

NAVIGATING YOUR CAREER WITH HCU

Teacher, Lawyer, Veterinarian, Accountant – How do you decide what you want to be? Choosing a career is difficult; there are so many things to take into consideration: what are my interests, how many years at a college and or university will it be, how much will it cost, will I be able to find a job after I graduate? These are just a few complications young adults and adults face when trying to decide on a career path, but when they are faced with a rare disease, such as Homocystinuria, narrowing down the field can be a bit more complicated. While navigating your career with Homocystinuria may seem complicated, it's not impossible – let's get you started.

Part 1: Choosing a career path

Step 1) Evaluate your skills, abilities, and interest

This may seem like a no brainer to most; however these things don't always add up to things you want to do every day for long periods of time. The saying "Do something you love and you'll never work a day in your life" is far from true. Even doing the things you love takes a lot of time, commitment, and effort and over time those wear on you and can create burn out. While a career doesn't have to be forever, it's important you can see yourself doing it for a long period of time at a pace that is realistic.

If you find an area you think you'd like to focus on, find a mentor in the field of interest. Having a mentor gives you someone to talk to about your interest. They can provide guidance, emotional support, help set goals, develop contacts and identify resources. Mentors can help you hone your area of interest in a more real world way.

If you don't have an area of focus, we highly suggest volunteering. There is a wide array of volunteer opportunities available for young adults and adults. Do you think you'd be interested in construction, architecture or engineering? Volunteer for organizations such as Habitat for Humanity. Interested in Education? Volunteer in school after school programs or volunteer during the day at a school. There are a wide variety of volunteer programs available. Volunteering helps you define what you want to do (and don't want to do), as well as, build important skills that are beneficial to the workforce. Additionally, volunteering is looked upon in a positive manner when building a resume.

Step 2) Know yourself

"To thine own self be true" – Hamlet.

We all need to hear this once in a while, but especially when we are picking a career and are navigating a rare disease and the obstacles it can throw at us. The first part of this is to know your strengths and limitations. With having a rare disease, it's easy to get stuck and fixate on the things that may be setbacks or obstacles; "I can't see well, my levels cause me to be anxious and depressed". While it's good

to be realistic, also focus on your strengths ; “I am more compassionate because I understand what it’s like to struggle”, “I have a plethora of nutrition information because of the low protein diet”. If you are struggling with finding your strengths or weaknesses, ask your closest friends/family and don’t be afraid to consult professionals or professional resources on how they view them. Also ask them what they see you doing long term.

Step 3) Engage in trial and error

“There is no better (teacher) than adversity. Every defeat, every heartbreak, every loss, contains its own seed, its own lesson on how to improve your performance next time.” - Malcom X

As rare disease patients, we have likely encountered some form of trauma. Use it as a teacher. Trauma teaches us about what we want from others, from life, and from ourselves. Using trauma as a teacher allows us to learn, adapt and change so we don’t land back in the same circumstances we once were in. The process of trial and error is not easy and will take time and energy – be patient with yourself. Part of learning from trial and error though, is practicing self-acceptance and knowing when you have reached your limit.

“To be of service, you need to be fit for service. You can’t be fit for service if you aren’t tending to your needs. You can’t tend to your needs if you don’t know what they are.”- Francie Fitzgerald

If Homocystinuria seems to be the setback, ask for realistic accommodations. As you engage in trial and error, remember to frequently pause and reevaluate what you think you want in a job.

Part 2: Navigating your Career with Homocystinuria

1. Disclosing Homocystinuria

- a. If you are using a career recruiter to find a job, let them know you have Homocystinuria and what accommodations at your job you might need.
- b. Do not bring Homocystinuria up in your interview.
 - i. A potential employer may not ask you medical questions or ask you to have a medical exam before extending a job offer. They cannot ask if you have a disability.
- c. When you get the job, make an appointment with Human Resources to discuss your needs.
 - i. Extra time for doctor appointments/lab work

2. Put your health first

- a. Know what is expected of you
- b. Set goals and boundaries
- c. Meal plan and prep so you can stay on diet at work
- d. Find a space you feel comfortable taking your formula while at work (it will help provide you the energy and focus you need to get through your day).

Additional Resources:

- U.S. Equal Employment Opportunity Commission:
 - <https://www.eeoc.gov/disability-discrimination>
- Information and Technical Assistance on the Americans with Disabilities Act:
 - <https://www.ada.gov/employment.htm>
- U.S Department of Labor: Wage and Hour Division: Family Medical Leave Act
 - <https://www.dol.gov/agencies/whd/fmla>