

# A Guide to Caring for Someone With a Urea Cycle Disorder

What a UCD Means For: \_\_\_\_\_

This information will guide you in how to help with UCD management. It also tells you what steps to take if there is an emergency.

Usually, \_\_\_\_\_ doesn't appear to be sick, so it can be hard to remember that a UCD can lead to a medical emergency. We don't expect this to happen, but we want to make sure you have all the information you need in case it does. We also want to make sure you understand what's required for day-to-day management of a UCD.

A UCD can cause the amount of ammonia in a person's blood to rise to unsafe levels. This can make him or her very sick. The symptoms of high ammonia don't appear quickly, and if you're not familiar with UCDs, it may be easy to miss the subtle signs that ammonia is rising. By the time someone with a UCD appears to be sick, it usually means that medical attention is required. If this happens, you should follow the emergency protocol at the end of this guide.

**To stay healthy and keep ammonia levels low, it is very important that \_\_\_\_\_ follows these rules:**



## Stick to a low-protein diet

- No extra food (snacks, treats, etc) unless it's approved by parents first.
- Low-protein is different—and more restrictive—than vegetarian.



## Avoid extreme temperatures (too hot or too cold)



## Other rules we follow



## Stay well hydrated



## Avoid strenuous activities (eg, in gym class or at recess)



## Take supplements and/or medicine every day

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# Day-to-day UCD needs



## Diet

\_\_\_\_\_ is on a low-protein diet and can have \_\_\_\_\_ grams of protein per day. This means we need to monitor food intake very carefully to make sure all meals and snacks fit within this diet.

### Instructions:

_____	_____
_____	_____
_____	_____
_____	_____



## Supplements

Supplements help add nutrients that are missing from a low-protein diet. These should be taken at the following time(s): \_\_\_\_\_

### Instructions:

_____	_____
_____	_____
_____	_____
_____	_____



## Medicine

A medicine called \_\_\_\_\_ helps remove ammonia from the body safely. This should be taken at the following time(s): \_\_\_\_\_

### Instructions:

_____	_____
_____	_____
_____	_____
_____	_____



## Activities

Having a UCD means avoiding strenuous exercise or activities and extreme temperatures. Here are some examples of activities that are and aren't okay, but check with us anytime if you're not sure about something.

**Safe activities:**

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**Unsafe activities:**

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## Common symptoms

\_\_\_\_\_ may have any of the following UCD symptoms on a daily basis:

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**We need your help watching for these symptoms and addressing them if they happen.**



## What to do in an emergency

UCDs affect everyone differently and at different times. \_\_\_\_\_ may not look sick most of the time, which can make it hard to remember that a UCD can put someone at risk for a medical emergency.

If \_\_\_\_\_ is having serious symptoms, it could mean a hyperammonemic crisis is happening. This is when the amount of ammonia in the blood becomes extremely high. A crisis can be very dangerous and requires medical attention right away.

\_\_\_\_\_ 's symptoms of extremely high ammonia are typically:

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**If you notice any of these symptoms or any strange or out-of-character behavior, this is what you should do:**

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We have a medical protocol that we take with us to the hospital so that the staff knows how to treat a UCD. A copy of this always needs to be taken with you in the event of a hospital visit.



## Emergency contact information

**Emergency contact number:** \_\_\_\_\_

Details: \_\_\_\_\_

**Emergency contact number:** \_\_\_\_\_

Details: \_\_\_\_\_