them out:

#### Pros:

- No need for disabilities services- Getting special housing accommodations for food allergies will need to go through disabilities services. While K-12 schools are filled with students who have food allergies and staff is used to dealing with requests to accommodate, food allergies are relatively new to disabilities services at colleges and universities. However, it is a growing chronic health condition they will also have to accommodate in greater numbers in years to come. We will explain how to approach Disabilities Services for accommodations in a later section. Having your own place will mean avoiding the disabilities office altogether. No disabilities services- Getting special accommodations to live in an apartment style dorm will need to go through disabilities services.
- Focus on school- If you live at home, you don't have to cook for yourself, your parents can cook for you.
- Cost Efficient- Living at home is very cost efficient. You don't have to pay for an apartment
  or a dorm or any new things to bring with you to college other than your normal school
  supplies.

#### Cons:

- No independence-going to college and living at home removes a lot of independence
  you have if you live in an apartment or dorm and you miss out on some of the typical
  college experience.
- Social Isolation- because you will not be living on campus with your classmates, you will
  have to work harder to make friends and find your niche.
- College choice limits- If you are going to go to college and commute, you will have to limit
  your college radius to around half an hour to 45 minutes away. This limits your college
  choice a lot and may keep you from going to your dream school.

#### All in all...

It is best to live in whichever option is best for you and fits your needs. You can even make your choice a combination. We know one food allergy student who took some classes online, lived in a dorm suite with a kitchen during the week and went home on the weekends where he could replenish safe food. It is important to know your options when picking your living arrangement so you can make an informed decision!

See the appendix for a checklist you can use throughout this chapter to help you keep your priorities straight when looking at colleges.

## Section 2: Pinpoint Your Priorities In College Location

When going to college, proximity is everything for students with food allergies. Here are some things that may be helpful and lifesaving to be close to.

## Being near an Allergist

For students who get allergy shots, need frequent asthma checks or allergy visits, being near an allergist can be convenient, especially if you are going to be living far from home where an emergency trip for a change of medication or for a weekly dose of allergy shots is not going to work. The good news is, many universities have hospitals associated with them and fairly close to campus. The allergists associated with the hospital are often at the top of their field and most up to date with current procedures. Make sure to check with your insurance to be sure your visit will be covered before making your first appointment. And make sure you know what lab you can use for blood testing to be covered by your insurance. It may help to have a parent go with you to your first appointment to help fill the doctor in and also for some moral support for you. Don't get rid of your allergist at home, just in case you need him or her during the summer or on breaks! If your home allergist is part of a major medical center that uses the Epic chart system, you can get a Care Everywhere ID number. This will allow your school allergist - if he or she is at a major medical center - to share and access records with your home allergist. Should you be taken to a hospital emergency room for a reaction while you are at school, on vacation or anywhere, The emergency room doctors can access your medical records with the Care Everywhere ID. And, if you have a health care power of attorney - to allow your parents to discuss your health care with any providers - that will be in your records - allowing an emergency room to contact your parents. More information on the Care Everywhere ID and Health Care Power of Attorney is in upcoming sections.

#### Being near Home

Being near home can have it's perks, your parents are there in case of emergency, you don't have to travel far or find all new doctors, favorite restaurants, favorite stores or any other amenities you have at home. If your parents are close enough, they can even bring you meals as an alternative to dining hall food.

#### Being near a Hospital

We all know the twenty-minute rule when it comes to seeking emergency care for allergic reactions in a prompt manner. Like the allergist, many urban schools have hospitals near by and same with many rural universities. Don't just ask is there a hospital nearby? Ask: Is there a hospital equipped to deal with something like an anaphylactic reaction that is life threatening or will they stabilize you and helivac (helicopter transport) or ambulance transport you to a larger more state of the art hospital?

## Being near a Pharmacy

While most schools have on campus pharmacies, if you are a a student who takes a lot of prescription medicines on a regular basis or you have a pharmacy preference, then you may want to consider going to a school in close proximity to a pharmacy. If you use a big box pharmacy at home that has a branch on campus you can transfer your prescriptions fairly easily but keep this in mind: chain-owned city pharmacies receive the same allotments of medicines as suburban and rural locations with fewer customers. Your home town pharmacy may always fill your prescription right away, a city or school pharmacy may need more days so submit refills before you actually need them. Some versions of medications contain allergens. Ask the pharmacist to make sure the version of the medication they give you doesn't contain your allergen, and it may take them days or more - to get the version of the medication that you can take. So again, when you move your prescription from home to school pharmacy, allow as much time as possible so you don't run out of maintenance meds. If you have any questions about inactive ingredients in medicine, Daily Med, which is run by the NIH is a great resource for searching your medicine and looking at the inactive ingredients.

#### Being near a Rescue Squad with Paramedics

There are two kinds of ambulances; there are BLS ambulances and ALS ambulances. BLS ambulances stand for basic life support. These ambulances are staffed by two Emergency Medical Technicians (EMTs). In most states, EMTs can do everything except give medicine, start IVs and put advanced airways in. ALS ambulances or advanced life support are usually staffed by at least one paramedic - which is equivalent to a nurse - and an EMT. In some rural areas because Paramedics are more costly to hire than EMTs, they only have BLS trucks and one or two floater Paramedics. This means, if you have a reaction and need more epinephrine or go unconscious and need an advanced airway to help you breathe, you may have first responders unable to perform these tasks and may have to wait until a paramedic who may be an hour away can arrive to help. You may want to consider being close to an ALS ambulance squad, so in case of emergency, you have the best help possible.

## Being near a Grocery Store

For many food allergic students, the convenience store on campus isn't going to cut it when it comes to their main source of nutrition. Being near a grocery store is especially important if you plan to cook for yourself. Make sure you are near a grocery store that carries a wide variety of allergy friendly food and brands you rely on at home. Even if you are not planning on cooking for yourself, being near a grocery store can be convenient and cheaper then the convenience store on campus. If your school isn't near a grocery store or you are afraid that you will not have proper transportation to get to a grocery store, there are some online options that deliver your groceries. Just make sure to try them out ahead of time before relying on them as your main source of food.

## Section 3: Staying Safe While Visiting Colleges

Once you have narrowed down your college list based on the accommodations each school can offer you, your own personal preferences of the college and also it's location, the last thing you need to do before applying is to visit the colleges you are considering. Most colleges offer tours multiple times a day, but make sure to go to their website and a schedule a visit before making travel arrangements. While visiting colleges, the last thing anyone wants is to have an allergic reaction, but having one on a college visit or on your way to a college visit would definitely damper your plans. Here are some tips for staying safe while visiting colleges:

If you are driving to a college for the day:

- Bring your own food, that way you don't have to worry about eating food in the car and reacting while on the road.
- Avoid quick food like fast food restaurants and places like Panara and Cosi because they
  use small kitchens and cross contamination is a huge risk and possibility.

If you are flying to visit a college:

- Call ahead and ask the airline about their food allergy policy. Bring extra food for the flight
  and have at least 4 epinephrine auto-injectors in your carry-on luggage as well as some
  Benadryl just in case.
- Know the airline's policy for carrying medicine on board. To avoid suspicion and for security, keep your epinephrine in its original packaging. Also carry your action plan signed by a doctor. You may also want to carry a letter from your doctor stating your food allergy and explaining the importance of the need for you to carry medication, food or drinks with you.
- Once you get on board, check your seating area. You can ever ask the gate agent if you
  can pre-board to give you extra time to clean your seat. Wipe the tray table and hard
  surfaces by your seat. Consider bringing a fitted bed sheet to put over the seat to help
  create a barrier between any crumbs that could be on the seat and your skin.
- Always keep your medicine on you, NOT in an overhead bin. You want to keep it as
  accessible as possible just incase you need it.
- Because going to college via airplane is not as accessible as a car, use this time to explore
  the surrounding areas. Find the nearest hospital, grocery store, pharmacy and anything
  else you may need while in college. You may also want to identify some food allergy
  friendly restaurants so when at college yourself, you don't have to play a guessing game
  of whether a restaurant is safe or not.

## Section 4: Asking The Right Questions

Asking questions is an essential part of any college tour. Having food allergies only adds to the questions that have to be asked. The one trick is though, to ask the questions you need answers

too without identifying yourself as a food allergy student. People with food allergies are protected by the Americans With Disabilities Act and are considered a disability under the law. Unlike being in a wheelchair or being blind and needing a cane, food allergies are an invisible disability which means unless you tell someone about it, no one will know.

Our guidance counselors and other food allergy students agree, it's best not to tell tour guides and admissions people about your allergies (including in your college essay) until after you are accepted into the school. Although not accepting you because of your allergies is illegal and unlikely, it could happen. Once you're accepted, you can ask about accommodations before you accept any offer.

That being said, there are still questions that you can ask and things you can look for on your visit that will help you get a basic idea of the accommodations that may be available without "outing" yourself. One thing to be careful about is not to ask questions you can easily google. Such as, "Where is the closest hospital?" because they only annoy the tour guide and take up valuable time you could be using to ask other more important questions.

#### Dorms

When you are on your dorm tour, notice the size of the dorm rooms. Would they accommodate any food preparation? We toured a freshman dorm with ceilings so low it would have been a fire hazard to have any appliance in the room. And most schools ban certain appliances in dorms. Do the dorm rooms have their own bathrooms or would you share common bathrooms with common showers where beauty products, soaps and shampoos with top 8 allergens could be used by other students? Are there common lounge areas where pizza, peanut butter and baked goods with top allergens are consumed?

## Do Ask:

- Is it mandatory for freshmen to live on campus?
- Do any of your dorms have kitchens?
- Do all rooms have refrigerators and microwaves?
- Are there singles available?

## Don't ask:

- Are there off campus apartments available? (google it)
- Do you have a question on the roommate questionnaire about food allergies? (outing yourself)
- Is peanut butter allowed in the dorms? (of course it is!)

## Dining Hall

If you think you will eat in a school dining hall, there are some things you can do before being accepted to find out if that school will be a good fit for you:

- Ask to tour the cafeteria during normal operating hours, and look for stations that are free
  of the top 7 or 8 allergens and have precautions taken to prevent cross contamination of
  utensils. Also look for separate microwaves used to reheat food that are restricted from the
  top 7 or 8 allergens.
- Ask what company provides the food service at the school. Most schools use one of two companies: Sodexo and Compass Group. You can contact those companies directly to hear about how they handle top 8 allergens and accommodate students with allergies to other less common foods and spices. Both of these companies have partnered with FARE (Food Allergy Research and Education) to make eating in a dining hall safer for food allergic students. They have leaders within their organization who understand the challenges of having food allergies at college. The biggest complaint we hear from students who eat at these allergy free stations is that a student who can't eat one top allergen (for example wheat) misses not being able to eat food with another top allergen (for example dairy). Because all of the top 7 or 8 allergens are omitted in every dish served in those allergy free stations. So just keep in mind that eating in a dining hall probably won't be like eating at home where you can omit only your allergens.
- Check out the FARE website (foodallergy.org). FARE has created the College Food Allergy
  Program which partners with colleges and universities to make all aspects of higher
  education safe for students. They will have a list of partnering schools that have
  participated in training and the creation of programs to be shared with schools
  nationwide.

## Do Ask:

- Is there a dietician on staff to meet with students?
- Are meal plans mandatory/what are the meal plan options?

## Don't Ask

- How are food allergies handled? (Tour guide most likely won't know and you are outing yourself)
- What kind of restaurants are on/near campus? (google it!)
- Does the dining hall serve peanuts? (of course it does!)

#### Safety

You can ask (The tour guide may not know all the answers):

- What happens if an ambulance needs to be called?
- Are the security guards trained as first responders?
- How does your student health operate?

## Don't Ask:

 Can RAs use auto-injectors? (most likely they have not been trained but you may be able to train them) See the appendix for a printable version of the questions listed, which you can bring with you on your college visit. There is also space to write your own questions!

#### Section 5: College Application Timetable

You are probably overwhelmed right now, but that's okay! Being overwhelmed is 100% normal. To make things a little easier, here is a basic timetable you can use to help you plan for college and when you should be doing what. We didn't include the normal college things like SAT prep and essay writing, so don't forget to do that, too!

Junior Year and Summer Between Junior and Senior Year

- Visit colleges. See <u>Visiting Colleges</u> for more information.
- Ask questions while on visits to determine whether you can eat dining service food or whether you need a kitchen.
- Contact the contractor that provides food service to the schools you are considering to see how they handle allergens in the dining halls.
- Find out what kinds of accommodations are available at the schools you are considering. Some schools have only dorms without kitchens. If you are an in-coming freshman, you can get an accommodation to live in an upper-classmen dorm so don't just look at freshman housing choices, look at all housing choices. There are also schools where a majority of students even freshmen live off campus in apartments or condos.
- Evaluate each school's distance from emergency health care, allergists and other doctors, grocery stores and restaurants where you can eat if you eat out.
- For each school, also answers these questions: If you buy a meal plan, can the dining dollars also be used at campus convenience stores where you can buy food with labels? If your parents would bring you supplemental food, how far is the school from home?

#### Summer Between Junior and Senior Year

- Finalize your evaluations of each school and prioritize schools based on what will be safe
  and do-able. This is also a good time to start preparing yourself. See <u>Pinpointing Your</u>
  Priorities In College Location for more information.
- Have a conversation with your allergist about precautions you should take based upon
  your allergies. Do you regularly carry epinephrine? Or, do you depend on your high school
  nurse and mother to have it in case you need it? Perhaps it's time to become more
  independent when it comes to allergy safety precautions.
- If you will be cooking for yourself, start shopping for your own food and preparing your own
  meals. That will give you an ideas as to whether you can handle doing the same thing in
  college.
- If you bring all of your lunches to high school because of your allergies, and you anticipate eating at a college food service, try working with the school food service to

- accommodate you. That will give you an idea of what it will be like in college. And do it yourself without parental involvement. Many high schools use the same food service contractors that serve colleges.
- Decide whether it is appropriate to apply early decision, early action or regular decision. If the school(s) of your choice have rolling admissions, the sooner you are accepted, the sooner you can start the next leg of the process which is pursuing your needed accommodations. Legally, you should be able to consider schools and apply to college just as you would if you were a student without food allergies. But practically, the sooner you begin the process, the better because requests for "reasonable accommodations" can be denied if the school doesn't have ample time to make them.

#### Senior Year

- Apply to college.
- Obtain acceptance.
- Start the process to obtain any needed accommodations as soon as possible senior year, even if you haven't committed. Here's why: Upperclassmen submit housing requests for the next academic year in late winter/early spring. Often they are "guaranteed" their current room assignment if they want it. That leaves what is left plus the freshman dorms for incoming students. Among those rooms there may be few singles if you want to avoid living with someone who brings peanut butter, tree nuts, dairy or whatever you are allergic to into your room and there maybe few air conditioned dorms if you need that for a co-existing condition like asthma. See Dealing With Disability Services for more information!

## Section 6: Don't Let Your Food Allergies Stop You!

I know so far, all of this seems very overwhelming. You are probably thinking to yourself, "How the heck am I going to find a college near emergency care or near your home town, or near a grocery or near an allergist and find the right place to live!?" But don't worry, there are lots of colleges that accommodate food allergies and want you to be part of their student body. Sure, you are going to have to work a little harder and ask a few more questions than most prospective students but you can do it!! Don't forget, you are a food allergy kid, which means you already are pretty strong! Don't give up, don't settle for less and definitely don't pick a college only for your food allergies, pick one because you love it and then make it work!

If you are feeling overwhelmed or like your parents aren't on the same page as you, schedule a meeting with your college guidance counselor at your school. I know when I was looking at colleges I wanted to go to a school 6 hours away but my mom wanted me to go to a school that was close and commute from home. She ended up making an appointment with my counselor to talk about both schools. My counselor was fantastic and helped both of us see each other's

sides and was eventually able to convince my mom to let me go to my top choice school which		
was 6 hours away.		

# Chapter 2: What To Do After You Are Accepted To College

Getting accepted to college is a super exciting moment, especially if it is the school of your dreams! But for food allergic students, once you get the letter saying yes, a whole new world opens up of things that need to be done, questions that need to be asked, visits you need to make and the list goes on and on. This chapter is intended to help give you and your parents a clear sense of what needs to be done after you are accepted.

In this chapter we will cover:

- How to deal with disabilities services on campus
- Good packing list of things to bring to college
- How to decide roommate or no roommate
- How to switch doctors, pharmacy and insurance
- Safety Systems
- How to navigate registration and orientation

## Section 1: Dealing With Disabilities Services

The college office of Disabilities Services is the first place to contact once you are accepted. You might not think having a food allergy is a disability. But it is - and it if you have one, your rights are protected under the Americans With Disabilities Act. The ADA is enforced in schools by the US Department of Education Office of Civil Rights. The ADA even applies to private colleges because most receive some public funds. You can contact the Office of Civil Rights before you contact the college, or while you are in the process of having your request reviewed by a college.

The Office of Civil Rights is staffed with regional offices of attorneys who can pull up previous cases that can help you get a college to grant your request. The most famous is the Lesley University case which led to requiring schools to waive mandatory meal plans for students who cannot safely eat a variety of foods in the school dining halls. But there are also cases the require housing and other accommodations. For instance, there was a college that tried to charge a student extra for his/her room accommodation. That was ruled illegal. Call the Hotline at: 1-800-421-3481 to be directed to a person in the Office of Civil Rights who can answer your questions. The OCR also has documents online that describe how they help students with disabilities, but because the law was intentionally written so broadly, you may need to refer to specific cases.

Here is the general language under 34 C.F.R. Section 104.43 (of the Americans with Disabilities Act) which states the following:

No qualified handicapped student shall, on the basis of handicap, be excluded from participation in, be denied the benefits of, or otherwise be subjected to discrimination under any academic, research, occupational training, housing, health insurance, counseling, financial aid, physical education, athletics, recreation, transportation, other extracurricular, or other postsecondary education aid, benefits, or services to which this subpart applies.

The college office of Disabilities Services will probably require you to fill out their own paperwork and to have your doctor fill out some, too. Your doctor may indicate - among other things- that you need a room with a kitchen, to live in a single, to opt out of a meal plan, to have meal accommodations made for you, that you need a car on campus to go to doctors appointments or get supplemental food, or that you need air conditioning for your asthma. What ever accommodation you want - make sure your doctor indicates that on the form.

While you can and should call the Office of Civil Rights for help, all requests to the office of Disabilities Services should be made in writing, which can include emails and faxes of forms. If you have a phone conversation, follow it up with an email acknowledging the date and time of the call and what was discussed. Tell your story in each email so that if the case needs to be escalated the emails will speak for themselves.

Once you have filled out the paperwork, the school has a reasonable amount of time to respond. About 2 months after we had submitted the forms and made a request for accommodations, we still had not received an answer from the college. Our guidance counselor recommended requesting a response early in the academic year in case Lily would have to choose another school. Lily was accepted via rolling admissions at the end of September her senior year, but still hadn't heard from the school regarding accommodations by the end of November. Here is what the letter said (feel free to use it in your own correspondences with Disability Services).

Dear (Director Disabilities Services),

As you might imagine we are eagerly awaiting your decision as to whether (our daughter) meets the criteria to receive medical accommodation from (your university) for the 2014 academic year, when she would be a freshman.

As (Student's) doctors have indicated in the submitted forms, (Student) has anaphylaxis reactions to physical contact, and in some case airborne exposure to (student's multiple food allergies). She does not eat school cafeteria food or restaurant food. She eats only food she or I prepare. She will need to continue preparing her own food at college by living in housing with a kitchen. We are requesting that (Student) be placed in apartment style university housing where she would have a kitchen such as (\_\_\_\_\_ Hall) or one of the other university owned apartment buildings.

In an email dated October 10, 2013 (Student) asked if you would notify us by November 15, 2013 if she met the criteria. In an email dated the same day, you indicated you received the paperwork from the doctors and would decide "in the next few weeks". While November 15 might seem like an arbitrary date, we need time to plan any necessary next steps to be sure (Student) has a safe college experience without suffering any hardships that would prevent her from having adequate time for her studies (if she didn't have a kitchen and couldn't easily and quickly prepare food) and proximity to her classes (if she had to live off campus).

Best regards,

Student's Mother

Most likely, once your accommodation is granted, you will be put in touch with other departments of the university such as dining services, student life, residence life and student health. Depending on the school, one department might take the lead in dealing with the student and his or her request.

Remember your request extends to any time you will be staying on campus. If you are going be staying over for an orientation or registration or accepted students weekend, you will need an accommodation, too. If one dining hall handles all of the food allergy needs but that dining hall isn't open during orientation - that is a problem.

If your accommodation isn't granted, be sure to get the rejection in writing and then contact the OCR immediately!

Here are some sample forms to give you an idea of what you will need to fill out for your accommodation. Allow ample time for filling them out because most schools require your doctor to fill out a few sections too. To find your school specific forms, google your school name and disability services and it should direct you to their disability website.

#### Section 3: Finding A Roommate

Roommates are an interesting thing. For some reason, it seems like you and your roommate either are joined at the hip or want nothing to do with each other. For a lot of kids, having a roommate is a new concept to them. They have their own room at home yet when they go to college, they are going to share a tiny room with a complete stranger. For some this sounds like a blast, but for others they want nothing to do with it. Every college handles the roommate process in different ways, which include random selection, requesting a pairing and indicating on a housing form (at select

colleges) that you have food allergies. We have said before that RA's in freshman dorms are rarely trained in food allergy emergencies and how to use an auto-injector. We can share a clever work around. One school that said that it could not train RA's in using epinephrine placed a student with multiple food allergies on a floor of all pre-med majors who were in a living-learning community - and more than happy to learn how to use an auto-injector.

As a food allergy student, the most important thing is safety. And with roommates things can go either way. Your or your parents may think it is safer to live with a roommate who can watch out for you when your family is not there. Disabilities services may say it is safer for you to live alone because of risk of allergen contamination. Try to remain open-minded when making a decision on whether to have a roommate. If your parents live close to the school, maybe you - and they - feel less worried about the risks of having a roommate. If your parents live far away from the school and would have trouble responding quickly to an emergency, you might want to take the safest route to preventing a reaction - living alone. Remember, preventing a reaction is goal #1, knowing what to do in case of a reaction is #2. As we said in another section, we know students with food allergies who lived with roommates who said they would keep allergens out of the room - but did not. We also know parents who refused to send their child to a school unless they agreed to live alone, and we know parents who allowed their FA student to have a roommate.

If you can live in a dorm and eat dining hall food, your chosen school may have single dorm buildings. So you won't be socially isolated because everyone is in a single. If you need a kitchen, you might have to live in a building with older students, which could be socially isolating - but remember in one short year you will be a sophomore. There are also advantages to living in a single dorm or apartment - a quiet place to study. If you or your parents are still worried that living alone is a safety hazard, consider purchasing an emergency alert system (see <u>Safety Systems</u>) that contacts a dispatch center at the press of a button. That dispatcher can call an ambulance and your parents on your behalf and even use GPS to know where you are located if you are not in your room or apartment. These systems may also be a good idea for students who are commuting to college by car alone. They can also be used as general safety protection from any threat when out and about on campus.

How about we look at the pros and cons of having a roommate:

#### Pros:

 An instant friend/allergy ally who can speak up for you if you are sick and can call 911 if something were to happen to you while in your room.

#### Cons:

- They may bring food you are allergic to or environmental allergens into your room
- They may not wash their hands before coming in your room.
- If they have allergies themselves they may be different then yours.

## Section 4: Switching Everything

If you are going to college far from home, you may want to consider switching or transferring your doctors, pharmacy, and insurance. Just because you are switching doesn't mean you should get rid of the ones you have at home, but it does mean you will have access to the proper care near your new home (college). You should also consider whether you can receive the general medical care you need from student health, or whether you should find a primary care doctor near your campus.

## Switching Doctors

If you are an allergic student, you and your parents should discuss whether or not it makes sense to have an allergist (and other doctors) on campus - if you go to a large university with a medical center - or close by. Here are some factors to consider when deciding whether to secure doctors near school before school starts, or whether to stick with the allergist you saw in high school:

- How far away will you be from your high school allergist? Would you have transportation to get there?
- How severe is your allergy? Does your allergist also treat you for asthma? How severe is that?
- How often did you see your allergist during high school? Did you have many non-check up visits for illness, asthma or testing and treatment for new allergies?
- How accessible is your doctor at home from a long distance? Will the office write prescriptions or change a dose when you describe symptoms over the phone?
- Will you be at college during the months you are most likely to need to see your allergist
  (asthma is typically worse in the winter, allergies are typically worse in spring and fall.)
- Do you receive allergy shots? Will they be administered by student health or another primary care near school?
- Will you be going to a school that has a major medical center or that is near one? If it's not on campus, how would you get to appointments?
- How much confidence do you, your parents and your high school allergist have in the student health facility at your college? Our high school allergist recommended against using student health. We found an adolescent medicine practice, which typically treats teens and young adults, right on campus.
- What are your co-conditions and how easy are they to manage without being close to
  those specialists or a primary care that often treats those conditions? (example:
  endocrinologist for thyroid disease, gastroenterologist for celiac)?
- How stable is your medical situation? Unfortunately some autoimmune diseases commonly
  develop during the years of hormonal changes which includes the typical time a student
  would be in college.

You may currently see a pediatric allergist and other pediatric specialists. You should discuss with your high school doctors whether you should see pediatric doctors at college. The decision may depend on accessibility. Once you have figured out what doctors you'll need to have at school, you will want your home doctors to be able to communicate with your school doctors.

The idea that we should all have electronic medical records that can be seen by all of our caregivers has not yet become common practice - unless all your doctors are in the same hospital system. Instead of carrying paper records from the home doctors to the school doctors, your current medical system (if it uses Epic charts) can assign you a Care Everywhere ID number. When you identify your team of doctors at college - which in our case is a primary care doctor for primary care and endocrinology and an allergist for allergies and asthma - you give them your care everywhere ID number. Our new doctors had access to all of our old records, including lab tests. Theoretically, the doctors in both locations can see updates to your chart. And maybe more important, if you have to go to the emergency room for anaphylaxis or an asthma attack, you can give the emergency doctors your Care Everywhere number and they can see your allergens, coconditions and any other information that might speed up treatment. We got the Care Everywhere ID number put on a medical ID bracelet so it is always accessible. Even if you aren't going to switch doctors, you may want to Care Everywhere ID number just incase you need to go to the ER.

#### Switching Insurance

Are you or your parents concerned that the family health insurance policy isn't adequate for you? My parents were worried that the high out-of-pocket cost of emergency room visits in our family policy would keep me from going to the emergency room when necessary because I wouldn't want to "waste" money. They also worried that a high co-pay for a specialist visit may discourage going when needed. So they took out a separate policy just for me. The policy requires me to pay for less at time of service and has a 0 deductible- and the monthly premium my parents pay is hardly more than what they pay for my younger sibling who is on the family plan. The young age of a college student keeps the premium low, and pre-existing conditions like allergies and asthma don't increase the price. Keep in mind that open enrollment for new health care plans starts in October. The federal government expanded the enrollment period in 2014 because of glitches with the system. Normally, enrollment period is October to December 31st.

We took advantage of the recent enrollment period for the affordable care act to improve our insurance coverage, and to make sure coverage would extend to the major medical center at college. Our insurance has local coverage and national coverage. When outside our local coverage area - where we are aware of the radiology and blood labs we can use - we have to be sure that we are using the authorized providers for that area. For instance - we can't use a certain national lab for blood draws in our region, but that national lab may be the authorized provider in the area the school is in. So, if any of your medical conditions require regular testing, make sure

your new providers are covered in the college area - and don't assume that because you had to use one lab at home that is the same lab to use at school. When in doubt, call your insurance company. And of course, make sure you have your insurance card to take with you to school.

## Switching Pharmacies

Switching pharmacies is super easy if you use the same chain at home and at college (for example: CVS or Walgreens). All you need to do is tell your health care provider you have switched and then ask the pharmacist at home to transfer your files to the pharmacy closest to school. Even different chain pharmacies make it easy to transfer one prescription to another. Just remember, if you are transferring to a different pharmacy chain, one thing you may want to keep in mind is, when you are home in the summer or on break, you may not have easy access to your prescriptions, so plan for that.

We also learned a couple of other things: city pharmacies receive the same amount of drugs as pharmacies in the suburbs that serve smaller populations. So, if you are used to calling for a refill the day before you need it, keep in mind that a busier pharmacy in a densely populated university area may need a couple of days to fill a prescription for asthma or allergies. Also be aware that some formulations of medications may contain allergens, and the pharmacy may need to special order a version without your allergen. Your home pharmacy may have been doing this for you for years without you realizing. So allow extra time if your medications need to be special ordered.

## Section 5: Safety Systems

Before we get ready to go off to college, most of us become more independent and spend less time at home. Parents of all teens worry about our safety when we are away from them. Add food allergies to that, and you might end up with a neurotic mother (but for good reason, don't get me wrong!). Mine started to panic after a visit to an emergency room for an anaphylactic reaction. The ER nurse gave her a lecture about how crazy she was to let me go away to college - let alone far away. I should do online college and stay home - she told my mother. As you can imagine, I wanted to go to college, and what she was suggesting sounded like jail! Here are some things that can help keep you safe and will help give you parents a piece of mind.

#### Automatic 911 Systems

One of the factors that had worried my mother since my housing accommodation was granted was that my college said I had to live alone, because having a roommate posed too great a risk of cross-contamination. This meant that if I had a reaction to something in my apartment, no one would be there to help me. That is when we started researching emergency call systems. There are many different kinds. Some work with a land-line phone and are stationary where you live. You press a button on the unit or a small remote device (usually a necklace or wrist band) and it calls a dispatch service that has your medical records on file and will call 911 if you can't. If you are

unable to speak because you are having trouble breathing, it will dispatch an ambulance to your residence. A more advanced version works like a mini cell phone with a GPS tracker and can be used anywhere away from the home unit. Additionally, a button that you can wear around your neck can detect if you fall (pass out from an allergic reaction). We purchased the advanced mobile help device. An added bonus is that if you are ever in a situation where you feel unsafe, such as walking home from the library at night, you can use the help button to call police. The costs and way the systems operate vary greatly. Some require you to buy equipment and pay for the monitoring service. Others give you the equipment with the service. Some cost less per month if you pay for a year at a time. Do your research. Make sure to choose one with a money back guarantee. We suggest buying it before you go to college, use it to get accustomed to how it works and do all the system testing that the company will require.

When my system first arrived to my house, I was skeptical at first. I didn't like the idea of wearing a button that was definitely not fashionable. Eventually, I realized how much easier it would make things in the case of an emergency and eventually, I became compliant and have used it since.

#### Medical Alert Jewelry

Everyone who has a life-threatening medical condition should wear a bracelet or necklace that identifies their conditions. They are easily ordered online at a variety of price points from non-profit and for-profit sources. This jewelry is great because if you are unconscious, not only does it identify you, but it identifies your health conditions and age which makes it easier for doctors to treat you fast and get you the care you need! From an EMT perspective, if I were to find a college student passed out on the ground, the first thing I would assume is a drug overdose or alcohol poisoning-not an allergic reaction. Wearing medical alert jewelry can help us know what could be causing your problems and get you the help you need as fast as possible.

#### Health Care Power of Attorney

If you will be over 18 years of age in college, and your parents will want to discuss anything related to your health with: student health, any doctor who treats you or emergency personnel in case of an allergic reaction or anything else - they will need a Health Care Power of Attorney. The form can be obtained at americanbar.org. If you live in Indiana, New Hampshire, Ohio, Texas or Wisconsin, you will need a state-specific form. If you live in Missouri, North Carolina, South Carolina or West Virginia you must have the form notarized, all other states the notary is optional.

If you are worried that parents will have access to information about reproductive health or anything else unrelated to your allergies and/or asthma, no worries. There is a place on the form to write in exclusions for information to which you don't want your parents or other trusted adult to have access.

Copies of the form should go to:

- Student Health (even if you have no plans to use Student Health for primary care.)
- All doctors who treat you near home and school ask that it be scanned into your chart.
- Your parents
- An electronic version of the signed forms should be stored somewhere on your phone and your parents phones in case they need to be emailed on the fly.

With your epinephrine auto-injectors with you at all times, an automatic 911 system, medical alert jewelry and a Health Care Power of Attorney, you and your family will be prepared for an emergency.

#### Section 6: Summer Registration And Orientation

Orientation & Registration is the last step before you are an official college student. While it is exciting, it can also be concerning for food allergic students. College is a chance to start over, erase the allergy kid label and start new. That being said, you now have to decide who you tell and how you tell them about your allergies.

Some schools hold summer student-only registration where all or most students go without parents and stay in dorms. Other schools hold dual programs for parents and siblings while incoming students are participating in registration and orientation activities. If your parents are joining you for summer registration/orientation and staying in a hotel and you are worried about staying in a dorm with a random roommate and limited access to safe food, consider staying in the hotel so that you can bring your own food and enjoy the activities rather than worry about what you can and are going to eat. If your school holds a student-only registration/orientation, or if you want to stay in the dorms, you are going to have to ask for the same accommodations (housing and/or dining) that you requested for the school year. Not all cafeterias on campus may be open during summer registration or orientation, so you want to be sure you have access to the cafeteria with allergy safe options.

Also consider that some food during orientation/registration may not be provided by the school at all. Vendors who operate delivery and food service business near and around campus may supply food during picnics and fairs that are part of the university programs to acclimate you to the school. Think pizza and ice cream. So, if your allergies don't allow you to eat that kind of food, you will have to ask the university to provide you with a boxed alternative or bring your own. And for the record, you are entitled to ask them to provide you with a boxed meal. if they are feeding everyone else, they should be able to feed you - if you trust them to do so safely. If you do bring your own food, bring things you can eat standing and walking - like you would at a fair.

As for telling your new friends about your food allergies they will either come up when they figure out you have accommodations, or they will find out when they go to eat with you. Don't be embarrassed by your food allergies. If you act like they are no big deal, your new friends will too.

# Chapter 3: Thriving At College With Food Allergies

You're finally in college and you have graduated high school! I think a congratulations is in order! Welcome to the best years of your life. College is a chance to explore your interests, be independent and become the person you have always dreamed of becoming. Yes there will be some downs in college, but I promise you will have lots of ups too! In this chapter we are going to cover everything you will need to know about college.

Here is what we will cover in this chapter:

- Tips on everything college
- How to go grocery shopping in college
- How to cook for yourself
- The importance of sleep
- Finding someone on campus to talk to
- · Going to the doctors by yourself
- Going to the emergency room by yourself

#### **Section 1: Tips And Tricks**

Going to college can be tricky and for a college student with food allergies the obstacles are even larger. Here are some tips we have compiled for what we think is almost every situation under the sun, feel free to use as many as you want!

## Dining in the Dining Hall

- Don't blow off your meetings with the dining staff, if you make it seem like you don't really care or like finding safe foods isn't your priority, then the dining services people are going to feed off that attitude and they won't take it as seriously either.
- Be reasonable. The dining hall staff cooks for thousands of kids a day, they are not your
  personal chefs. When asking for an accommodation, do not ask them to make you pizza if
  you are allergic to milk and tomato and have celiac and expect them to come up with
  alternative ingredients to your allergens.
- Rotate your meals. Don't eat the same thing for breakfast lunch and dinner. You will be
  missing out on the key nutrients that you need. Switch it up. If dining services can only
  make you one safe food, maybe it is time to look at some other accommodations.
- Don't get too comfortable, yes it is important to feel safe, but you don't want to have a false sense of security. Every time you order something, remind the staff of your allergies because you never know if ingredients have changed, staff have forgotten your allergies or if there are new staff who may have slipped up.
- If you have a dairy/milk allergy, be sure to always refer to it as a "milk" allergy when speaking to food handlers. It may sound counter intuitive since you aren't just allergic to

milk - but all dairy products. Milk is an ingredient in sour cream, yogurt, cheese, ice cream and butter. On food labels for those or any other milk containing food the label will say "contains milk". No label ever says "contains dairy". So, if your food handlers and preparers are looking at labels to check to see if a food is safe for you - you want them to be looking for "milk". Also, some people mistakenly think eggs are dairy because they are commonly found in that section of the grocery store, even though eggs come from chickens.

- Don't eat in the dining hall without your epinephrine. Obviously no one wants to have a reaction in the dining hall, but be prepared in case you do have one.
- Be smart. Don't eat food that looks suspicious or that you are uncomfortable eating.
- Avoid places where cross contamination is likely to occur like salad and pasta bars and
  other self-serve stations. If you want a salad, ask the chef to make you one in the back
  and set it aside for when you are ready for it. Same goes for all the other food at the self
  serve bars.
- Don't forget to say thank you. Yes you have every right to be accommodated but being gracious will go far and make the staff more willing to accommodate you and help you out.
- If there is a problem with getting safe food, ask to speak directly to dining the dining manager. Don't have your parents call.
- Be willing to take the time to consider what food you want and to communicate that in advance if necessary. In a huge school with allergen free stations there may be variety every day. In a small school with fewer kids, you may be able to meal plan once a week with a dining manager who can tell you what will be served to the general population and what they can do to make it safe for you. But you have to be willing to meet, talk on the phone or exchange emails. We attended a conference with dining hall staff and food allergic kids. The complaints we heard from dining staff were about students not willing to communicate. And the complaints we heard from students were about lack of variety.

#### Living With a Roommate

- Explain to your roommate your food allergy upfront. Don't try to hide it as it could put you
  in danger.
- Show them where you keep your stationary epinephrine pen (if you choose to leave 2 in your room and have 2 on you) and your action plan so if you have a reaction they will know where your pens are and be able to help you. Explain the symptoms of anaphylaxis. "My tongue will swell up and I will have trouble speaking clearly. That is when you give me the epinephrine if I can't do it myself." If they want to, you can even let them practice with your training device.
- Lay out what you need. If you need them to keep food you are allergic to out of your
  room, let them know that. If you need them to was their hands before coming in the room,
  ask them to do that. You can supply hand wiped to keep by the door. Make reasonable

- requests, that don't require them to alter their lifestyle. Always give them a way out and explain that you will not take it personally if they feel they need to find another roommate.
- If your roommate breaks your agreement or puts you in harms way, tell them about it.

  Explain to them why it could harm and kindly ask them to not do it again. If it happens on a regular basis, talk to your RA. Your RA is there to help keep you safe and resolve any issues between you and your roommate. You may be able to move to a different room.
- If you have a mini fridge in your dorm, label your food so that your roommate doesn't accidentally cross contaminate it or eat it. Also, make sure everything in the refrigerator is in a sealed container or plastic bag.
- Share your food. You don't want your roommate going hungry, so buy lots of safe food both of you can enjoy. Single serving packets also help insure your safety and keep the bugs and roaches away!
- Keep plenty of clorox wipes available as they can help clean messes up in a pinch but will
  also remove the allergen residue left behind on door knobs or common use appliances
  and furniture.
- Use disposable plates and utensils. This isn't the situation in which to be eco friendly. You will
  not have the proper cleaning facilities to remove allergens from reusable dishes or utensils.
  Instead, buy plastic utensils and paper plates, bowls and cups.

#### Rushing and Greek Life

- Know the culture of the organization. Although rushing is usually kept secret it is often easy to discern as to whether or not you will be expected to do something out of your comfort zone. Although hazing is not allowed at most schools, it still happens, so be smart.
- If you are in a situation that could endanger you, stop. Being part of a sorority or fraternity is not worth your life. There are plenty of other ways to build community and get involved on campus that will not put you in an unsafe situation.

#### Parties

- Don't drink from punch bowls, kegs or funnels.
- Don't smoke from hookahs or bongs. If people have put their mouth on it, it is a no go since allergens can be passed through saliva.
- Alcohol can contain "food" ingredients. For example, vodka has potato in it, most beer has gluten in it. Know exactly what is in your drink before ingesting it.
- Consider bringing your own drink.
- Parties are essentially a huge group of people getting together to blow off the steam from the week. In other words, you have a lot of responsible people in one place who want to be irresponsible for the night.

- Food allergies make it impossible to let our guard down without risking our safety. Don't let
  other's carefree behavior make you forget about your number one goal, which is to be
  safe.
- If you do choose to drink, find a sober friend who will know what to do if you have symptoms of anaphylaxis.
- Don't get high or wasted to the point where you are not able to monitor your food intake.

## Talking To New Friends About Food Allergies

- Most likely your food allergies will come up quickly in conversation, especially if you have special housing accommodations. Don't be embarrassed or make it a big deal, and your new friends won't think it is a big deal.
- Do let your new friends know the symptoms of a food allergy reaction, in case of an emergency. Tell them and show them where you keep your emergency medicines. Teach your new friends how to use your auto-injector in case you need it. I promise you they will love learning about it! You will quickly know who real friends are based on those who care about the fact you have food allergies and those who don't.

#### Talking To New Teachers About Food Allergies

- Chances are, all your teachers knew about your food allergies in high school, but college
  is different. Many of your classes will be so big that the professor won't have time to keep
  track of your name let alone your allergies. In this case, telling your professors about your
  allergies may be unnecessary.
- If you feel more comfortable having your professor know, you should tell him or her. Most
  colleges make professors hold office hours, which are times you can go ask for extra help.
  Go to your professor early on before lots of people come with questions and introduce
  yourself and tell him or her about your allergies.
- If you are in a class that deals specifically with food like a cooking class or a lab, let your teacher know RIGHT AWAY so that they can make sure you are able to remain safe while completing the work.

## Talking To Your RA About Food Allergies

- RA's are excellent resources for first year students. They are there to have your back, give
  you tips and keep you safe. During the first week of school, introduce yourself to your RA
  and explain your food allergies.
- Give him/her a food allergy action plan so that he/she can help keep you safe. Show your RA where you keep your emergency medication and how to use it just in case.

#### Dating With Food Allergies

- Before you get too close, explain to your date about your food allergies and what he or she needs to do to keep you safe such as brushing their teeth, washing their hands or avoiding your allergens.
- Please know that teeth brushing alone does not remove allergens from saliva. Before
  kissing your date, make sure they have not eaten your allergens for at least 4 hours and
  that they have had an allergen free meal. Doctors say that this is the only way to truly rid
  your date's saliva of your allergens.
- Only expect them to avoid a reasonable amount of food. If you are allergic to milk, that is unfair to expect him or her to avoid all milk products. If you are only allergic to peanuts, it is ok to ask them to avoid peanuts because peanuts are relatively easy to avoid. Be careful. Even if he or she has claimed to avoid nuts, they may have unknowingly eaten something that contained your allergen (remember their body will not have a reaction if they eat your allergen so they will most likely not know). Always have them brush their teeth and wash their hands before kissing.
- Go on non-food dates such as dates to the amusement park to remove attention from food and your food allergies from the focus.

## Studying Abroad With Food Allergies

- Consider going to a country where there is medical care similar to the U.S. such as Europe
  or Israel. Some countries don't even have auto-injectors. Some countries have a larger
  percentage of food allergic citizens than others, so they are more accustomed to
  accommodating allergies.
- Avoid going to a country where you do not speak the native language. It is easy for food allergens to get missed in translation.
- Know the words for your allergens in the country you are visiting.
- At home or abroad you can carry a card that explains you allergies in several languages.
   This is always smart because there are often non-native speakers in a restaurant kitchen as restaurant jobs are often first jobs for new immigrants. Allow your server to take the card back to the kitchen.
- Know the culture around food. Some countries' culture may revolve around 7 meals a day
  vs. 3 like we do in the US. Some cultures view turning away food as a sin and can be
  offended. Some cultures may have communal bowls where everyone eats out of the
  same bowl together. These are all things to consider.
- If you are going on a program where all the meals provided are pre-prepared, make sure
  the chef knows your allergies and is willing and able to accommodate you before you
  leave.
- Tell your chaperone about your allergies and about your medications in case of emergency.

- Consider traveling with a friend who knows your allergies and how to keep you safe so you feel less alone.
- Avoid home stays as they make it impossible for you to control the environment you are
  living in, and could expose you to different kinds of allergens like pets and dust.

## Cooking With Food Allergies

- Cook a weeks worth of meals at once and freeze them in individual portions to keep food from going bad.
- Offer your friends meals when they want in exchange for going with you to the grocery store.
- Learn kitchen safety at home before moving on campus to avoid silly mistakes that could lead to a smoke alarm going off or worse, a fire.
- Don't change your diet too much. If you are used to eating fresh vegetables daily, continue to do that so you don't mess up your body's "rhythm".
- Find supermarkets close by that have the specialty items you rely on. If you can't find exactly what you want, try ordering it online.
- Make cooking safe food a fun activity for you and your friends. Try inviting them to help
  make a meal. They will learn more about your allergies and the extra hands will make your
  cooking time fly by.

#### Initiating Auto-Injector Training

- Talk to your RA about training your floor on how to use auto-injectors and how to train students in auto-injector administration and recognizing anaphylaxis.
- Consider starting an auto-injector training initiative club by talking to the club supervisor. At Pitt, we named our initiative Project ePITTnephrine. You can come up with clever names too.
- Talk to allergen friendly food companies about supplying food for your events as an added bonus.
- Talk to auto-injector companies like Mylan, Sanofi, Amedra, and Lineage about supplying free trainers at your events.
- Emphasize that training can make you a hero!

#### More Advice?

- Looking for advice on a topic not here? Submit your question down below.
- Have advice we don't have? Submit it down below for others to see.
- Join the FARE Teen Food Allergy Support Group on Facebook
   https://www.facebook.com/groups/FARETeenFoodAllergySupportGroup/ a group only for teens to talk about food allergies and ask questions.

- Join the College Food Allergy Social Group on Facebook
   https://www.facebook.com/groups/760938040611135/
   also run by FARE for college students.
- Keep reading, we get more specific about certain topics further in this section.

## **Section 2: Going Grocery Shopping**

Grocery shopping in college is in many ways different then shopping at home. If you are far away, you may only have access to unfamiliar grocery store chains that may not carry exactly what you want. You may also not have the transportation availability or the time to simply run down to the grocery store for one or two things. In this section we are going to cover different kinds of shopping, making a thorough list and having a plan and the modes of transportation available to you as a college student.

Unlike at home, going to the grocery store may not be feasible or easy. For that reason there are many different options for grocery shopping. If you choose, you can go the old fashion way. You can go to the store, get what you need and be on your way. If the store does not have exactly what you want, you can ask the manager about ordering the brands you rely on. If going to the store takes too much time, there are now options for online grocery shopping. Online grocery shopping gives you the convenience of shopping from home and gives you a wider array of products than may be available in the store. Online grocery availability vary by area so keep that in mind. If you plan to do online grocery shopping, keep in mind it will take time for your groceries to be delivered and that it is important to check the ingredients in the foods carefully before ordering. There is also a hybridized way to do it by buying your specialty items online while going to the store for your more mainstream every day staples.

No matter your method, it is important to go shopping with a plan. The last thing you want is to come home from the store realizing you forgot a key ingredient in your recipe. Try planning your meals in advance of shopping so you know exactly what you need to buy. Also as you run out of things it is easy to write them down so you don't have to try to remember what you have and what you don't have. On your final list, it is helpful to group food by category so you can go aisle by aisle without having to run back and forth. It will save you time and keep you from forgetting items. Have both a paper version and an electronic version so if you lose the paper, you have it on your phone and if your phone dies you have it on paper.

Getting to the grocery store can sometimes be the hardest part of the entire process. If you live in a city where there are busses, try using google maps to help plan your route. It will tell you exactly what busses to use, when they come and where to get off. If you are taking a bus, a wheeling cart is definitely a good investment. Another options is cabs. Although more expensive than busses they will take you door to door and you don't have to worry about getting lost. If you can provide proof of needing a car, your university may allow you to keep a car on campus even if freshman

typically aren't allowed. Keep in mind, parking may come at a price - as high as \$900 a semester - and if you are going to school where winters can bring lots of snow and you will not be driving your car for a few months this might not be the best option for you. Lastly, some universities have ZipCars. Once you are 18 and have a valid license, you can rent a ZipCar. These are less expensive than cabs but more expensive than buses. Only use this option if you feel confident driving to the grocery store and know where you are going.

#### **Section 3: Cooking In College**

If you are going to cook for yourself, you are going to need to not only know how to cook, but be able to do so in an effective way so you don't take too much time away from your social life of studies. In this section we are going to talk about one of the easiest and most cost efficient ways to prepare meals; setting up a meal schedule.

Preparing a meal schedule is easy to do but it requires some flexibility on your part. At home, your parents might have prepared one dish per night for 4 or 5 people. In college, chances are it is just you. Theoretically, you could adapt recipes to make enough for one portion and cook every night but that would be a lot of effort, so her is my suggestion. Make an entire meal once a week. Divide the dish up into 7-8 servings and place in plastic, freezer safe containers. You can also add some frozen veggies on the side if you wish. This method wastes the least amount of ingredients. If you find yourself as someone who needs variety. Try making 2 dishes at a time and freezing both of them so you have a little more option.

## Section 4: Taking Care Of Yourself

College can be a time of spontaneity and lots of responsibility for schoolwork. In turn, sometimes we forget to take care of our bodies in the midst of preparing for exams or writing papers. This section will cover the importance of taking care of your body by eating right, taking your medicines, and getting adequate sleep.

Food allergies are an autoimmune condition. Many people with food allergies have other autoimmune conditions such as asthma, thyroid disease and celiac disease. Seventy percent of the immune system is in the gut - which is why it's important to eat lots of fruits and vegetables. Eating hard to digest food such as too much meat, prepared food, fried food and sugar is taxing to our digestion and our immune system. If we don't eat enough fiber from fruits and vegetables "junk" food will sit in our gut, rot and produce bad bacteria, which will cause our immune system to malfunction. Sometimes digestive enzymes and probiotics are needed to help us absorb the nutrients we need from our foods that boost our immune system.

Taking your medicines can be a pain, especially if they have bad side effects or have to be taken at a particular time that is inconvenient. It is important though to try your hardest not to miss doses of your medicine because they will help keep you healthy. If you have trouble with missing doses,

try getting a weekly medicine container and pre-organize your medicines for a week. This will also help you keep track of how often you miss your medicine doses so you can adjust your schedule. If you take prescription meds, make sure to refill them at least a week before you are out just in case the pharmacy needs to order your prescription.

In addition to healthy food and our medicines, our bodies need sleep to function properly. Expecting any college student to get plenty of sleep may sound ridiculous. But for a student with immune system issues it is a necessity. So, while you are budgeting time for shopping and cooking, budget time for sleeping as well, even if it means napping... but not in class.

## Section 5: Finding Someone To Talk To

If you have ever had an allergic reaction to a food or an asthma attack you may experience anxiety about being safe in the world. Following the guidelines in this website can go a long way towards keeping you safe, and therefore keep your anxiety in check. But everyone needs help navigating the tricky things like dating with food allergies and staying safe in other social situations and the feelings related to being "different". If you worked with a therapist while in high school, you might be able to continue your relationship and sessions via phone, facetime or skype. Otherwise, every college has a counseling center- and you would be surprised at the large percentage of students who use the service and most are free. Sometimes it takes a few tries to find the right therapist. If you don't feel comfortable or find yourself being less than honest with a counselor - don't waste your time - and switch immediately to someone else.

## Section 6: Going To The Doctors By Yourself

If you are anything like me, you are not a fan of going to doctors appointments. Going to the doctor might be a necessary thing during college though and it is important to know how to go to the doctors on your own. Here are some tips to make going to the doctors a little less stressful:

- Bring a friend: Your friend can help distract you while you are waiting and keep you
  company but you friend also functions as a vital set of ears. Sometimes when the doctor
  says something, we don't fully absorb it. Having an extra set of ears will help ensure none of
  what the doctor says will be missed.
- Make a folder: Make a folder with all of your medical records, especially if you are seeing
  multiple doctors of different specialties. It is good to have all of your documents in the
  same place so you can refer back to them if you need them.
- Use your calendar app: Enter your appointments in your calendar app. The last thing you want to do is forget an appointment, since chances are someone else would have loved to have your appointment time. Allow plenty of time in both scheduling and leaving for your appointment, so you have some wiggle room in case you have a delay.
- Update your parents: Even though you are in college now, you parents are still a key part of your treatment team. Keep them updated and let them know what is going on with you

medically so if something happens and they need to advocate for you, they are up to date on all of your conditions.

Write down questions- if you have questions or need a prescription refill, write them down so you can make sure to have all of your questions answered and so you don't forget.

## Section 7: Going To The ER By Yourself

The only thing I can think of worse than going to the doctor by yourself is going to the emergency room by yourself. If you do have to go to the ER in college for food allergies or asthma, just remember you are not alone (there are probably at least 5 other kids from your school there too). Here are some tips to follow if you find yourself stuck in the ER:

- As soon as you or your nurse gets a chance, contact your parents and let them know what is going on. Even if you feel like you may have done something stupid, it is important to keep them updated, it is only fair. If you are under 18, they can talk to the hospital personnel. If you are over 18, you hopefully have a copy of your health care power of attorney on your phone, or can have your parents fax it. If the hospital is part of the health system where you see your doctor, your health care power of attorney should be on file.
- If you have a Care Everywhere ID, give that to the emergency room personnel. It is important that they know your medical conditions and don't just think you are a drunk college student (vomiting can be a reaction to too much alcohol or a food allergy.)
- If you have to spend the night, ask a friend to bring you some pjs and toiletries if they can. Your own things will make you feel less nervous. If your friend can stay with you, that will make your parents less nervous.
- Upon discharge from the ER, find the pay window to pay your copay for your visit. If you rode on an ambulance to the ER, that is billed separately.
- If you used your auto-injector, ask the doctor for a refill and fill it in the hospital's pharmacy if it is open, or take it to your pharmacy immediately.
- Make a follow-up visit with your allergist ASAP to review the reaction and see if any of your treatment needs to be changed.

# Chapter 4: Food Allergy 101 For The Newly Diagnosed

So...you have just been diagnosed with food allergies huh? It is like you have been thrown a curve ball. All of the sudden, you favorite foods have been taken away, and it stinks! Luckily, you are now part of the exclusive food allergy community. In this chapter, we are going to cover everything you need to know about your new diagnosis. After this hopefully you will feel more confident when it comes to understanding your allergies.

Here is what we are going to cover in this chapter:

- Food allergy basics
- Anaphylaxis and the importance of your auto-injector
- What should go in your "epi-bag"
- Finding safe foods and reading labels
- Dining out safely and in the dining halls
- Resources you may find helpful

# Section 1: Food Allergy 101

Food allergies are complicated and they are not fully understood which is part of the reason that we don't have a cure or a way to prevent a reaction. In short, an allergy develops when the immune system recognizes the food allergen protein as a foreign invader. The body starts to produce antibodies against the allergen. The next time you ingest the allergen, the body recognizes the protein of the food as a foreign body and sends the antibodies to attack it. As your body is attacking the allergen, it releases a chemical called histamine which produces hives and other allergic symptoms. Sometimes they body reacts in a way that gives you hives, while others it reacts in a way that makes you vomit. An important thing to remember is that prior allergic reactions can't be used as a way to predict a future reaction, because your reaction can be worse the second time. People can be allergic to anything but the most common food allergens are milk, eggs, peanuts, tree nuts, shellfish, fish, wheat and soy and they can develop reactions at any time. Here is a video that will help explain the science behind food allergies. You can find the guidelines mentioned in the video, below the video if you would like to download them.

https://www.youtube.com/watch?v=AKViKC3u9hk

# Section 2: Anaphylaxis And Your New Friend The Auto-Injector

Chances are if you have been diagnosed with a food allergy, your physician will have talked to you about anaphylaxis. Anaphylaxis is a severe and potentially life threatening allergic reaction. Symptoms of anaphylaxis include wheezing, swelling of the lips, tongue and throat, vomiting, hives, increase in pulse rate, and decrease in blood pressure. Anaphylaxis is scary and can only be reversed by the use of an epinephrine auto-injector. If you have to use the epinephrine auto-injector, call 911 and go to the hospital immediately in case your symptoms progress. Because

allergic reactions are unpredictable, you should always carry your auto-injector on you and let your friends know where you keep it in case they need to help administer it to you. Here are some videos on how to use an epinephrine auto-injector. You should watch the video that corresponds to the auto-injector you have.

Epipen Video: <a href="https://www.youtube.com/watch?v=tjlLFYPE3Uw">https://www.youtube.com/watch?v=tjlLFYPE3Uw</a>
Auvi-Q Video: <a href="https://www.youtube.com/watch?v=bZl5vXwZUOg">https://www.youtube.com/watch?v=bZl5vXwZUOg</a>

## Section 3: The Epibag

So, now that we talked about carrying your auto-injector and how it can save your life, let's talk about the other things that are good to have on had in what I call the "epibag". An epibag is your lifeline and is filled with essentials. You can order special made epibags online, use a pencil case, a makeup bag or even a Ziploc bag. The bag doesn't matter, what matters is what is inside. Here are some ideas of what to keep in your epibag, you can add items or leave out items depending on your own individual needs.

# Epibag Essentials:

- 2 Auto-injectors (If prescribed)
- 1 Rescue Inhaler (If prescribed)
- Inhaler Spacer (if needed)
- 2 Doses of Antihistamine (won't stop anaphylaxis but will help minor reactions)
- 1 Bottle Antihistamine Eye Drops
- Topical Antihistamine
- Clorox Wipes, travel size (for wiping tables, desk, etc)
- Safe Snack (just in case)

#### Section 4: Reading Labels And Avoiding Cross Contamination

Reading labels are an important part of keeping you safe from allergens. Let's take a look at this label for dark chocolate. As you can see, on the very right there is an list of ingredients. All food manufacturers are now required to list the top allergen ingredients in plain English and not in chemical or derivative forms. If you are allergic to milk and soy, you could not eat this chocolate. Some companies write allergen advisory statements as seen below. Allergen advisory statements usually list if a food "may contain", "was made on equipment" or "made in a facility" with a highly allergenic food. This is not required by the FDA though so if you are ever unsure about a product being safe to eat, you can call the manufacturer. Some doctors say to avoid products that "may contain" your allergen. I think it is a good idea to avoid any food with an allergy advisory warning for your allergen. It is better to be safe than sorry!

Nutrition Serving Size 1 oz ( Serving Per Contain	•
Amount Fer Servin	9
Calories 140	Calories from Fat 50
	"¿Daily Value"
Total Fat 6g	9%
Saturated Fat 2.5	g 13%
<b>Sodium</b> 15mg	<b>1</b> %
Total Carbohyd	rate 18g <b>5</b> %
Dietary Fiber 3g	12°₄
Sugars 12g	
Protein 3ç	
Vitamin A 0%	· Iron 15%
kin e kaptilikant skurte kramer I halmum	e of trains fail officiestero
Filmmer Cary values once the	ee based in a 2000

Dark Chocolate
Ingredients: Dry roasted
chickpeas, semi-sweet
chocolate (sugar, chocolate,
cocoa butter, milkfat, soy
lecithin, natural flavor), glaze
Allergy Information: Made in
a facility that also processes
nuts, soy, wheat, dairy
Manufactured By:
Nutty Bean Co.
San Jose, CA. 95112
www.nuttybeanco.com



This brings us to our next topic, cross contamination and food allergies. Cross contamination happens when a food containing your allergen touches safe food. For example, if you are allergic to milk and the chef makes you a hamburger on the same griddle that grilled cheese was made on a minute ago. If some of the grease from the grilled cheese has milk proteins in it and it gets on your hamburger that is called cross contamination. To put it simply cross contamination happens when a safe food comes in contact with a non safe food and the proteins from the non safe food get on the safe food. In order to avoid cross contamination, it is important to be explicit with the chef if you eat out that all utensils must be clean. It is also important, if you are living with someone else and they cook with your allergens that anything used in preparing the food containing your allergen is thoroughly cleaned and "decontaminated".

#### **Section 5: Dining With Food Allergies**

Whether at a 5 star restaurant or an all you can eat buffet, food allergies will pose risks that you probably never thought about before your diagnosis. Each kind of restaurant can pose a different threat and it is important to understand the risks associated and how to minimize them.

If you have a dairy/milk allergy, be sure to always refer to it as a "milk" allergy when speaking to food handlers. It may sound counter intuitive since you aren't just allergic to milk - but all dairy products. Milk is an ingredient in sour cream, yogurt, cheese, ice cream and butter. On food labels for those or any other milk containing food the label will say "contains milk". No label ever says

"contains dairy". So, if your food handlers and preparers are looking at labels to check to see if a food is safe for you - you want them to be looking for "milk". Also, some people mistakenly think eggs are dairy because they are commonly found in that section of the grocery store, even though eggs come from chickens.

You may never have considered bringing your own food to a restaurant meal with other people who are eating at the restaurant. If your food allergies are complicated, the restaurant will usually appreciate that and go out of their way to make you comfortable. And, it removes all of the stress around ordering, explaining an allergy and hoping that your meal has been prepared safely. In 5 years of bringing food into restaurants, we have only have one that objected (and a vegetarian restaurant that want to make sure that we didn't bring in meat - which we didn't.) Our personal rule is that we tip as if the person who brought their own food ate something of the same value as everyone else. This is especially important if you are dining with just one other person.

#### Fast Food Chains

Fast food restaurants prepare foods in large quantities every day. Because some of the food is prepared - often shipped frozen, they can't remove an ingredient that was put in the food during pre-preparation - such as fries soaked in milk, frozen and then shipped to the outlet that cooks them. It is also difficult to ensure that no cross-contamination happens in their kitchen since some steps of the final cooking and assembly process may take place before a customer even orders. Also remember that ingredients can change at fast food restaurants - just as they can at a fresh food restaurant. So, if you think that something is always safe to eat at a specific restaurant, always double check by asking if it contains your allergens. Lastly, consider the trustworthiness of the employees at the restaurant. We know a college student who can't eat a top 8 allergen. She goes to a college that has food courts of fast food restaurants instead of dining halls. She says she would never eat at one because the workers are young, part-time employees (mostly students) and she doesn't trust them to thoroughly check for ingredients added during the manufacturing process that took place before the food reached the restaurant.

#### Made to Order - Semi-Fast Food Restaurants

These restaurants use assembly line style of food production. With open bins of condiments for sandwiches, pizza and salad ingredients there is a high risk of cross contamination. If you are allergic to one ingredient in the bins, there is a risk that ingredient was dropped into the other bins. The risk is similar to a salad bar. Furthermore, if the employees don't change gloves between each order prep, the gloves could be contaminated. If they put sandwiches into panini presses or a premade thin crust pizza into a warmer, there is a risk your food would be exposed to the ingredients from someone else's food. Pizza parlors that sell gluten free pizzas put the gluten free pizzas into ovens where non-gluten free pizzas are made.

# Buffets

Buffets have the same issue as fast food chains. The food is not made to order and therefore it is hard to get them to adapt a recipe to fit your needs. An added challenge of buffet restaurants is that all the food is out in the open. It is not uncommon people use one spoon to serve themselves one thing and then put the same spoon in something else or one food drips into the bin of a different food. Cross contamination runs rampant in buffet restaurants and it can be difficult to avoid. If you do decide to eat a a buffet restaurant, talk to the chef about what is safe for you to eat. You can even request that they give you your meal from a bin that has yet to go out on the buffet and therefore has not been cross contaminated with anything else. Some buffet restaurants also prepare made to order meals and might be able to make you something that is not being served on the buffet.

#### Sit Down Restaurants

Sit down restaurants are your best option as food is typically specially made. As soon as you are seated, notify the waitress of your food allergies and ask to talk to the chef. Explain to the chef your food allergies and about how you can't eat your allergens but you also can't have food prepared on the same surface as your allergens. You can even give the chef a chef card. Chef cards are cards that explain your food allergies and cross contamination. The idea is to list all of the ingredients you can not eat. For example, if you were allergic to milk, you would list cheese, butter, milk, cream, etc... that way they would have your allergies written down and it avoids the issue of the chef putting something in your food you are allergic to. If you would like a chef card, you can download one <a href="here">here</a>. Another thing to keep in mind is the cuisine. It makes it easier to find safe foods if you go to a cuisine that does not favor your allergens. In other words, if you are allergic to peanuts, it is much easier to eat at an Italian restaurant than a Chinese restaurant. For more tips on allergy friendly restaurants, visit <a href="Ezeatings">Ezeatings</a> and <a href="Allergy Eats">Allergy Eats</a>, two websites that can help take the guesswork out of finding a safe place to eat. Lastly, if you have a great experience, show your gratitude by leaving a tip. It is nice to show appreciation for people who go out of their way to keep you safe.

#### Section 6: Recommended Resources

Food Allergies are not something you want to go at alone. Here are some resources that we hope will help you!

### Food Allergy Education

- Food Allergy Research and Education
- Web MD Food Allergies
- Mayo Clinic Food Allergies
- American College of Asthma and Immunology
- Food Allergy & Anaphylaxis Connection Team
- Wikipedia Food Allergies

- Medline Plus Food Allergies
- American Academy of Allergy and Immunology

# Food Allergy Support Groups

- Food Allergy Support Group Directory
- Facebook-Teen Food Allergy Support Group
- Facebook-College Food Allergy Social Groups

# Food Allergy Friendly Food Companies

- So Delicious
- Enjoy Life
- Home Free
- SunButter
- Ian's Foods
- Surf Sweets
- Dayia Foods
- Udi's Gluten Free
- Ener-G Foods
- Earth Balance
- Amy's Kitchen
- Van's Foods

# Food Allergy Merchandise

- Navan Foods
- Allergy Apparel
- Allermates
- Activaide
- Allergy Haven
- Omax Care
- Rescue Shot Case
- Blue Bear Aware
- EpiEssentials
- Kozy Epi

# Food Allergy Blogs

- The Nut-Free Mom
- It's an Itchy Little World
- Onespot Allergy
- Lexie's Kitchen
- Allergy Foodie
- Cybele Pascal
- Learning to Eat Allergy-Free
- AllergyHome

- The FARE Blog
- Kids With Food Allergies Blog
- Food Allergy Mama
- Food Allergy Buzz
- Allergy Alli
- Teen FAAB
- <u>Teen with Food Allergies</u>
- Food Allergy Teens Blog

# **Chapter 5: Food Allergies And Co-Existing Conditions**

Food allergies are enough to manage on their own but adding in other co-existing conditions complicates everything. In this chapter we are going to touch on some co-existing conditions that you may have and hopefully you will find some useful tips for managing your other conditions along with your food allergies.

Here is what we are going to cover in this chapter:

- Environmental Allergies
- Asthma
- Eosinophilic Esophagitis
- Celiac Disease
- Eczema
- Thyroid Disease
- Diabetes

# Section 1: Environmental Allergies

Seasonal and Environmental allergies can be tough when you are away from home and out of your normal environment. Some people with environmental allergies get allergy shots. If you are one of those people, talk to your doctor about what works best for you. If your doctor is far away, see if the student health will give you your shots or if you should find a doctor near campus. If your doctor is worried about a reaction, avoid scheduling your shots before classes just in case you don't feel well.

If you are considering schools in a different climate than that which you grew up in, do a little research to find out the top allergens in that area. In a northern climate trees and grasses, ragweed and leaf mold are the major allergens. In the southern climate, flowering plants and trees bloom all year long. In the city, smog and dust may be more of a concern than a rural or suburban campus where plants are the main allergens. In rural areas whole fields of ragweed send allergens sailing in the air for weeks.

You might even consider the type of pet your roommate has at home. Pet hairs and dander are hard to remove from clothing, bedding and furniture. Will your roommate be going home on weekends and bringing pet allergens back into your room?

Dorms can harbor dust and mold, which may be triggers for some allergic individuals. Although you are in a new environment there are a few things you can do to avoid allergens.

- Wash your sheets weekly to avoid allergen build up.
- Wash clothing you wear during pollen season after wearing outdoors.

- Don't sleep in clothing you have worn outdoors.
- Keep jackets and coats away from your bed.
- Dust regularly to avoid dust build up on windowsills and furniture.
- Consider purchasing something to filter the air. These can range from charcoal filters that absorb impurities to more elaborate filters.

#### Section 2: Asthma

Asthma can be a tricky thing to manage in college, if your asthma is not controlled. Once your asthma is controlled, it is important to take your medicine. Missing doses can result in missing class and in college playing catch-up is hard to do. The first step in managing your asthma is keeping your living environment clean and trigger free. If you need special living conditions such as an airconditioned room (which might help control mold growth in a hot humid climate), contact your school's Disability Services office to file a formal request and discuss the available accommodations. If things like smoke and perfume trigger you, request to be paired with someone who doesn't smoke and who doesn't use a lot of perfume. If these are big triggers for you, you may want to consider requesting a single. Most importantly, always carry your rescue inhaler and an asthma action plan (which you can download below) on you in case of emergency.

Some social environments could be a challenge with asthma - such as bonfires and parties where there is smoking. Hopefully you have some experience from high school to draw upon so you know what situations are the most important to avoid for your health. If you are from a warm climate (especially a warm moist climate) and you are going to school in a climate that has a cold winter, you should be prepared to cover your nose and mouth when walking outside in low temperatures. Dry winter cold air can cause wheezing. Even if you grew up in a cold climate, you probably didn't walk outside in cold winter air as much in high school as you will in college. On top of that, if your asthma is worse when you have an upper respiratory infection - which are also common in the winter - you may need to change your maintenance medication for the winter.

# Section 3: Eosinophilic Esophagitis

Having EoE in college throws a lot of curve balls your way. If you are on a feeding tube or feed at night, you may want to consider requesting a single from Disability Services. Having a single will allow you to feed in private and you also will not have to worry about waking others up at night. Because EoE reactions can be less predictable than your typical food allergic reaction, you may want to inform your professors about your disease and figure out a system in case you need to miss class. If your parents are currently caring for you at home (your feeding tubes, night feedings, etc...) you may want to start doing it for yourself before you get to college so that you feel confident when it does come time to doing it on your own.

For more information on EoE, feel free to check out these websites! http://www.aaaai.org/conditions-and-treatments/related-conditions/eosinophilic-esophagitis.aspx http://www.eosinophilicesophagitishome.org
http://www.gikids.org/content/5/en/EosinophilicEsophagitis
http://patients.gi.org/topics/eosinophilic-esophagitis/

#### Section 4: Celiac Disease

Celiac disease can be very manageable in college and many of the tips and tricks for food allergic individuals going to college are the same for those with celiac disease going to college. Luckily, the National Foundation for Celiac Awareness has their own college guidelines, which can be found by clicking <a href="here">here</a>. Because gluten free diets are now a common trend, one important thing to do when meeting with dining hall staff or when asking about ingredients is to make it clear that you have celiac disease and you are not on a trendy diet. One of the biggest issue with celiac is cross contamination with gluten. Having celiac disease is not the same as electively avoiding gluten and it is important that you make sure food preparation staff know that so they can help keep you safe. Separate microwaves and toasters for gluten free food can be provided at dining halls. Depending on a person's food allergy, celiac may be more difficult to manage in college than the allergy - wheat is in more food products than peanuts or tree nuts, for example. Keep shelf stable gluten free foods on hand in your room in case of emergency and the dining hall can't accommodate you. If they have to bring in outside food to manage a power outage or other systems failure - it will probably be nut free and peanut free - but not gluten free.

## Section 5: Eczema

Having eczema in college can be unpleasant and embarrassing. No one wants to walk around with itchy and inflamed skin in front of their new friends. If you have eczema, it is important to take care of your flare-ups and not ignore them. Be sure to bring plenty of lotions with you to college and bandages if you need them. If long baths help you, it is important to realize most colleges do not have tubs. Some schools though have dorms with private bathrooms. If you require long bathing sessions to help your eczema, consider talking to disability services about an accommodation. The last thing you want is for people to think you are a shower hog! Here is a video where one student talks about what it is like dealing with eczema in college. <a href="https://www.youtube.com/watch?v=Qa8NmCg4vas">https://www.youtube.com/watch?v=Qa8NmCg4vas</a>

# Section 6: Thyroid Disease

Managing thyroid disease is fairly simple in college. You may want to consider having an endocrinologist near by or a general practitioner who feels comfortable managing your thyroid disease. This will make it easy and convenient for check-ups and regular blood testing. Because thyroid disease can affect the way you feel, it is important to notify your doctor as soon as you start to feel symptoms like your thyroid isn't well controlled. If you need lab tests, make sure to call your insurance company before testing if you are unsure which labs will take your insurance. Remember to get lots of sleep and take care of your body, because thyroid disease is an autoimmune disease and it is important to support your immune system.

# Section 7: Type 1 Diabetes

# **Chapter 6: Personal Stories**

Below you will find a compilation of anonymous personal stories from college students with food allergies. These have been provided to show that going to college with food allergies is very possible, but isn't always without struggle. All of the stories are different and address different problems students with food allergies may have while in college. If you are currently a student in college or have graduated and you have a personal story you would like to share, we would love to add it to our page! Click here for directions on how to submit your success story.

# Going To Culinary With Food Allergies

Ever since I was a little kid, I have loved to cook. I am not sure it if was because of my food allergies and being exposed to cooking at a young age, or if it was just that I was born with a love for food itself. All through high school, I dreamed about going to culinary school. Every night when I came home from school, I would cook dinner for my family. Sometimes I would make Italian food, or American food, but as I got older, I ventured into more exotic dishes and exotic cuisines. My favorite response from my family was never, "Oh this tastes great!" rather I loved when someone said, "Wait this doesn't have nuts in it?"

During my senior year of high school, I decided that I wanted to go to culinary school at Johnson and Wales. They have a top rated program and it felt like the perfect place to expand my skills and my knowledge of food. When I told my parents that I was my number one choice, their faces turned white. At first, my mom said no. She was afraid that it would be too dangerous for me because of the frequent use of nuts in cooking, especially in baking. I was adamant though, and she allowed me to apply. When I got accepted, I was over the moon. I knew that I could finally follow my dream of becoming a professional chef. My mom though was not because she was still scared.

Today, I am in my third year at Johnson and Wales and I love it! I have been very lucky to have professors who understand my allergies and are willing to work with me so that I can be safe. The interesting thing is, that restaurants now have to become more and more accommodating for people with food allergies. I think that in a way, as people learn to adapt their recipes for me, it will help them become more flexible chefs in the real world. That being said, there has not been a time when I feel unsafe, but when I do, I have learned that it is important to tell my professor. After all, safety is the most important rule in the kitchen, sometimes though; safety for me is more than just not starting a fire or cutting my finger off with a knife.

If I had one bit of advice for food allergic students, it would be to follow your heart, because if you don't, you will spend the rest of your life wishing that you had.

### I'm Not Invincible!

I'm a dare devil which is a bad mix for someone with celiac disease and an anaphylactic egg allergy. My dare devil/spontaneous side never really impacted my health though until my freshman year in college. I was too caught up in not being the allergy/celiac kid, that I spent the first semester eating dining hall food that had gluten in it. About 15 minutes after dinner I would run up to my room and spend almost the entire night barfing and curled up in the fetal position. Being sick all the time left me with no energy for schoolwork. I missed classes, failed tests and was in jeopardy of being put on academic probation after my first semester.

If that wasn't bad enough, the day before I was going to go home for thanksgiving break, I went to a party and drank from the punch bowl. Shortly after, I realized that the "punch" had egg in it but it was too late. I started having an anaphylactic reaction right in the middle of a frat party, and I didn't have my epipen. Luckily, someone had one though and they gave it to me and called 911. When I got to the ER, they gave me more medicine and made me stay the night. In the morning, the doctor ordered an emergency endoscopy because of my celiac. When I woke up he showed me the pictures and my intestines were so inflamed. I realized that my body could no longer function with my reckless behavior.

The next semester, I cleaned up my act, got good grades and stayed healthy. I am a sophomore now and I haven't had any issues since last Thanksgiving. I now work really closely with the dining services to make sure that I have safe food. If I could give one piece of advice, it would be not to be afraid of looking like the allergy or celiac kid. Honestly in college, people really don't care, and if they do, they aren't real friends. Your real friends who don't care about the fact you have allergies or celiac will be there when you need them. Oh, and don't forget to carry your epipen!

#### Roommate Struggles!

One of the things I couldn't wait for about college was having a roommate. I know it sounds weird but I couldn't wait to have a "brother" the way my older brother's roommates became like their brothers. After the first few weeks of college, my roommate seemed like the kind of brother that you can't stand. He came in around 3:30 am every morning and woke me up. He left our room a mess with piles of dirty clothes that started to smell. But worst of all, he smoked and always smelled like an ashtray. I have asthma along with food allergies and one of my triggers is smoke. At first, I though I could handle it and make due, but pretty soon I was up all night coughing.

Fed up with my roommate, I went to my RA for help. He was super cool and talked to us both about respecting each other's space and health. For about a week, my roommate kept his clothes clean and tried to keep from smelling like smoke. Then though he did the unthinkable, he decided to save room in our mini-fridge by combining his milk with my milk. The only problem was, I am

allergic to milk, so my milk was rice milk. The worst part was, I only found this out after I put the milk on my cereal and had an allergic reaction.

A few days after the reaction, I went to the disability services and requested a single since his ignorance was affecting my health. Within a week, I had a single and I was able to move out on my own. Since then, I haven't had any issues. If I could give one piece of advice to future college students, don't get a roommate unless you know them and you know they will keep you safe. I originally didn't want a single because I thought it would be isolating, but it really isn't and it gives you a nice quiet place to study!

# Commuting Out Of Fear

My parents told me they would only pay for college on one condition: I live at home and commute. I am lucky enough to live in a major city with good schools at my fingertips, but I never saw myself commuting to any of them. Before going to college I thought that the most important part of the college experience was moving out and living with a roommate in a dorm. I knew, as a commuter that would not be part of my college story.

I am a senior in college now and I still live in the room that I did when I was a baby. Honestly, I don't hate it as much as I thought I would. I enjoy having the freedom to live how I want, I enjoy not having to take chances with the dining hall, I enjoy that I can eat home cooked meals and I enjoy that I have a quiet place to study after a long day.

Sure commuting to college has its benefits and its drawbacks, but I am here to tell you that you can still experience college—even if you live at home.

### Food Allergies Made Me Get In Touch With Reality

It was halfway through my first semester at college when I realized I was failing out. I was an A student in high school; I studied a lot, I took lots of honors and AP classes, I had friends, but I never failed a class. Sure I guess college had been a little different. I never really partied in high school—my mom never allowed it, but in college it seemed like I was "partying" with the guys on my floor almost every night. Multiple nights I put down my bio book or my stat book or my chem book and picked up a red solo cup instead. I had never had a problem with drinking with the guys before. I am have anaphylactic allergies to peanuts and eggs, so allergens in the alcohol was never really a concern.

The last time I parties with the guys was the night before my chem midterm. I felt prepared enough but was stressing out so I went to my buddy's room to chill and have a bit to drink. Eventually one thing led to another and we got drunk, like really drunk. Apparently, I agreed to eat a peanut

butter granola bar on a dare. The next thing I remember was waking up in a hospital bed with my parents sitting next to me.

According to my RA, I went into anaphylactic shock after eating the sandwich and they had to call 911. The campus police came along with the paramedics. Because I had so much to drink, the epinephrine wasn't as effective and I had epinephrine drip in the ICU for 3 more days. I missed my chem midterm, and my bio and stat midterm. When I went to talk to my professors about making them up, they all told me the same thing; I was failing their class.

I immediately turned my act around. I stopped drinking and partying and studied. I was able to bring my grades up and pass all my classes. Had it not been for my food allergies and my trip to the ER and ICU, I may have flunked out of college. If you can learn one thing from me, put your studies first because food allergies and alcohol don't exist.

## Diving In To College With Food Allergies

I have always loved to swim. I think it is because in the pool, I feel free; there isn't allergens or food and my asthma doesn't bother me when I swim. I was lucky enough to get recruited to college to be on the swim an dive team. Although I had been on my local swim team since age 4 and my high school team since freshman year, I knew that college level swimming was going to be a lot different. Not only was I going to have the challenge of dealing with juggling academics and my sport, but I was also going to have the challenge of dealing with food allergies.

Having food allergies can be tough when you are playing a college level sport. I am allergic to milk, eggs, peanuts and tree nuts so it can sometimes be hard to avoid when we are traveling. Another issue is that all of my allergens contain essential ingredients for building strong muscles and bones. Luckily, when I arrived at school, I was able to meet with a nutritionist on campus to help devise a plan so that I would be getting enough nutrients to keep my body as healthy as possible so I could perform to my peak level. I also was able to work out how to stay safe and healthy while we were on the road.

I am a senior now, and I can happily say that I have not had a single anaphylactic reaction in college. Although it has taken a lot of persistence, I have managed to stay healthy. If I had one piece of advice for incoming college students, It would be to follow your heart because food allergies shouldn't be what stops you from reaching your goals!

# **Chapter 7: Parents Only!**

Statistics show every 3 minutes, a food allergy reaction sends someone to the emergency department – that is more than 200,000 emergency department visits per year. But when you are the mother of a child with severe food allergies, it seems like the only person who is ever in the hospital with anaphylaxis is your child. The biggest fear about college is that he or she will have a reaction and you won't be there to make sure proper emergency care is administered.

While eating lunch at school the March of senior year, Lily developed an allergy to a food to which she never had a reaction. A food she had packed for herself in her lunch. Two epinephrine injections, one ambulance ride, a nebulizer treatment, iv medicines and a dose of steroids later she was breathing and talking to the emergency room staff about going to college six hours from home. I was totally freaked out. I wish I could say it was our first emergency room visit. I wish I could say it was her first ambulance transport. The emergency room nurse told me I was crazy. She should stay home and do online school.

After we visited the college of her choice and saw how tiny those freshman dorms were with no place and no way to cook, we made a deal. Lily could go away to college if she agreed to live alone in an apartment and cook for herself in an environment free of cross-contamination. To prepare, she began food shopping and cooking for herself as a senior in high school. She would also handle all her meds, refills and calling the doctor's office on occasion when needed. She even took herself to the primary care doc who would treat her without a parent even though she was under 18.

If you are the parent of a child with multiple food allergies who has had reactions, who has asthma, and who really wants to go away to college, I highly recommend reading every single section of this website, don't skip a word. But try to let your teenager take the lead turning all of the advice into his or her personal action plan. The more he or she does alone, the better prepared she or he will be to go to college.

There are a few parts of the plan that may need your intervention: dealing with disabilities services, preparing the health care power of attorney, calling the medical center for the Care Everywhere ID number and buying the mobile emergency alert system.

Pulling out of the hospital parking lot that March evening I knew the mobile alert system was the only way I was going to get any sleep for the coming four years. Lily has only been in college for a couple of months as I am writing this. But I can share a few positive observations:

Living alone and taking care of yourself is empowering and allows you to take control of your health and safety. Once you get passed "who is going to be there if she has a reaction?" (mobile emergency alert system), it really takes away the stress. Think about it, no roommate to spray a perfume that is going to give her an asthma attack!

High school is the worst. Aside from the new allergy Lily developed during her senior year, every other food reaction and asthma attack she had in high school - and there were many - were caused by the carelessness or thoughtlessness of other students or school staff. Some high school students are not super careful about the impact their actions have on other people. Even some adults who work in schools don't understand the severity of an allergy. In college, buildings where people eat are separate from classroom buildings. Meetings where people eat aren't generally held in classrooms. It's easier to pick and choose who you surround yourself with and the activities in which you participate (no mandatory trip to the homeless shelter to cook with ingredients to which you are allergic). Not everyone at college does every single activity. So if you opt out, you aren't left out. You just do what you want to do. I think that makes a huge difference and is the main reason college is safer than high school. And, generally college students are more mature than high school students. So don't think that because your student has had a tough time controlling reactions in high school that college will be the same, or worse.

That said, if your student has multiple severe complex allergies to ubiquitous ingredients, and tries to eat and drink at restaurants, dining halls and parties - college may be a minefield. That is why we have rule #2: no drinking - it lowers your ability to make good decisions and you don't really know what is in the alcohol. If your severely food allergic teen can't abide by that, maybe he or she isn't ready to be far away from home. Think I am being naive and unrealistic? Think again. I know my daughter doesn't want to have a reaction at college and I know that I can trust her to put her health first. Maybe your child isn't as allergic to as many things. Then you don't have to have that rule. But if you are paying for college, you get to make that decision - just like you get the final say on the best living arrangement for your child.

Lastly, having food allergies in college and not being able to do everything that everyone else does or eat what everyone else eats or try alcohol is not fun. Managing doctors appointments on top of studies is a pain. I realize that. So, do what you can. You can't change reality. But, you can send fun halloween decorations instead of candy in a care package. You can send gift cards for movies. You can send safe snacks. You can go on the first visits to the new doctors together during summer registration. You can encourage your student to pursue his or her passion in every single way possible during those undergrad years. They should take advantage of every opportunity. They won't even notice they aren't out partying because they will be totally engrossed in becoming the adult version of themselves. And you will sit back and be proud.

# Closing

Dear Reader,

It seems as though you have finished the guide. Thank you for taking the time to read it and we hope you enjoyed it and found it useful! We will always be here on the web for you if you ever feel like coming back. Please also enjoy the other features on our page such our inspiring college success stories (if you have a story, submit it <a href="here">here</a>), our resource section with links to helpful tools, and our blog. We will be adding to our guide as time goes on. If you feel as though we missed something, please contact us by clicking <a href="here">here</a>. Once again, thank you for visiting our Food Allergy Survival Guide! Have a great day!

Best,

Lily Roth

# **Appendix**

# **College Priority Checklist**

Fill out this checklist to help you keep your college location priorities straight as you begin to look at colleges.

I want to live:

(Refer to chapter 1, section 1)  ☐ At Home ☐ In a freshman dorm ☐ In a single freshman dorm ☐ In an apartment style dorm ☐ In an off campus apartment ☐ Other:	
I am going to need to be near: (Refer to chapter 1, section 2)  ☐ Home ☐ An allergist ☐ A pharmacy ☐ A hospital ☐ A pharmacy ☐ A rescue squad ☐ A grocery store ☐ Other: ☐ Other:	
I want to say within hours from home: (Refer to chapter 1, section 3)    <1 hour by car   1-3 hours by car   3-6 hours by car   7+ hours by car   2-4 hours by plane   4-6 hours by plane   6+ hours by plane   Other:	

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# **College Question Sheet**

College:	Date:
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Here are some questions you might want to ask your tour guide in regards to food allergy living on campus. On the next page you can write down your own questions to ask!

# **Dorms**

Suggested Questions To Ask:

- 1. Is it mandatory for freshmen to live on campus?
- 2. Do any of your dorms have kitchens?
- 3. Are there singles available?

# Don't Ask These Questions:

- 1. Are there off campus apartments available? (Google it)
- 2. Do you have a question on the roommate questionnaire about food allergies? (Outing yourself as a FA student)
- 3. Is peanut butter allowed in the dorms? (Of course it is!)

# **Dining Hall**

Suggested Questions To Ask:

- 1. Is there a dietician on staff to meet with students?
- 2. Are meal plans mandatory/what are the meal plan options?

# Don't Ask These Questions:

- How are food allergies handled? (Tour guide most likely won't know and you are outing yourself)
- 2. What kind of restaurants are on/near campus? (Google it!)
- 3. Does the dining hall serve peanuts? (Of course it does!)

# Safety

Suggested Questions To Ask:

- 1. What happens if an ambulance needs to be called?
- 2. Are the security guards trained as first responders?
- 3. How does your student health operate?

# Don't Ask These Questions:

 Can RAs use auto-injectors? (most likely they have not been trained but you may be able to train them)

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write them down afterwards as a record.
Question 1:
Answer:
Question 2:
Answer:
Question 3:
Answer:
Question 4:
Answer:

**My Questions:** Here is some space to write your own questions. You don't have to write the answers down while on your tour, but you may want to

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