

Task	Fitness	Realization	Family	Income
Power	Recreation	Personality	Partner	Prosperity
Success	Nutrition	Spirituality	Friends	Power
Job	Health	Life Meaningful	Contacts	Finance



Balancing Life and HCU

by Danae' Bartke

Life can get be busy; work, kids, school, extra-curricular activities and that's just the beginning. Now you add the demands of HCU to the pile and you feel ready to tap out. Unfortunately though for life there is no one to jump in and take over for when the responsibilities just seem like they are too much – this is the reality for parents and patients with Classical HCU. Know you aren't alone and we are here to help!

While life seems a bit crazy right now with the uncertainty of everything, we do have some advice on how to fit HCU into the picture without adding to the stress. While each piece does require time, they all will help save time in the long run.

- **Your time is limited, prioritize:**

- There are 24 hours in a day and you ultimately have to decide what you are going to say yes or no too. Many have a hard time saying no, but in order to make room for priorities you have to learn to say no to things that might not matter as much or just less. This may mean instead of watching your favorite TV show one night, you sit down and meal plan or order your low protein foods.
- Pro tip: Establish a schedule for when you are going to

order and take your low protein foods and formula. Also set a consistent time for when you are going to fill your pill container for the day, week, or even month. Put it into your electronic calendar and set a reminder so you don't forget!

- **Meal Plan:**

- While meal planning initially takes some time, it will save time and help keep you on diet in the long run. Those days where you are short on time, you won't have to figure out what you are going to make, because it's already decided for you. Meal planning saves a lot of time and ensures you have the products and supplies on hand. Sit down and figure out what you are going to make for the week and then add it to your grocery list. Try to make the protein a side, rather than the star of a dish. That way your regular protein meal and low protein meal can be basically the same. Instead of throwing that meal plan away, file it away in a 3 ring binder for reuse later on.
- Pro tip: Add the protein and any other nutrient information to each meal so you can quickly add it to your daily log.

- **Cook and Freeze Extra:**

- Again, since you are meal planning, plan on making extra! We inevitably all have those evenings where either something comes up, or you just can't fathom cooking. When you do cook a meal, cook extra and freeze it.

- **Educate and ask for help from those close to you that you can trust:**

- Without a doubt there will be a time where something comes up and you need help. We cannot recommend enough finding a friend, relative, or babysitter – or maybe all 3 and educating them about Homocystinuria – what it entails, how to read labels, how to prepare the food, where to find low protein items. This way you can get the well-deserved break you need. It's important for your mental and emotional health you find people who can help you carry this load.
- As your child grows, do not forget to start instilling some self-care skills and teaching them how to take over their

diet– they will one day become an adult and need to know how to do all the stuff that HCU encompasses! Bonus is, that as they become independent with their care– you can remove it from your plate!

Remember, there is no one that can tell you exactly how to make HCU work for you and your family, but remember there is a community behind you to support you and cheer you on along the way!