

**UCD
AND
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UNDERSTANDING UREA CYCLE DISORDERS



This booklet is intended for people with urea cycle disorders



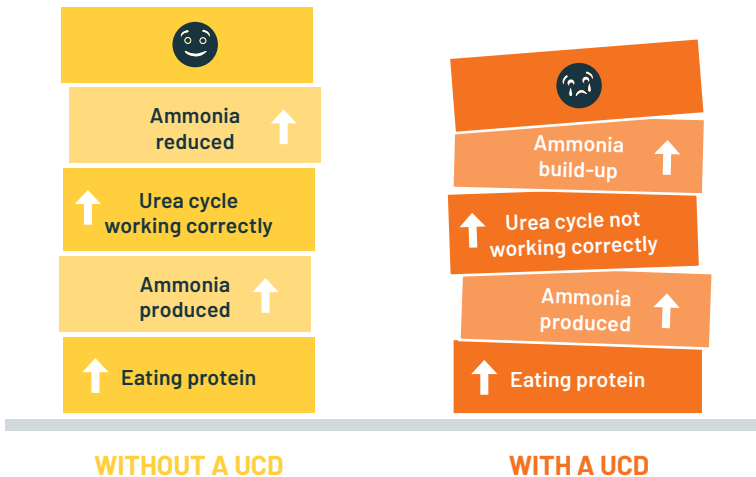
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WHAT IS A UCD?

A UCD (which is a shortened name for a 'Urea Cycle Disorder') is a condition that affects how your body breaks down protein, from foods such as meat, eggs and dairy (like milk or cheese), during high-intensity exercise, or when fasting. When protein gets broken down, your body produces ammonia. Ammonia has to be removed from your body, as it is a waste product and can make you feel ill. This is handled by the 'Urea Cycle'. When you have a UCD, one of the steps in the urea cycle doesn't work and ammonia builds up in the body.

AMMONIA BUILD-UP



If you have a UCD, you may need to take steps to manage your ammonia levels and symptoms. Finding the right treatment plan can allow you to live your life to the fullest, despite your UCD.

WHAT ARE THE SYMPTOMS OF UCDs?

Even if your ammonia levels go up by a little bit, you might start to feel poorly and experience symptoms. Ammonia levels are different for every person living with a UCD, symptoms can be vague and might be different depending on your age.

SYMPTOMS MAY INCLUDE:

- Feeling very tired
- Finding it difficult to think clearly
- Feeling wobbly/dizzy
- Headaches
- Shaky hands
- Body parts moving or twitching when you don't want them to
- Finding it hard to speak
- Not feeling hungry or not wanting to eat protein (such as meat, eggs and dairy)
- Tummy ache
- Feeling sick or vomiting
- Feeling very angry or upset

WHAT ARE THE SYMPTOMS OF UCDS? CONT

If your ammonia levels become very high, you might experience something called 'hyperammonaemia'. This can be very dangerous, and it's important that you and your family know what to do if you or they think that you might be experiencing this. Symptoms of hyperammonaemia can vary from person to person and can be different depending on your age.

The symptoms are likely to be similar to those listed on the previous page but might be more severe and can include seizures or fitting, and seeing or hearing things that aren't there. It is important that you keep an eye on your symptoms so you are able to notice any changes. If you or your family think that you are experiencing hyperammonaemia you should speak to your doctor or go to hospital straight away.

If you find it difficult to talk about your symptoms, you can ask your healthcare team for a communication tool which may help to make this easier.



WHAT CAN CAUSE INCREASES IN AMMONIA LEVELS?

A few things can affect your ammonia levels. You should be aware of these so you can take steps to prevent them from affecting your ammonia levels and causing symptoms.

INFECTIONS

Infections (such as cold, flu and coronavirus) can significantly affect your ammonia levels. You can reduce your chance of infection by washing your hands frequently with soap or alcohol-based hand sanitizer and by avoiding contact with anyone who may be sick. You should also make sure that you get your seasonal flu vaccine every year.

STRESS

Major life events (such as surgery, accidents, school stress, pregnancy etc.) could also increase your ammonia levels. If you are going through any major life events which may be stressful it is important to talk to your doctor about this, as this could affect your ammonia levels.

PROTEIN

Eating too much protein will increase your ammonia levels, so it's very important to stick to a low-protein diet if you have been told you need to follow this. If you are struggling to stick to your low protein diet, you should speak to your doctor.

EXERCISE AND FASTING

Exercising too much or fasting can make your ammonia levels increase to dangerous levels, so it's important to take it easy and not push yourself too hard. Before fasting, or starting a new physical activity, you should always talk to your doctor.

WHY IS IT IMPORTANT TO MAINTAIN TIGHT CONTROL OF AMMONIA LEVELS?

Unbalanced ammonia levels can cause symptoms that affect your day to day life and could lead to hyperammonaemia. Even a small increase in the ammonia levels in your body can make you feel unwell and cause symptoms.

AMMONIA LEVELS



HOW CAN AMMONIA LEVELS BE MANAGED?

There are a number of ways that you can manage your ammonia levels, and your doctor will be able to tell you which of these are most suited to you as everyone's needs and requirements are different.

You may have been told to follow a low protein diet, to help manage your UCD by reducing the amount of protein your body needs to break down. There are lots of low protein recipes available online and your doctor will be able to tell you how much protein you should have each day. They may also give you supplements to make sure that your body is getting all of the energy and nutrition that it needs. As well as this, your doctor may give you a medicine to keep your ammonia levels at safe levels. It is really important that you stick to your treatment, and follow what your doctor tells you, as this will help you manage your symptoms better, allowing you to live life to the fullest.

There are many different options available for treating UCDs. By talking to your doctor about your symptoms, they will be able to make sure that you are taking the most suitable medicine to keep your ammonia levels under control.

Closely following the treatment plan given to you by your doctor will help you get the most out of your treatment and give you the best opportunity to control your ammonia levels and avoid UCD symptoms.

FURTHER SUPPORT

UCDs can sound scary and complicated, but you are not alone. For more information and support you can visit [metabolicsupportuk.org](https://www.metabolicsupportuk.org). From the website, you can download resources that will help you communicate your symptoms to others, if this is something that you struggle with. If you have any concerns about your UCD, you should speak to your doctor.



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