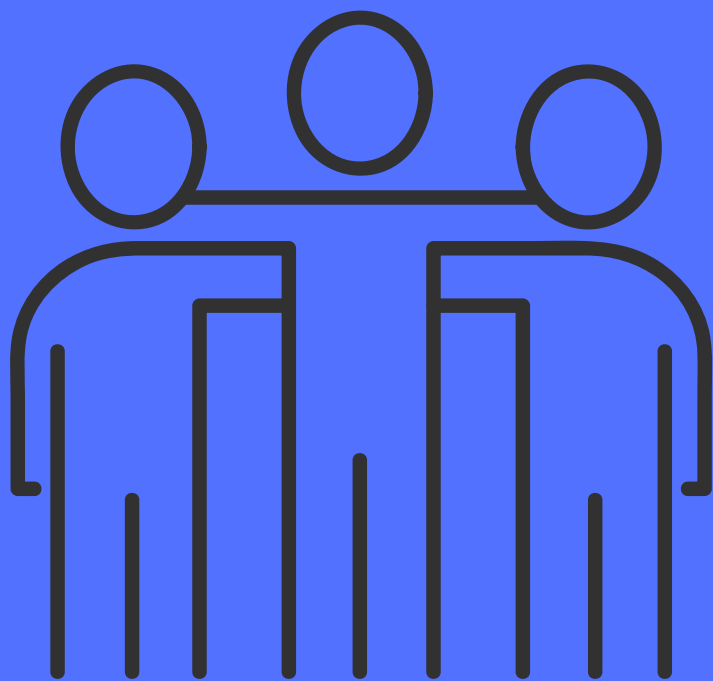


HCU NETWORK AMERICA

OFF TO COLLEGE



A Classical Homocystinuria Guide

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Thank you to HCU Network America's Patient-Parent Advisory Committee for their Assistance in developing the content of this booklet.

INTRODUCTION

Dreaming of college and counting down the days till you leave? At the same time, are you packing and thinking about how HCU needs to be factored into your new and exciting lifestyle?

Young adults with Classical Homocystinuria (HCU) from across the country have come together to share helpful advice in the pages of this booklet. They want you to worry less, learn from their mistakes, and enjoy this exciting time in your life (hint: it only happens once).

In addition, we at HCU Network America are here to help you navigate all the stages of college. Check our website for additional resources.

HCU Network America

HCU Network America is a National 501c3 non-profit organization whose mission is to inform and provide resources for patients and families, create connections, influence state and federal policy, and support advancement of diagnosis and treatment for HCU and related disorders.

HCU Network America is the hub of information and resources for all things HCU.

Topics include:

- Connecting with other young adults with HCU
- Touchy subjects
- Scholarships
- Talking to professors about HCU
- Health Insurance

Check! We've got it all covered – and more. Get excited.

DISCLAIMER



This booklet does not contain medical advice. Be sure to discuss any medical decisions with your doctor. All information shared by peers is regarding their own personal experiences.

Information contained has been scientifically reviewed and approved by the HCU Network America's medical advisory team.

THANK YOU TO OUR SPONSORS

HCU Network America would like to thank our 2020 sponsors for their continuous support for the Homocystinuria community. We would like to thank Aeglea, Ajinomoto-Cambrooke, Codexis, Flavis, Galen, Nutricia, Orphan Technologies, Recordati Rare Diseases, Solace Nutrition, Taste Connections and Vitaflo USA. We would also like to thank HCU Network America's Patient-Parent Advisory Committee for being an organizational sponsor on this project, and for HCU Network America's Medical Advisory Team for their scientific review and approval of this resource.

Together with these partners we are combining forces to make resources and support available to any family in the United States going through this transition, providing a "Gold Standard" of resources and support for this time in life – helping to simplify, rather than further complicate it.



Taste Connections, LLC



Innovation in Nutrition
USA

OFF TO COLLEGE



COMMON COLLEGE CHALLENGES

While everyone has different experiences at school, it's important to keep in mind that challenges are common, some more so than others. We want to share some of these challenges before you leave so you can be better prepared to tackle them once you are on campus.

Challenge: Having a sporadic schedule or no routine

College students are known for having crazy schedules. Your classes take place at different times on different days; homework, studying and social events dictate your free time; and your eating and sleeping schedules are a slave to the above factors each day. This can be a tough environment in which to manage HCU because it can make it difficult to see patterns.

Solution:

It may be impossible to keep the same exact schedule each day, but that doesn't mean you can't have some consistency. Pick a few elements of your day – i.e., breakfast, lunch or going to the gym – and try to do it at the same time every day. This will help to structure your day a bit more and give you a starting point for determining what adjustments might need to be made in your medical diet management. The more consistent you are with your day the easier it will be to spot the patterns. If you get into a routine of drinking your medical formula at the same time each day it will become a habit and will help with maintaining the stamina required for a busy college student. Also, it's common to feel completely scatterbrained as a new college student – setting alarms to eat and take your formula/medications could really be helpful!

Challenge: Stress

With midterms, finals, and ten-page papers that you may have procrastinated on until the last minute, it's inevitable that you're going to experience a great deal of stress at various times throughout college. The problem with stress is that it can raise your homocysteine levels.

Solution:

Figure out what helps to relieve your stress and make time for it. Maybe do some yoga, play intramural kickball, or lie down and watch a movie. Choose something you know relaxes you and take time for yourself. It is important to have a bit of quiet time to reflect and stay healthy.

Challenge: Dining Hall

The dining hall can present a challenge to students with HCU. It can be tough to access nutritional information and serving sizes, making counting grams of protein/milligrams of methionine feel more like picking lottery numbers than an attempt at science.

Solution:

When possible, try to limit eating foods with high levels of protein. Instead, opt for vegetables, fruits, salads and other foods that you know are naturally low in protein. Lastly, know your staples. Choose a few foods that are usually available, and try to find out the exact protein counts. It is absolutely acceptable for you to ask the staff to see the nutritional labels on the foods they are serving. This can help you to have a better idea of the protein content in the dining hall foods. Then you can make your own judgement on whether it fits into your daily intake or not.

It is very important and critical to being able to maintain a healthy variety of low protein foods to actually meet with the dining hall manager prior to each semester's start. This allows them to be aware of your specific dietary needs, brainstorm ideas with you and discuss the possibility of ordering your low protein food products like pasta, rice, breads etc. You are paying for a meal plan so this should be at no additional cost to you. You

should also educate the dining hall staff on what your limitations are for protein and share with them some of your favorite meals so they can prepare them for you. It is almost guaranteed they will not know about HCU, so the more details you share about your diet and the foods you cannot eat, as well as, suggestions of foods you can eat will help them help you each day.

Communication is key to successful dietary management in college. Have them assign a few key staff members that you can text each day with a plan for your meals. This will help you to have your meals ready when you arrive at the dining hall with your friends and be able to eat your meals at the same time and not have to wait for your food to be prepared.

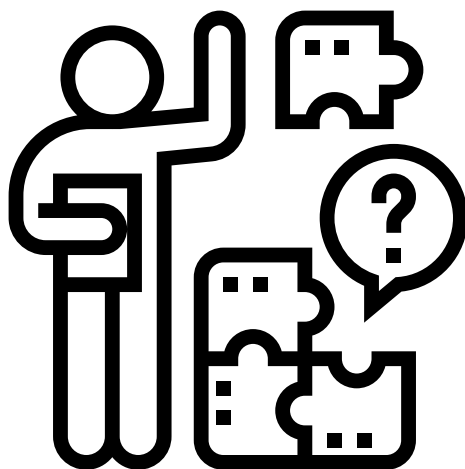
If the dining hall is not meeting your needs, remember that you can let the management know that the current routine is not working and come up with a better system. Always be your own advocate. This is critical to the success of your dietary management. You can also stock your dorm with packaged and microwavable food options. You should have a mini fridge and possibly a microwave that you can store fruit, salads, etc. Also if you have leftovers from the dining hall (pasta, rice etc.) you can bring it back to your room and heat it up for another day.

Challenge: The Freshman 15

No one wants to unexpectedly gain 15 pounds. It can often happen in college due to the late-night eating, higher-than-normal consumption of fast food and alcohol, and unlimited dining hall access.

Solution:

While it's tempting, try not to go up for seconds when you're eating in the dining hall. By doing this, sticking to the advice on the previous page, and by making an effort to be active a few days a week (hello, intramural sports), you should be in good shape (no pun intended).



QUICK TIPS

- Keep some sort of routine each day – whether it's the time you wake up, when or what you eat, and/or when you go to the gym.
- Be prepared. Keep low protein snacks and your medical formula in your room, as well as, in your backpack so that you're ready to go if you and your friends do something spontaneous.
- Stay away from foods that you know are higher in protein/methionine at the dining hall. Instead, opt for the foods that you can easily look up the nutritional information for or already know are acceptable in your daily protein intake.
- Join an intramural sport or make a gym buddy! It will help you make friends, stay in shape and relieve stress.

FAMILY COMMUNICATION AGREEMENT

Students, you want your parents to loosen the reins a bit and let you take responsibility for your own health and medical diet. Parents are worried about how you're going to manage your HCU while away at school. It may be the first time parents and their child have been separated, and this can cause some anxiety in the parent or caregiver.

You can refer to this as a guide to create your own college communication agreement so that everyone feels comfortable with the transition.

Example:

Students:

I promise to...

- **Wear** a medical alert ID.
- **Find** support on my campus.
- **Register** with Disabilities Services.
- **Keep** low protein foods and medical formula on hand, always.
- **Get into a daily routine of drinking my formula and taking betaine.**

Parents:

As long as you promise to...

- **Not ask** if I have been keeping up with my formula and supplements unless I bring it up.
- **Let** me be the one to tell others about HCU and my diet.
- **Send** me care packages and/or help pay for extra supplies.
- **Not overreact** or get mad at me when I tell you the truth.
- **Trust me** to advocate for myself and be there if I find I need support.

MORE IDEAS...

- When will you check in? How often?
- How often will you discuss your health/medical diet?
 - What can be said? Who will bring it up?
- Who will prepare a sick day kit?
- Who will be responsible for scheduling appointments?
 - Sometimes it is easier to give the parent permission to continue scheduling appointments so the student isn't receiving phone calls during their busy class schedule.
 - You may need to let the physicians know that the parent has permission to do so on your behalf if over the age of 18.



It may be hard to believe, but soon you will be graduating from high school and heading off to college! College is a new and exciting time in your life, but it also requires a lot of planning. You've probably started spending some of your free time checking out schools, talking to friends and family about college, and beginning to put together an idea of what you want for your next four years. It's okay if you don't know what you want yet – that's what looking is for!

Make sure you know what kind of things you care about in a school – then you'll know what questions you want to ask. Do you want a large, medium or small campus? Do they guarantee housing for

their students and for how many years? How far away are you willing to live from your family and physicians? It is important to know details about their dining facilities and how they handle special diets. These are just a few factors that can help you in the decision process of what schools are a good match for your wants and needs.

Best of luck in your search! Don't ever be afraid to reach out to your family or the HCU community for advice or direction. You have a wonderful support system in the HCU community.

HAPPY TOURING!

Scholarships

There are limited scholarship opportunities for students living with HCU and rare disorders – so start browsing!

Many local and regional PKU and Allied Disorder groups offer scholarships to patients with HCU within their communities. Check out our list of PKU and Allied Disorder groups to start finding out if your local group offers college scholarships! <https://hcunetworkamerica.org/other-metabolic-organizations/>

NeedyMeds has a list of scholarships based upon many different criteria – diagnosis, condition, field of study and more https://www.needymeds.org/scholarships/list_aos_scholar/AA

Disability/Auxiliary Services

Many students don't think of HCU as a disability. But when it comes to being prepared, registering with your school's Disability/Auxiliary Services when you get to campus or even before you arrive can be very beneficial. At this point in the game, just check to see if they've had previous experience with students with HCU (these may include low protein diet, vision, food, housing, transportation and academic accommodations) and how they have helped accommodate in the past. Chances are they have not, but you can then help and educate them so they are ready for you when you begin the fall semester.

See Registering for Accommodations, page 23

Health Services

Make sure you are aware of where you would seek medical care on campus if needed and what the campus health center is capable of helping with. Some questions to ask the admissions/health center staff at the school you tour:

- What services does the health center provide?
- Where would you be able to have your formula shipped (mail room, health center, dining hall)?

Residential Life

Dorms are an important part of college life. Consider the following questions regarding campus life at potential schools:

- How are the dorms set up i.e.: quads, triples, doubles? How many roommates do most freshman live with?
- Will you have a resident director and/or hall advisor?
- Is there kitchen access in the dorm? Could you have a fridge and microwave in your room?
- What does freshman housing generally look like? Where are the dorms?
- Do they have options for choosing a shared floor bathroom facility or private/semi private bathrooms?
- Is there any specialty housing you might want to apply for (healthy living etc.)?

Dining Services

Eating on campus can be a challenge without proper planning. Make sure that you are aware of what each school provides in terms of dining services.

Consider the following questions when looking at the dining options on campus:

- How does the meal plan work? Are there options that will fit the diet?
- Access to supplemental food (i.e., restaurants, stores on campus, etc.)?
- Where are dining halls located relative to resident halls and classes? And how many are there?
- Is the dining hall willing or able to order your low protein food products or even purchase staple foods that you eat from supermarkets? This should be at no additional cost to you if you have purchased a meal plan.
- Does the dining hall provide nutrition information and/or measuring cups? (Note: you can advocate for yourself once on campus and request these). They should be able to show you the nutrition labels on the products they serve to the students. It is very important to have a few dining hall staff members as your direct contacts. You should exchange contact information. You can establish a routine of you reaching out via text message to let them know what you would like for that day for your meals. It will take some thought and planning on your part.

- **Be flexible and patient.** Be open to trying new foods. It will be a process for everyone to get familiar with the new routine. It will eventually just become a way of everyday life at school.

Access to Supplies

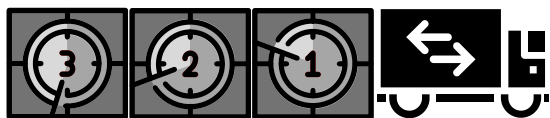
You'll need to restock your medical formula, supplements and betaine while at school. Consider how and where you'd get your supplies at each campus.

- Where is the closest pharmacy? Is there an easy way to get there? Can Freshman have a car on campus?
- How does the mail room handle packages that need to be refrigerated?
- Does the health center help with supplies

Distance From Home

There are schools all across the country and you might find yourself loving a school far from home. Make sure you consider what it would be like to be a one-hour car ride vs. a six-hour plane ride away from home. Distance from home is a very important consideration for all college students, but especially for students living with HCU. How far away from your home and doctors are you comfortable with? For some people, the distance might be too much; for others, it's exactly what they want. If you choose to go a long distance from your medical facility, perhaps you should make sure there is one nearby your college that is equipped to meet your medical needs. Perhaps your current doctor could make recommendations.

PREPARING TO MOVE OUT: A TIMELINE



You've already used the HCU "Looking at Schools Guide", chosen the school for you, and been accepted – congratulations! Here are some tips from our staff and students to help make your transition to college as smooth as possible.

To help you get prepared, packed, and ready to go, we put together a timeline so that you know exactly what you should be doing and when you should be doing it.

3 Months Before Move-in

Create a Plan for Supplies

There are many options for getting supplies while at school (mail-order companies, local pharmacies, restocking at home, etc.). Here are some ideas to help you create a plan well before move-in day.

- Where will you be getting your supplies from?
- Where will HCU supplies be sent?
- Who will be ordering them?
- Who is responsible for making sure any payments for supplies are made?
- How long will your supplies last?
- How will you know when to reorder them?
- Where will you go to restock your supplies and how will you get there?
- When will you need to update your prescriptions?
- Where will prescriptions be filled?

Schedule Appointments

We know sometimes it's a few months before you can be seen by a provider and once you get to campus it might be hard to find time. Just schedule it, you can always reschedule later if you need to.

Make the Space

If you're going to loft your bed for extra storage, some schools require you to call and pre-order the lofting package ahead of time. Risers can also be bought at stores that sell home supplies (Walmart, Target, etc.) and can add a few inches off the ground. Check with the college residents department because some schools do not allow risers. Many students use plastic storage bins to house supplies while living in the dorms.

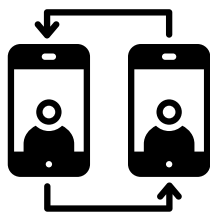
Staying Cool

You will want to have a plan for refrigerating your medical formula if you prefer it to be cold. You might want to consider purchasing a mini fridge for your room instead of using a public fridge. Most colleges give you the option to buy and bring your own (there are specific size regulations) or you can rent one from the college. Most times, if you rent one from the college it will be a micro-fridge (microwave/fridge combination).

PREPARING TO MOVE OUT: A TIMELINE (CONTINUED)

Connect with Your Roommate

Send a text, social media message, or email to your roommate over the summer and get to know each other a little bit. You can tell them about your HCU if the time is right, but if not, it will be much easier to talk to them about it at school if you know each other beforehand. If you live close to each other, meet up for coffee or a meal to get to know each other better! When you do tell them about your HCU, do it in a way that is most comfortable for you. You can share as much or as little as you feel is necessary to help them understand why you have a medical diet and drink a medical formula.



Create a Communication Plan

When you go off to school, you don't want your parents constantly asking you about your health/diet. In order to avoid any conflict between you and them, create a communication plan for all of you so that you get the freedom you want and they get the peace of mind they need.

Try to cut your parents some slack – they only have your best interest at heart. Keep in mind that this agreement is going to change as your needs and their needs change throughout your years in college. As time goes by, it will be less of an issue because all parties involved will be more at ease.

College brings about a lot of changes – changes in your lifestyle, possibly more stress, and HCU management. Talk to your metabolic team before you leave, and make a communication plan to use while you're at school. Here are some questions that you and your care team should answer together in order to create a plan:

- What is the best method of communication for both you and your provider to connect? Email? Phone? Maybe going through a Patient Portal to email the doctor or nutritionist is best. Get their thoughts on this.
- What will you do if there is an emergency and you need to see a doctor right away?
- How often will you be scheduling check-up appointments with providers and when?
- How often should you get your bloodwork done to make sure you are on the right track at college. Sometimes this is most important in the beginning months of school to just see where your levels are and if any adjustment to your dietary plan at college needs to take place.
- Check with your doctor to see if there is a medical laboratory available near your college that is equipped to draw bloods for HCU (if you are not within driving distance to your actual facility). The lab would require a standing order prescription in order to have your blood drawn and covered through your insurance.

See page 9 for further ideas

2 Months Before Move-in

Set up various Medical Alert IDs

We know that sometimes it's hard to find the right medical alert ID, but it's especially important to have one while you're away from your normal support system.



Types of Medical IDs

- Medical ID Tag/Bracelet – There are many companies on-line that you can custom order a bracelet that you feel meets your needs and perhaps ask your doctor what information you should provide on the medical tag.

We recommend including your full name, emergency contact number, your diagnosis (homocystinuria), allergies, and notation if you require a low protein diet and/or formula.

- Medical Alert Apps – Did you know you can create your medical contact card directly on your phone? Medical alert apps allow first responders to view important medical information on your phone screen, without the needing to unlock the phone. With the personal details that will be available on the emergency contacts card including medical conditions, blood group, emergency contact number, etc, you will be able to receive the assistance that you may need in an emergency situation. Besides this basic information, you also have the option to add additional information such as allergies, medicine, and disease.
 - iPhone users: this is a built-in feature; you just need to set it up! Check out Apple's directions to complete your profile.
<https://support.apple.com/en-us/HT207021>
 - Android: this is not built in, but there are many apps. The one we recommend is ICE – In Case of Emergency Medical Contact Card.
https://play.google.com/store/apps/details?id=tech.chitwansoft.emergencyinformation&hl=en_US&gl=US

Get Some Bags

Make sure you go to school with a few different bags that can hold all your belongings and your dietary needs- especially when you're traveling back and forth between home, weekend trips, vacations, and just trekking across campus!

PREPARING TO MOVE OUT: A TIMELINE (CONTINUED)

1 Month Before Move-in

Prepare a Sick-Day Kit

It's important to take care of yourself when you're sick. Prepare a sick day kit before you leave, as getting sick can come on suddenly. This is a great way for your parents to help you to prepare! Some suggestions of items to include in your sick day kit: water, sports drinks, saltine crackers, a letter from your doctor explaining HCU, and sick day guidelines (including when to call and your care team's daytime and after-hours phone numbers), a copy of your insurance card, thermometer, ibuprofen, antibiotic ointment, adhesive bandages, and cough syrup.

Create a List of Contacts

Before you leave, sit down with your parents and create an important contacts list. Make sure you have the phone numbers and contact information for all your HCU-related needs, as well as important people. This includes: insurance company, pharmacy, mail-order supplier, metabolic clinic, and all other doctors you see.

Don't forget to put the contacts and numbers into your phone so that you have them when you need them!

Bring Your Insurance Card!

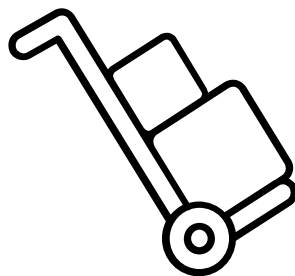
Up until now it is likely that your parents have been going with you to appointments and handling a lot of your medical care, but now you are moving out! Make sure you have your own insurance card (for both medical and for prescriptions, in case they are different)

in case you need to pick up a prescription or see a doctor, even if it's for a minor thing like a flu shot!

Pack!

All the items that we've been discussing? Make sure you take them with you! Sometimes it is very helpful to make lists. This way you can categorize things and check them off as you pack.

Move-in Day



Have Some Snacks Ready!

You'll probably need extra energy to carry boxes up the hills and stairs, unpack all of your things, and construct shelving units etc.- have some low protein snacks and water, as well as your formula, ready on move-in day!

Check Your Fridge

As silly as it sounds, make sure your fridge is plugged in! And be sure to check the temperature settings - some high settings may freeze your formula!

Go Food Shopping

Take a trip to the local grocery store with your parents and load up on low protein supplies and snacks for the room. Also buy plenty of water bottles. It is helpful to also have a supply of paper products, bowls, plasticware, cups etc. Also buy snacks that will be easy to just toss in your backpack each day in case you get hungry or don't have time between classes to eat.

Make Supplies Accessible

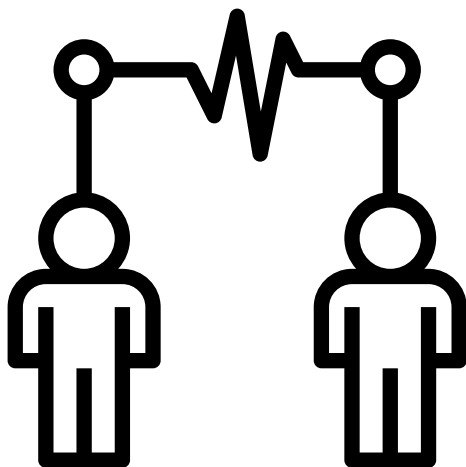
That plastic bin is not going to be useful if you can't get to it. Try lofting your bed so you can fit your medical supplies and food underneath—they should be easy to get to should you need to take your medication/betaine late at night or early morning before class.

Find the Closest Pharmacy

Look for the closest pharmacy to your school. Make sure it's part of the network for your prescription plan. If you normally use a chain pharmacy like Walgreens, try to find the closest pharmacy in the same chain as they will have access to your prescription records. Figure out the easiest way to get there. Put their information into your phone. Even if you use a mail-order pharmacy, there may be times when you need to visit a store in person.

Talk to Your Roommate

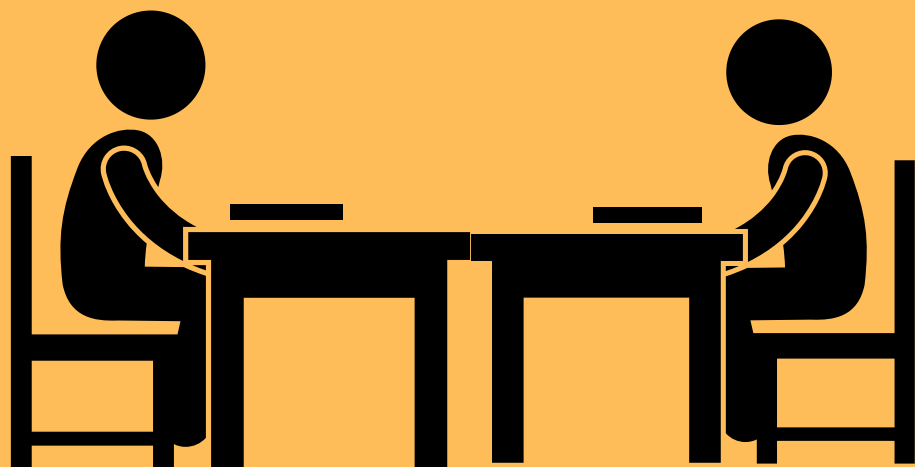
Make sure you aren't keeping your roommate in the dark about your HCU. If you haven't brought it up already, let them know the basics about what to expect in terms of managing your diet/medical needs. Think back to how you decided to bring it up, and stick to the plan if you feel comfortable. Let them know they can ask you questions and make it clear that you are not expecting them to take care of you.



Remember Your Parents

While you're excited to move out and get started with college, keep your parents in mind throughout the process. They're probably sad and nervous that you'll be moving out of the house so be extra nice and help ease their worries whenever you can. (Keep in mind they are probably feeling anxious.) It's natural for them to feel this way no matter if their child has HCU or not. It is just part of the process.

LIFE ON CAMPUS



STUDENTS FOR RARE

About Student for Rare

Students for Rare is a National Organization for Rare Diseases program that strives to spread awareness and recognition of rare diseases, establish professional relationships and partnerships and encourage students to pursue future opportunities within the rare disease space. By uniting students of all disciplines, we reach the next generation of professionals, advocates, researchers and medical professionals ensuring rare diseases will not be overlooked in the future.

How do I get involved?

- **Join a chapter! Visit NORD's website:**
 - <https://rarediseases.org/get-involved/educate/educational-initiatives/for-students/students-for-rare-chapters/>
- **No chapter? Start one!**
 - Requirements:
 - Host at least 3 campus events to promote rare disease awareness and education on campus.
 - Become a registered student group on campus.
 - Have a faculty advisor.
 - Adhere to the NORD Chapter Constitution and Bylaws.
 - Submit an annual report summarizing the activities of the previous academic year.
 - Fill out application NORD's Students for Rare webpage
 - <https://rarediseases.org/get-involved/educate/educational-initiatives/for-students/students-for-rare-chapters/>

BENEFITS OF STUDNETS FOR RARE:

- First priority consideration for scholarships to NORD's annual Rare Disease & Orphan Product Breakthrough Summit and Living Rare, Living Stronger Patient & Family Forum.
- Opportunities to network with other like-minded students around the country who are also interested in rare diseases.
- Opportunity to promote your major campus events and achievements on NORD's social media channels.
- Earning occasional opportunities to work on special projects for NORD.
- Accessing educational opportunities such as special webinars and student meetings specifically designed for students in the Students for Rare program.
- Branding your club with the NORD Students for Rare Chapter logo on your materials and social media channels.

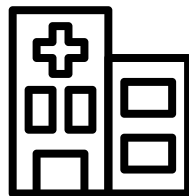
CLINICAL CARE: FINDING A NEW DOCTOR

There are a million things that can get in the way of you seeing your doctor once you arrive on campus, but it's extremely important to continue to do so. We will walk you through finding a new provider and give you some tips on other challenges that may come up when it comes to seeing your health care provider on a regular basis.

Reasons to Begin Looking

- You attend school hours away from home and are unable to see your health care providers as regularly as you'd like.
- You feel guilty and/or not empowered after leaving appointments.
- You feel your health care provider doesn't understand or is unable to help you.

There is no single right or wrong way to go about it. Some people see their usual provider while they are home on vacation, some find one closer to school, and others stay in close contact through virtual visits.



Reasons to Begin Looking

Finding the right provider can be a lot like dating. Personality types, approaches to care management, priorities, and location are all important points to consider.

- If going out of state, talk to your doctor about which providers they think would be a good fit.
- Check out the [HCU Network America's Find a Clinic feature.](#)
- Ask other patients on social media
- Homocystinuria groups if they have experience with doctors in the area you are moving to.

ASK QUESTIONS

To help you determine if a health care provider is right for you, we suggest asking the provider or their team the following questions, and evaluating their answers, during your first appointment:

- How much time do you spend in an appointment?
- Who does the HCU care team consist of?
 - (geneticist, nurse practitioner, dietitian, psychologist, social worker etc.)
- What do you think are the important parts of HCU care?
- How much personal experience do you have with HCU?
- How open are you to new technologies, research, and therapies?
- Who is on call when you are not available?
- Are you available between scheduled appointments and can I stay in contact with you remotely?

Last Meeting: Last Provider

- Discuss any concerns you may have about transitioning providers.
- Ask your provider's office to transfer your patient records to your new provider.

First Meeting: New Provider

Preparing for the Appointment

- Find out what you'll need before your appointment. Some doctors require you have lab work done prior to your appointment. Make a call to your new doctor's office and find out exactly what you need to do before getting there.
- Be open and honest about what you want and expect from your relationship. That might be a kick-in-the-butt or acknowledgement and support! Either way, be assertive! Your doctor is there to help you, so let them!
- Write down questions for your new doctor before your visit. In addition, try writing down what you are struggling with. Here are some questions to get you thinking.
 - What has been successful for your HCU management and what has not?
 - When is the most challenging time of day?
 - Are there activities that you are struggling to maintain diet with?
 - What are the social barriers to managing your HCU right now?
 - What motivates you?
 - What are your goals?

At the Appointment

- Bring a friend or family member to the appointment. They can be your support system before and after the appointment.
- Bring everything you need with you. That includes all your insurance cards, and any other paperwork that the doctor's office has requested.
- Ask questions during the appointment to clarify things and to make sure you understand the recommendations or information from your provider.
- Take notes during the appointment so you remember what was discussed.
- Make the adjustments that your doctor has prescribed. It's easy to leave the doctor's office and forget about the changes you said you'd make.

Schedule Your Appointment

Whether with the same doctor, or a new one, schedule your next genetics appointment ASAP so that you don't forget. You can always reschedule it if you need to, but get it on the calendar or odds are you will forget.

Evaluate Your Visit

Do you like your doctor? Do you feel more empowered about your care than when you walked in? Were your questions/concerns addressed? These are really important questions to ask yourself. If the answer is "no", evaluate if there are things that could be done to make the relationship better.

Here are a few challenges that students commonly face with seeing their healthcare provider regularly – and some possible solutions.

Challenge:

My school is in a rural area, I don't have a car, and the nearest geneticist is hours away.

Solution:

- Ask your friends with cars if they'd be interested in going on a road trip.
- Schedule appointments to take place while you're at home for breaks or holidays.
- Explain your situation to your doctor and ask if they can do virtual check-ups.

Challenge:

I know that my homocysteine level is not where I want it to be, and I don't want to feel worse than I already do about it.

Solution:

- Your doctor's job is to help you better manage your HCU and identify what's not working. Ask your geneticist and dietitian for tips/advice
- that will help you have better success.
- Read through the questions in the Finding a New Doctor for ideas to discuss and work on with your doctor.

Challenge:

I don't have enough data for a constructive appointment (I have trouble keeping a diet log).

Solution:

- Again, it's your doctors' job to help you better manage your HCU and identify what's not working. A good doctor will help you figure out how to get back on track.
- As you know, HCU isn't just about the numbers. You should be able to have a productive appointment with your doctor, even if you're lacking a large amount of data. Talk about what is and isn't working – be honest!

REGISTERING FOR ACCOMODATIONS

Many students with HCU don't register with Disabilities/ Auxiliary Services office at their school – but why not?! Some students simply don't know that it's an option and others are just completely turned off by the term "disability". We hear you, but give us a few minutes to explain why we suggest you register.

Reasons to Register:

1. Plan Before and Emergency

If you aren't registered with Disability Services, you aren't guaranteed any sort of accommodations for problems that may arise due to your HCU. You cannot register for accommodations retroactively. If you fail/miss a test because of a medical situation and you haven't registered, you'll have to accept the grade.

2. Don't Sell Yourself Short

It is scientifically proven that high homocysteine levels can seriously affect your academic performance. Perhaps you can get a passing grade on a test while your homocysteine level is high but imagine what you can get if it wasn't. Set yourself up for success.

3. Advocate for Yourself

Most professors are extremely accommodating, but once in a while you will encounter a professor who isn't. Registering with Disabilities Services overrides whatever rules your professor has established around food and drinks in the classroom, preferential seating, copies of power points, the ability to make up exams, etc.

4. Don't Let HCU Limit You

Accommodations can also extend to housing, dining, and registering for classes. This can include where you live, roommate situations, meal plans, and early class registration.

How to Register

1. Find out is in Charge of Accomodations

Each campus is different. The office in charge of accommodations could be called Disabilities Services, Auxiliary Services, Accessibility Services, or something similar. Try searching "Disabilities Services + (Your campus name)" to find the office you should connect with.

Still unsure? Try checking in with the health center, residential life staff, or student affairs.

2. Register Before You are on Campus

Reach out to the office responsible for accommodations as soon as you know which school you will be attending. Many campuses have a deadline for any special accommodation requests., so don't miss it.

3. Provide Appropriate Documentation

While every campus is different, it's a good idea to have the following documentation from your doctor:

- A diagnosis of your HCU along with it's symptoms
- An explanation of how your HCU is a disability

You will need to request specific accommodations along with an explanation of why they are appropriate. You may need separate letters for housing, dining, academics etc. Ask if this is the case or can it be all inclusive in one letter from your physician.

Sample Accommodations

While these are some of the most basic accommodations you can ask for/expect, everyone is different. It's up to you to communicate with the staff in charge of accommodations about what else you may need. Don't be afraid to advocate for yourself. Below are some sample accommodations you can ask for.

Academic Accommodations

- **Document Accessibility.** People with HCU related vision impairment need modifications to the format of course materials. Accommodations could include: enlarged print handouts, access to assistive technology, secured preferential seating.
- **Note Taking Assistance.** Assistance with note taking such as a provision of PowerPoints and materials presented on overhead, or peer assistance with note taking.
- **Test Proctoring.** Use of student learning service exam rooms for distraction reduction, extended time, or access to computers with adaptive software.
- **Rescheduling.** Rescheduling of exams or major assignments if student is ill or has been required to fast due to impact of HCU on cognition (e.g., executive functioning) during illness or fasts.

Class Scheduling and Registration

- Early class registration in order to maintain a specific schedule.

Housing and Access to Nutrition

- Permission to eat/drink in class as recommended by your provider.
- Kitchen access in housing, specifically the ability to have a refrigerator and microwave in your room, if full kitchen isn't a possibility.
- A living situation that will make you feel comfortable when managing your diet/medical needs.
- Dining hall accommodations by providing low protein food products and meals.

KNOW YOUR RIGHTS!



Individuals with HCU qualify for accommodations and protections under federal law. There are three federal laws related to protecting students with disabilities: The Individuals with Disabilities Act (IDEA), The Americans with Disabilities Act (ADA), and The Rehabilitation Act of 1973, Section 504. All these laws deal with disability, and it can be emotionally difficult to think of ourselves as disabled. As we consider the effects of homocysteine on the brain, we are confronted with the reality that we may face extra challenges in the classroom. HCU is specified as a qualifying condition in the policies of the US Department of Agriculture (USDA). The use of the federal protections, such as Section 504 can help ensure individuals with HCU have equal opportunity for success at school.

Symptoms of high HCU levels in the classroom may not look different from what you see at home, however, they can be more pronounced in a large group setting

- Attention and memory issues
- Planning and organization issues
- Fatigue

Be proactive in contacting your student learning center on campus. Request a visit with that office as part of campus tours or orientation. Establishing a relationship with student learning (office will be called different things at different universities) yearly will help set the student up for success. Universities and professors are generally less accommodating and less understanding when changes are made late in the semester.

Suggested Resources

- U.S. Department of Education – Protecting Students with Disabilities
 - <http://www2.ed.gov/about/offices/list/ocr/504faq.html>
- Hampshire County Schools: Children with Disabilities and Special Dietary Needs
 - <http://boe.hamp.k12.wv.us/DocumentCenter/View/4082>

MANAGING SICK DAYS

Sneezing, coughing, achy, exhaustion; whatever your symptoms, getting sick happens to everyone. Usually, it comes at just the wrong time. While you might be feeling awful, it's really important to keep an even closer watch on your homocysteine levels while you're sick. Here are some tips to keep in mind next time you're stuck in bed watching re-runs and sneezing up a storm.

Rules of Thumb for Sick Days

- Ask a friend to check in on you. College is a much different environment than home. Unless you tell someone you're really sick and can't get out of bed, you can't expect them to know. That's why it's important to tell someone you're sick, and ask them to check in every few hours. Maybe you need more supplies from the store. Maybe you're really sick and need to be taken to the hospital. Maybe you won't need anything at all. Whatever the case may be, your friends won't mind checking in to make sure you're okay.
- "Treat the sickness first". When you are sick, you may not feel like eating. If you lose your appetite don't worry about maintaining protein levels. Focus on getting well first. Take the relevant medicines prescribed or over-the-counter products and get as much rest as possible.
- If you have a prescription, keep some to "caloric modular" (Pro-Phree, PFD2, etc) on hand. To ensure your caloric, vitamin and mineral intakes are maintained, supplement your regular formula with the appropriate amounts. Ask your metabolic dietitian to help with determining the correct amount.
- **Hydrate.** Hydration is important while sick regardless of whether you have HCU or not. Being hydrated if you have HCU is especially important since being dehydrated puts you at elevated risk for blood clots. Drink Gatorade or similar to avoid dehydration.

SICK DAY READY KIT

Prepare the list before you leave for school. The following items will come in handy when you start feeling ill and don't want to see anything but the inside of a pillow.

- Low protein foods/ Can of Pro Phree/ Cough Drops/ Antacid / Cold Medicine / Your doctor's sick day guidelines / honey / copy of insurance card / crackers / fruit juice / tissues / ibuprofen / tea bags/ electrolyte drinks / hot/cold packs / diet and regular soda / thermometer.

WHEN TO CALL YOUR DOCTOR

- You have symptoms that might signal dehydration, or some other serious condition – your chest hurts, you're having trouble breathing, or your lips/tongue are dry and cracked.
- You've been sick or had a fever and aren't getting better.
- You are vomiting and can't keep food down.

HAVING "THE TALK" WITH FRIENDS AND ROOMMATES

Struggling to explain to your friends why, despite eating a lot of "vegan" foods, you can't have tofu or beans? Or why you have to drink formula every day? Or why can't you eat a bowl of regular pasta? And "wait, what is it you're allergic to?"

The bottom line is that it's really important for the people around you to know (and understand) your HCU. While it's normal to be self-conscious sometimes, just remember that your metabolic disorder and all the restrictions and necessities that come along with it make you unique – and your friends will probably think it's kind of cool. Chances are they will want to learn more about what it is and how they can help you. Let us help you start the conversation.

THINGS TO EXPLAIN

Classical Homocystinuria

Most people have no idea what a metabolic disorder is, let alone what the word "Homocystinuria" even means.



Start simple: "My body doesn't break down protein the way everyone else's body does, therefore I have to eat a low protein diet. Yup, I know that sounds crazy. It is a very rare (1 in 200,000) inherited condition. Do you know what an enzyme is? It is a chemical that breaks down something else. I am missing that chemical (or don't produce enough) to properly break down or metabolize protein".

For "The Talk" We Suggest:

- Use humor to help diffuse any tension you feel about telling your friends about HCU.
- Feel comfortable in what you're telling them. The more comfortable you are in what you're telling them, the more comfortable they are going to feel about it!
- Start simple! Then add details from there.

HAVING "THE TALK" WITH FRIENDS AND ROOMMATES

What Happens if I Eat too Much Protein?

It's crucial for your friends to understand and recognize the importance of your diet, medications and supplements.

Again, keep it simple: "If I eat too much protein, a toxin builds up in my system called homocysteine. A buildup of this toxin can negatively affect every system in my body: the musculoskeletal system, my eyes, my vascular system, my cognitive abilities and even my emotional well-being. So this is how I have to live, to be at my healthiest self (here you can explain what you have to do in terms of your daily protein intake, whether you take B6, or betaine, how much formula you drink and why)".

How Friends Can Help

Even if you've never had an HCU related emergency where you needed help, it is important to explain to your friends the following: in the event of any medical emergency, the medical personnel need to know that you have HCU. They also need to know your medications and your specific restrictions. For example, in the event of a dental emergency, you CANNOT receive nitrous oxide (commonly known as laughing gas) because that would rapidly and greatly increase your homocysteine levels. It is also important that your friends understand the importance of you being hydrated. Dehydration can have serious and detrimental effects on HCU patients.

What Else Can They Do (also, maybe what they shouldn't!)

What you share depends entirely on you and how you feel. Here are just a few suggestions based on conversations we've had with other young adults with HCU.

DO

- DO ask me questions about HCU when you are curious.
- DO treat me the same way you treat your other friends.
- DO respect my feelings about HCU.

DON'T

- DON'T ask me "should you be eating that?"
- DON'T look at/comment negatively on my diet.
- DON'T comment on how bad my food or formula may smell.

EMOTIONAL WELLBEING: DEALING WITH "BURNOUT"

College can be mentally and emotionally demanding on its own. Add HCU, and it can be downright overwhelming. But keep in mind – not only is it normal to feel burnt out by your HCU sometimes, it should be expected. Here are some ways to try to avoid burnout, as well as how to deal with it when it comes up.

What is Burnout?

Burnout is a little different for everyone, it's when you're downright sick of your HCU. (We know, that sounds like every day, right?) But there is a difference between your everyday annoyances with HCU and burnout. Our students have described it in a few different ways. They were overwhelmed, frustrated, and exhausted. Some students stop taking medications, others tend to go off diet while still others fail to drink their formula.

How to Deal

Connect with Others Who Get it.

There is something about connecting with someone who just gets it. This is where joining HCU Network America or Students for Rare Chapter might come in handy. Connect with other HCU college students around the world on a regular basis so you feel like you have "your people" who really understand you. Joining a Students for Rare Chapter might not give you the same connection as the HCU Community, but many patients find there is overlap they can relate to in the Rare Disease community.

Stay motivated, not "perfect". Many people with HCU feel like they should always have blood levels of homocysteine readings in their target range, and become frustrated when, despite their best efforts, they don't reach their goals. This doesn't have to be a source of stress if you accept the fact that good metabolic disorder care doesn't mean being perfect. If you forgive yourself for the occasional higher level, you'll be relieved of the

stress associated with trying to achieve perfection. You'll likely reap more rewards from this approach in the long-term.

Find ways to relieve stress. Exercise, yoga, writing, drawing, painting – take some time to do something that you love. It will help.

Know when to seek professional help.

If you're experiencing mood swings, depression, or helplessness, it's important to talk to a professional. Some of our students have taken advantage of these services and found them to be very helpful. We've had students who felt they needed support dealing with their anger surrounding HCU, and people with HCU are more at risk for conditions like anxiety and depression. Some students also needed help with feelings of shame over "out of range" blood levels. Your parents, geneticist team, therapist who is familiar with HCU can help you create strategies to relieve some of the burden. Most universities have free counseling services available. Contact your school's health services to find out what type of counseling they offer.

DRINKING ALCOHOL WITH HOMOCYSTINURIA

1. Talk to your genetics team

Be sure to get your medical team's recommendations about whether drinking alcohol is safe for you.

2. Carry Identification That Says You Have Homocystinuria

This can be a medical alert bracelet, necklace, or a wallet card.

3. Know Your Drinks

- Know the protein in beer, wine, liquor, juices, sodas and mixers.
- Be familiar with the types of drinks that are low in protein, e.g. Ciders vs. Beers/Lagers.
- Know the alcohol proof in the drinks that you consume.
- Know the proof of distilled spirits.

4. Educate Your Drinking Buddies

Your drinking buddies should know you have HCU so they are familiar with what type of drinks you can and cannot consume.



5. Eat a Snack

Never drink on an empty stomach.

6. Be Prepared

- Before going out drinking, be aware of how many drinks you are going to have which will keep you within your protein limit.
- Stay hydrated.
- Have a plan to get home.

7. After the Party

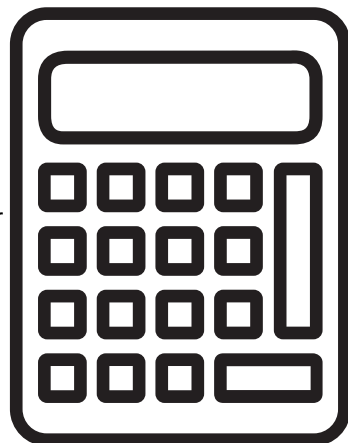
If it's a late night that ends up with drinking into the early hours of the next day, make sure you account for any additional drinks consumed the next day as they will count towards your protein for that day.

TECHNOLOGY ON CAMPUS

College often means an ever-changing and spontaneous lifestyle. Current technologies can help make navigating that environment with HCU easier. Let's face it, we don't have much control over life with HCU, but one of the perks of growing up is that you get to take control over choices like this.

Tracking Protein Intake

Growing up you may have had a cute little chart to track protein intake which helped foster your independence. Maybe your parents didn't feel so good with that, and they kept a paper diet log. Long gone are those days of losing track of the notebook or paper where your diet log was kept or having to go hunt down the nutrition information to add it into your paper diet log. Now a days there are numerous apps to help not only find the protein, but also track it!



Things to Consider

There are many options out there if you have decided to use an app to help you figure out the protein content and log what you are eating. The most important thing to consider is what is best suited for your lifestyle.

Reliable nutrition information: Is the nutrition information reliable? Can anyone upload and share nutrition information, or is it coming from a reliable source?

Rounded vs. Unrounded: Depending on your protein tolerance, you may be fine with accepting rounded protein – but if you have a lower tolerance, those 2/10th of a point start to add up!

Ability to export your diet log electronically: Part of the great wonders of tracking apps is being able to export your diet log to your dietitian, or your parents – if you choose.

Barcode, no barcode? Some apps now let you scan a food item – this allows you to scan an item and be on your way – one known risk is sometimes the information is inaccurate and regularly rounded.

Build/modify recipes: Many apps let you build recipes and modify them as you see fit – this lets you experiment or tweak things to fit your daily allowance.

Create new entries: Can't find a food item that you regularly eat? Many apps let you add new food items to your entries.

Low Protein Tracking Apps

Many low protein food and formula companies have developed apps to help track protein. Here are a few of our top rated items.

How Much Phe: Don't let the name fool you, How Much Phe is for any metabolic disorder that requires a low protein diet. How Much Phe allows you to:

- Web-based, but can be saved as an icon to your phone.
- Find the unrounded protein in over 7,000 items and growing
- Track unrounded protein, or exchanges.
- Add custom foods.
- Build/Modify recipes.
- Meal plan ahead for a day, week or longer.
- Export your diet log.
- <https://howmuchphe.org/>

AccuGo for HCU:

- Only available for iPhone.
- Can work offline.
- Can track protein or methionine.
- Copy/move and delete entries with ease.
- Allows you to menu plan.
- Information based upon USDA based food items.
- Ability to export daily food records.
- <https://apps.apple.com/us/app/accugo-for-hcu/id955040363>

HCY Metabolic Diet:

- Web based.
- Syncs with data given to GMDI Metabolic Pro Database.
- Daily nutrient tracker.
- Add your own food or recipe.
- Exports your diet records.
- Allows you to track methionine and protein.
- <http://www.mdapp.org/>

Share

Technology has made it possible to share your diet log data easily (even in real time), but the decision whether or not to share is a personal one. Your health data belongs to you alone – and it's up to you to decide what and when to share and who to share it with.

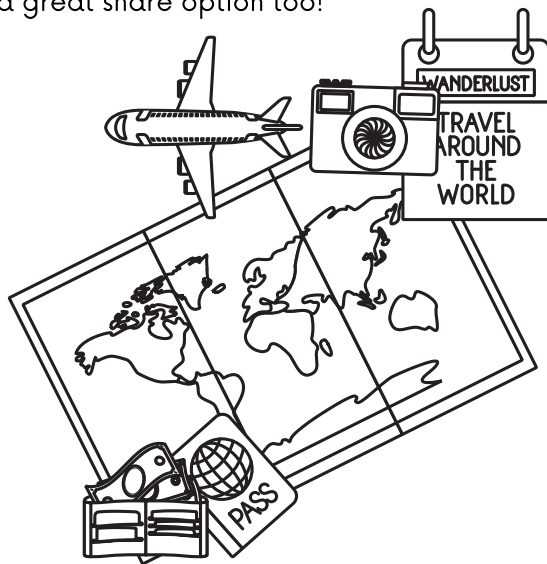
Some students choose to share their data with their parents because it can help ease their worries and provide them with a familiar support system. But when going off to college, this topic can often come down to balance of respect and privacy and openness and support.

If you decide to share your data with your parents, be sure to have a conversation about boundaries and mutual respect. Setting appropriate expectations about how and when to react and respond to the data they receive can help avoid arguments and nagging later. Keeping the lines of communication open can help during times of stress, when you may decide to suspend data sharing for a

while, or when you need more support than usual.

You can also choose to share your data only when you are sick, asleep, or going out at night. The choice is yours. And remember, your parents aren't the only option for sharing your data – a friend can be a great share option too!

Keep in mind that not everyone will want you to share your data with them. For some, the responsibility and data overload can be overwhelming. This doesn't mean they don't love you or care about you. Make sure you have honest conversations with anyone you choose to share with about their needs, as well as your own.



ON THE GO WITH HCU

It's inevitable that some point you will be off campus and need to get something to eat. Be it for a quick meal, or to get a complete haul of groceries it's good to be prepared.

For this reason, we recommend a one of a kind app called Go Low Pro.

Go Low Pro Features:

- Focused on you: Uses location to find locations near you. Filter by restaurant/store/brand to easily find what you need.
- Designed for low-pro: Gluten free is great, vegetarian is fine, but this app is designed JUST for low-protein diets to manage metabolic disorders.
- Brands you know: seeded with products by the members of the PartnershipforPKU.org the app will help you find products your low protein diet requires.
- Powered by you: Share new restaurants and stores complete with product details and pictures. The more you use the app, the better it gets for everyone!
- Traveling? Save room in your luggage: search by postal code and find locations near your destination to pick up low-pro supplies.
- <https://golowpro.org/>

ENTERING THE WORKING WORLD

Welcome to the “real world!” As you prepare to launch yourself into your career or maybe find a new one, check out the resources below to help you navigate your options and know how to protect your rights in the work place.

HCU Network America

Provides help, support, information, publications and resources to manage, educate and raise awareness of HCU. The website includes a list of clinics available to HCU patients across the US, as well as, news and events.



Your Legal Rights on the Job!

Employers are required to provide reasonable accommodations only for the physical or mental limitations of a qualified individual with a disability of which they are aware. Generally, it is the responsibility of the employee to inform the employer that an accommodation is needed.

The Americans with Disabilities Act (ADA) requires that employers provide accommodations unless to do so would impose an undue hardship on the operation of the employer's business. If the cost of providing the needed accommodation would be an undue hardship, the employee must be given the choice of providing the accommodation or paying for the portion of the accommodation that causes the undue hardship.

How Do I Know I Qualify as “disabled” under the ADA?!

A person can show that they have a disability in one of three ways:

- A person may be disabled if he or she has a physical or mental condition that substantially limits a major life activity (such as walking, talking, seeing, hearing or learning).
- A person may be disabled if they have a history of a disability (such as cancer that's in remission).
- A person may be disabled if they believe to have a physical or mental impairment that is not transitory (lasting or expected to last six months or less) and minor (even if they do not have such an impairment).

ENTERING THE WORKING WORLD

What can they do to accommodate me?

Accommodations will change based upon how HCU impacts you. Reasonable accommodations are any change or adjustment to a job or work environment that permits a qualified employee with a disability to participate in the job application process, to perform the essential function of the job, or to enjoy benefits and privileges of employment equal to those by employees without disabilities. For example, reasonable accommodations may include:

Visual Accommodations:

- Enlarged print resources
- Software that helps read items to you

Skeletal Accommodations:

- Preferential parking, so you are closer to the building
- Special office chair
- Desk that allows you to stand and/or sit

Central Nervous System Accommodations:

- Frequent short breaks
- Noise canceling headphones
- Written communication (so information is reiterated and easy to reference)

Diet Related Accommodations:

- Schedule adjustment for blood work/doctor appointments
- Guaranteed breaks for formula and lunch
- If they order food for special occasions - they can include you in the communication, so you have an option for something that works for you (it might just be a salad and fries).

Well, when should I tell my employer or future employer?

We cannot stress enough that you are not required to tell your interviewer about your disability. They cannot not hire you based upon the fact you have a disability. If they do find out in advance, that cannot be their reasoning for not hiring you.

After you are hired, go to your Human Resources (HR) Department, and let them know. If you do not have an HR department, you need to speak to the person you directly report to, or the company or division or department head – whoever you feel most comfortable discussing your needs with.

They cannot lessen your pay, or remove benefits of your job based upon the accommodations you request, or that they provide.

LETTER FROM A STUDENT

For nearly everyone who does it, heading off to college brings a mix of emotions. Yes, there is a lot of excitement, but that comes with some degree of worry and likely a healthy dose of stress. That is understandable, as it is a big change, particularly for freshmen. For many, the experience represents the first time that they are on their own, away from family and long-standing friends. These young adults must take on a new, higher level of responsibility and independence. For anyone, it can be one of the bigger challenges they have faced to that point. For those of us who live with HCU, and our families, the worry, stress, and the challenge associated with transitioning to college – and, really, true adulthood – is only amplified. We must navigate all the same changes as our peers with the added ‘bonus’ of independently managing our disorder through complexities such as entirely new schedules, meal plans, social situations, and more. It can be tough! Although, take some comfort in the fact that you are a lot less likely to gain the ‘freshman fifteen’ when on diet. Kidding aside, I would like to take this opportunity to share a bit about my experience as someone with HCU who attended college and was able – with a little trial and error – to achieve success in managing my disorder along the way. Hopefully, in doing so, others with HCU who are off to college will be able to see the same level of success.

The success I experienced in navigating college with HCU was due in no small part to a couple of steps that I took before I ever stepped foot on campus. The first step was to factor in my disorder and dietary needs when evaluating schools. For me, it was important to visit each of the schools I was considering whenever possible so that I could tour the dining halls and meet with dining staff to better understand how they would accommodate my needs. Ultimately, those accommodations were an important part of my decision as to which school to attend. For me, it appeared (key word; more on why later) that Rensselaer Polytechnic Institute (RPI) in Troy, NY fit best with my criteria across not only my dietary needs, but also academics, campus life, career prospects, and other important factors. Once I had decided on attending RPI, I took that second important step that I thought would set me up for success, which was to meet with one of the coordinators for the school’s dining services. For my freshman year, the plan we made was for me to access and prepare my own low protein foods from an area dedicated to people with various dietary needs, as well as, access the normal dining options available to all students. We also planned for my formula to be delivered to the campus post office on a monthly basis. Having taken these steps, it appeared to my family and I that I was heading into my freshman year with all the arrangements necessary to manage my HCU, stay on diet, and keep up with formula.

As it turns out, those plans were not as solid as we thought. Freshman year was, well, essentially a failure when it came to having all the arrangements needed to

manage my disorder effectively. Taking time to prepare my own low protein foods meant my new friends were often done eating by the time I sat down to join them, and I would not say DIY meal prep left me with a wide variety of tasty or healthy options. After some time, I just about gave up on the low protein foods and cobbled together meals from what I could find among the options available to all students. On top of that, the three heavy boxes of formula (HCU Coolers) I needed each month were being delivered to a building that was over a quarter mile from my dorm room. Every four weeks, I had to trek up to the campus post office, borrow a hand truck, and wheel the three heavy boxes halfway across campus back to my room. It. Was. A. Pain. The steps I took before going to school were important. However, I discovered during freshman year that the arrangements made were not as 'user friendly' as I had thought and HCU was an additional burden over the course of that year. Heading into sophomore year, it was time to go back to the drawing board.

My parents and I requested a meeting with the dining staff and shared a simple sentiment: that really did not work, so fix it. That may seem a little harsh, but remember that you pay a lot of money to go to college (cost of attendance at RPI for 2020-2021: \$75,824... crazy, I know) and everyone deserves to get a satisfactory experience in exchange for that enormous cost. The dining staff heard us loud and clear, and we completely changed the plan for sophomore year. First, they tasked one of the lead chefs, Jason, in the dining hall nearest to my dorm with cooking for me. Yes, I was essentially assigned my own personal chef. Second, we arranged to have my formula delivered to that same dining hall, which was only a short walk from my dorm. Having sorted all that out, I then sat down with Jason and we talked through my dietary restrictions and my preferences. That was incredibly important to the success of the new arrangements because I was able to educate him on all of the dos and don'ts of the diet, which, as we all know, are not always easy to understand at first. During our conversation, there was one more thing I did that led to success: I choose to give up some of my picky eating habits to allow Jason more flexibility to cook up tasty and healthy food. Our efforts, and complaints paid off. Jason found his groove and he prepared some great meals for the remaining three years. With the new arrangements, HCU was no longer a drag on my college experience. In fact, working with Jason was an enjoyable part of my time at RPI. It also meant that accommodating HCU went from a major burden to a major highlight as part of my college experience.

I know my story above contains a lot of info! Let me summarize some of the aspects of my experience that are, hopefully, helpful for any readers who they themselves are about to go off to college:

LETTER FROM A STUDENT (CONTINUED)

- **Do** consider your disorder and dietary needs when looking at schools. Dining is an important part of the college experience, and you will see greater success across the board if you account for that.
- **Don't** forget to make arrangements for your formula, betaine, and other necessary medications. And remember that college life can be busy, and schedules can be hectic, so think carefully about how easy it will be for you to access those things on-demand and amid an ever-changing schedule.
- **Don't** be afraid to push the school and dining staff to think 'outside the box' in order to meet your needs. You're paying a large sum to have a great college experience, and they should support that.
- **Do** what you can to turn HCU into a positive part of your college experience. It can be! It can take some effort and planning, but make sure you're setup for success and enjoy your time at school!



- Benjamin Lewis,
Rensselaer Polytechnic Institute Class of 2012



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