



TRANSITION TO ADULTHOOD





# INTRODUCTION

## THE TRANSITION TO ADULthood JOURNEY

Thanks to advances in research, people with homocystinuria are living healthier and more active lives than ever before—juggling busy schedules, careers and family. If they aren't doing these things, that's okay too; life doesn't always look the same for everyone.

This guide is intended to help people with homocystinuria gain the knowledge and skills they need as they grow up to more independently manage their condition. Our flexible toolset is designed for people with homocystinuria to use with their caregivers and care teams to support the transition from childhood to adulthood.

### HOW TO USE THIS GUIDE

- Chapters in this guide cover the basics, as well as medical, social, financial and legal aspects.
- The horizontal bar at the top of the chart lists several categories for performing the task, whether an individual might need help with the task, can do it on their own or will learn to do it on their own, for example.
- The code in the left-hand column indicates the type of homocystinuria.
- As you go through these worksheets, review each task and click the box that indicates whether you need help with certain tasks or can do them independently.



### OVERALL PROJECT GOALS

- Support families' ability to have a transition plan
- Create understanding that transition plans are fluid and individual
- Understand that the Transition Program does not have a definitive start or end, it will evolve with research, treatments and resources

### OBJECTIVES

- Create a visual roadmap for families to navigate the transition process, ensuring that each aspect of transition is inclusive to all abilities and types of homocystinuria.

# THE BASICS OF HOMOCYSTINURIA

I am sure by now you realize that friends, family members and even restaurant staff have many questions about your disorder and sometimes this can become frustrating, uncomfortable and cumbersome. Whether it be Classical Homocystinuria, the Cobalamin disorders or Severe Methylenetetrahydrofolate Reductase Deficiency, it is important that you become fluent and at ease in answering some of the questions people ask.

In order to do this, it's imperative that you are knowledgeable about your particular condition. You are likely already aware that the homocystinurias are a group of congenital inherited disorders in which the body is unable to metabolize certain building blocks of proteins. This results in an elevation of an amino acid, homocysteine, in the urine and blood. You are also probably aware that the diagnosis is most frequently made a few weeks after birth determined by the newborn screening test.

Because you are so familiar with your everyday routine including diet control, medical formulas and/or medications, as well as your follow up blood level control, you forget that those around you are completely unaware of these treatments. As you educate yourself and then others, and you go as far as understanding the research studies being done to improve the treatment and outcome, you will realize that you are not alone in



this. Experts are interested in your health and well-being including friends, family, and everyone else that you may encounter.

– Danae' Bartke, Patient and Executive Director, HCU Network America

Code	Task	Need someone to do it for me	Can do it with support	Will learn to do it on my own	Can do it on my own	Need more info	N/A
A	I know what type of homocystinuria I have.						
A	I can explain the basics of my condition.						
A	I can remember my most recent blood levels (Homocysteine and Methionine).						
A	I understand the symptoms and complications of homocystinuria if untreated.						
A	I understand how homocystinuria is inherited.						
A	I know how to access online resources related to homocystinuria.						

## Code

A All HCUs

C Classical

Cbl Cobalamin

M MTHFR



# MEDICATIONS & MEDICAL NUTRITION

After a diagnosis, the most important thing for you to do is to be able to access and maintain your prescribed treatment. Like your peers, you likely want to sleep in, test the boundaries, and hate being reminded about what you need to do. You want to do all the normal young adult activities, such as learn to drive, graduate high school, go off to college, form meaningful relationships, start a job and become legally responsible for yourself.

But unlike others, you must navigate these milestones while adhering to your specific treatment plan and learning to care and advocate for yourself. It's a complex time, but with dedication, you can work through any obstacles that may stand in your way!



Code	Task	Need someone to do it for me	Can do it with support	Will learn to do it on my own	Can do it on my own	Need more info	N/A
C	I have a general understanding of what foods are safe for me to eat.						
C	I can read a nutrition label.						
C	I can make an accurate estimate of foods without a nutrition label.						
C	I can accurately track my protein intake for the day.						
C	I can make my medical formula.						
C	I can remember to take my medical formula.						
C	I can find good food choices when I am away from home.						
Cbl	I allow my caregivers to give me my injection.						
Cbl	I know what supplies are needed to get my injection.						
A	I can sort and remember to take my prescriptions and other medications.						
A	I know the names of my medications, medical formula and medical foods and I understand what they do.						
A	I can order my prescriptions.						
A	I know how my medications need to be stored.						

Chart continues on next page ►

## Code

A All HCU's

C Classical

Cbl Cobalamin

M MTHFR

## MEDICATIONS & MEDICAL NUTRITION

Code	Task	Need someone to do it for me	Can do it with support	Will learn to do it on my own	Can do it on my own	Need more info	N/A
A	I can use and take care of my own medical equipment and supplies.						
C	I can order my low-protein foods.						
C	I can order my medical formula.						
C	I can cook meals appropriate for my dietary needs.						
Cbl	I know how to prepare my injection.						
A	I remember to refill my prescriptions and get my other medications before they run out.						
C	I remember to order more medical formula before I run out.						
C	I can plan meals for the week that are appropriate to my dietary needs.						
Cbl	I can give myself an injection.						

### NOTES

#### Code

A All HCUs

C Classical

Cbl Cobalamin

M MTHFR

# MEDICAL APPOINTMENTS

Health care transition, or HCT, is the process of getting ready for health care as an adult.

During childhood, your parents and caregivers usually help with your health and health care needs—they call for appointments, fill out forms and keep track of medications. As you get older, managing those needs becomes your own responsibility. Achieving this independence requires an organized transition process to gain independent health care skills.



Code	Task	Need someone to do it for me	Can do it with support	Will learn to do it on my own	Can do it on my own	Need more info	N/A
A	I can communicate independently with my medical team during visits.						
A	I feel comfortable speaking with my doctors and asking questions without my parent or caregiver.						
A	I decide who I want information shared with (family, friends etc.).						
A	I know how to contact various medical professionals (Primary, Genetics team, specialist).						
A	I can set up doctor appointments and blood draws.						
A	I meet independently with my medical team during my visits.						
A	I know whom to contact for non-urgent needs (refills, questions, etc.).						
A	I am comfortable making major medical decisions.						

Chart continues on next page ►

## Code

A All HCUs

C Classical

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M MTHFR

# MEDICAL APPOINTMENTS

Code	Task	Need someone to do it for me	Can do it with support	Will learn to do it on my own	Can do it on my own	Need more info	N/A
A	I can provide a summary of my medical history (such as dates and types of surgeries, family history, allergies and medications).						
A	I know my rights to keep my health information private.						
A	I can get myself to doctor appointments.						
A	I know who my various medical providers are and their roles in my health.						
A	I remember to implement new procedures and follow up items from doctors.						
A	I know how to get your medical records if needed.						
A	I have an up-to-date medical summary, either printed or digital.						
A	I know how to fill out medical forms.						

## NOTES



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## SOCIAL & RELATIONSHIPS

As we transition from childhood to adolescence to adulthood, we begin to make more complicated decisions, take on more responsibilities and become more independent. But we don't travel this journey alone—parents, friends, teachers, coaches, and eventually romantic partners all provide us with the confidence, support and advice that we need as we become well-rounded and happy young adults. Creating a support system around you that you can count on is important. Therefore, one of the most critical decisions that you will continue to make is the people with whom you choose to surround yourself, and the relationships that you cultivate.



Code	Task	Need someone to do it for me	Can do it with support	Will learn to do it on my own	Can do it on my own	Need more info	N/A
A	I can decide if I want to date and choose whom I want to date.						
A	I can express what I want and don't want (verbally, by sign, device, or another way), and tell people how I make choices.						
A	I make healthy decisions and set boundaries in my relationships.						
A	I understand consequences of making decisions that will result in me committing a crime.						
A	I understand how smoking, drinking and/or using drugs can affect my condition (worsen symptoms, react with my medications).						
A	I know who to contact if I feel like I'm in danger, being exploited, or being treated unfairly (police, attorney, trusted friend).						
A	I know what types of birth control are safe and how to practice safe sex.						
A	I know which medical professionals to speak to when I wish to start a family or if I were to become pregnant.						
A	I understand how pregnancy can impact homocystinuria.						
A	I make decisions about marriage (if I want to be married and to whom).						

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# INDEPENDENT LIVING

“When I grow up, I’m living alone. Do you hear me? I’m living alone.” Many of you may recognize this quote from Kevin played by Macaulay Culkin, in the 1990 movie, “Home Alone.”

For those who haven’t seen the movie, Kevin’s wishes are fulfilled when his family accidentally leaves him home alone while they go on a European family vacation. Throughout the movie he is faced with learning rather quickly how to do everyday tasks, like getting groceries, doing laundry, cooking for himself and overcoming fears of the basement. Unlike most kids though, he has to fend off robbers in a series of dramatic staged planning and booby traps. In the end though, he finds himself missing the comfort of his family and can’t wait for them to come home.

Like Kevin, many of you can’t help but dream of having your own space without the parental confines of home. While you all dream of having our own space without



someone else’s rules, growing and having that space is much easier said than done, especially when navigating homocystinuria. Through careful planning and discussion with your parents and care team, you can determine the level of independence that is best for you based upon the spectrum of your abilities.

Code	Task	Need someone to do it for me	Can do it with support	Will learn to do it on my own	Can do it on my own	Need more info	N/A
A	I know what my allergies are and what I need to do if I have an allergic reaction.						
A	I wear a medical alert bracelet (conditions, allergies).						
A	I make safe choices around my home. (Turning off the stove, shutting doors and locking them).						
A	I know how to maintain a healthy lifestyle (diet, activity, etc.).						
A	I keep my living space clean and livable.						
A	I can get groceries and run other errands on my own.						
A	I know how get help if I need it.						
A	I know when and where to go for emergency care.						
A	I know how to manage my money and pay bills.						

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## EDUCATION & CAREER

As you navigate through your transition to adulthood, it is important that you understand exactly how your condition may impact your educational, job or housing decisions, while also being aware of the resources and support that are available to help you in this process.

Financial aid or scholarship to continue your education as well as resources to help you prepare for and seek out opportunities in the job force are readily available. People like school guidance counselors and social workers can assist you in finding these tools. In addition, knowing whom to speak to about potential health, educational, and/or dietary accommodations in school or in the workplace is key!



Code	Task	Need someone to do it for me	Can do it with support	Will learn to do it on my own	Can do it on my own	Need more info	N/A
A	I have people I can turn to for help with school work/classes.						
A	I have thought about what I want to do after high school.						
A	I know how to look for a part-time or full-time job.						
A	I know how my condition might affect my job choices.						
A	I know how to contact a social worker for help.						
A	I know how to access information about college or vocational programs of interest.						
A	I have applied for a part-time or full-time job.						
A	I know how to apply for financial aid/scholarships for school.						
A	I know how to where to go to and who to speak to if I need accommodations at school or in the workplace.						
A	If I go away to college, I know who on campus should be informed about my disease						
A	I know my options for housing as an adult (on my own, group home).						

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# INSURANCE

Every time you visit a doctor, get your blood drawn or pick up a prescription from the pharmacy, you will be billed for those services provided. Just like buying groceries or clothing from a store, it costs money to receive a service or product.

Health insurance is important to help you pay for those expenses related to your diagnosis and health needs. Health care services can be very expensive and can cause financial hardship. Ensuring you have adequate health insurance and knowing how it works can make sure you do not have problems accessing the services you need to stay healthy.



Code	Task	Need someone to do it for me	Can do it with support	Will learn to do it on my own	Can do it on my own	Need more info	N/A
A	I remember to carry my health insurance card with me.						
A	I know what insurance I have.						
A	I know who has taken out a health insurance policy for me.						
A	I know how to identify the important details on my insurance card (name of the policyholder, policy number, group number, etc).						
A	I know what the terms “deductible”, “co-pay” and “out-of-pocket” mean.						
A	I know how to find an insurance plan.						
A	I know whom to contact with questions about my coverage or to dispute a problem.						
A	I know when I will need to get my own medical coverage.						
A	I have an adult insurance plan in place.						

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## LEGAL

Our legal system is a set of rules created and enforced through social or governmental institutions to regulate behavior. Legal professionals help you understand the law and advise you in regard to your needs. Understanding your personal rights and how it relates to the laws that are in place, is a vital part of becoming a productive member of society.

It is especially important when you have a medical condition because there are laws that protect your rights and the services you need to stay healthy. Seeking advice through legal professionals can also help you prepare for your future and access services that will help you lead a healthy lifestyle.



Code	Task	Need someone to do it for me	Can do it with support	Will learn to do it on my own	Can do it on my own	Need more info	N/A
A	I know what government programs and benefits (SSI, SSDI, DRS, Waivers) I may be eligible for as an adult.						
A	I know how to sign contracts and other formal agreements, such as powers of attorney.						
A	I know about guardianship or power of attorney for health care.						
A	I know whether I need to set up a special needs trust or ABLE account.						

## NOTES

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