

# GOING TO SCHOOL – HINTS AND TIPS FOR YOU AND YOUR CHILD

- A teacher's awareness of your child's situation will mean they can better understand and respond if problems come up
- The teacher can make an informed decision about how they respond to common situations (for example, why your child might be late to school, can't finish homework on time or needs access to a mobile phone)
- It allows your child to discuss any concerns or worries they may have with a teacher they trust or the school counsellor
- It helps you and your child's teacher if you work together to support your child
- A meeting with the new teacher (and other staff) at the start of each academic year and also consider a mid-year reminder for all staff via a meeting, email or a training day/ staff meeting session

The following suggestions can be used to support you when discussing your child's Urea Cycle Disorder with their school or childcare. Together with your Specialist Metabolic Team prepare a checklist or school plan that might include the following:

- Who might you want to inform?
- Consider requesting a letter to the school from your metabolic team
- Taking medications and supplements to school
- Food at school and school meals
- A plan for Physical Education (PE) lessons
- A pre-prepared plan to follow if your child feels unwell at school

## Who might you want to inform?

- The headteacher
- The class teacher or any supply/temporary teacher
- Any staff members involved with breakfast/morning or afterschool clubs
- The tuck-shop or canteen staff/ dinner ladies
- The school nurse/ counsellor
- PE teacher to ensure your child can partake in exercises that are safe for them

## It's helpful to discuss the following with your child's school:

It's important that your child's school has a basic understanding of Urea Cycle Disorders and the importance of the low protein diet, taking medications, symptoms to look out for and an understanding of what to do in an emergency.

The following suggestions can be used as discussion points with anyone involved in looking after your child:

- Your child's condition is genetic and non-contagious
- Children with a Urea Cycle Disorder cannot break down protein in food and eating too much protein can cause a buildup of the toxic chemical Ammonia in the body
- All children need a certain amount of protein for growth and repair of the body, but in your child's condition the extra protein can cause them severe harm
- Eating the wrong foods will not always make them immediately sick, but may have a detrimental effect over time as the toxic ammonia levels start to rise in the body
- Your child is on a very specific diet that is carefully calculated by a specialist metabolic team, with portions measured out daily by the child's family – so it is important that there is a system in place at school to supervise the type and amount of food they eat during the day
- Advise the school that your child will need to attend clinic appointments which sometimes may result in absences from school
- It is important that the school inform you if your child has eaten any food that is not allowed as part of their special diet
- Explain what happens when your child becomes unwell and how this can affect your child. (You may want to use the communication tool on this website to help your child inform teachers of their symptoms)
- Discuss your concerns about your child at school (for example, homework extensions, taking their medication, getting picked up on time, or bullying)

### **What might you like to discuss with your child?**

Talking to your child is an important part of preparing for childcare and school.

It is important that your child understands and can manage their diet appropriately when going to school.

Things you might want to talk to your child about include:

- Knowing which foods they can and can't eat
- Bringing home uneaten food in their lunch box so that you can calculate exchanges
- Avoiding buying food from the school canteen/ tuck shop or only buying food they know fits in with their special diet
- Avoiding swapping lunches with friends
- Deciding when is best to take their supplements and any medication they may be on
- How to explain their special diet to other children

### **Food at School**

You will need to decide whether to provide your child with a packed lunch or to discuss with the school the possibility of low protein school meals.

You might also want to consider giving the school a list of foods that are 'free' (contain minimal or no protein) or are allowed in measurable quantities.

### **Emergency plans**

The school must know to inform you immediately if your child feels unwell or has an accident, because urgent treatment may be needed to prevent more serious problems occurring.

You might want to consider the following:

- Provide the school with two or more emergency contact numbers
- Provide the school with details of your child's metabolic team