



A TEACHERS GUIDE TO PUPILS WITH A METABOLIC PROTEIN DISORDER

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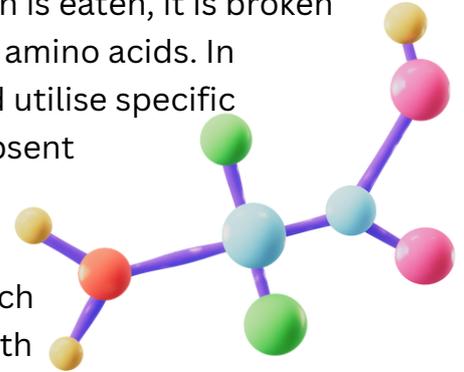
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What is a Metabolic Protein Disorder?

A metabolic protein disorder is a rare inherited condition. Individuals born with one of these disorders cannot use protein in the usual way. When protein is eaten, it is broken down by enzymes in the body and made into smaller parts called amino acids. In metabolic protein disorders, the body's ability to break down and utilise specific amino acids is impaired because one of the needed enzymes is absent or only present in small amounts.



If untreated, this can lead to a buildup of certain amino acids which can be toxic, or a deficiency in other substances needed for growth and development. This can cause damage to the body including the brain. This may affect cognitive function and create difficulties in learning, behaviour and social interactions.

Your pupil: _____

Has the disorder: _____

Known as: _____ **for short.**

What is the treatment?

The treatment for this metabolic protein disorder is a special **diet for life**, that must be adhered to. This includes a

- Low protein diet: this will help prevent the build up of toxins in the blood
- Synthetic protein supplement: this will help prevent the build up of toxins in the blood, while at the same time providing enough for growth and development
- Special medications may also be recommended

A protein disorder is **different from an allergy**. If a child with a protein disorder consumes food he or she should not eat, there is no immediate reaction. It is important their parent/guardian is told as soon as possible so they can make changes to the diet later that day. If this continues to happen on an ongoing basis this can cause damage.

The Diet

The low protein diet is **for life** and is divided into 5 main parts

1

Foods to Avoid or Restrict

High protein foods such as meat, fish, eggs, cheese, milk and milk products, many vegetarian foods, chocolate, bread, pasta, seeds and nuts are rich in protein and so they are either not allowed or restricted.



2

Natural Protein

Children with a metabolic protein disorder need a small amount of natural protein to help them grow. The amount we give is counted in **exchanges**. An exchange is 1 gram of protein. Every child will be advised a number of exchanges they can have per day. The exchanges are often provided from foods like breakfast cereals, potatoes, pasta or rice.

3

Synthetic Protein

As high protein foods cannot be eaten, the other amino acids and the vitamins and minerals they contain are replaced by a special synthetic protein. This can be in the form of a drink, a paste made from powder or occasionally as tablets. This is spread out over the day. It is very important for the child's growth and development and it helps to control their blood levels.



4

Free Foods

Free foods have little or no protein and can be eaten without counting. Examples include most fruit, vegetables, salads and small amounts of butter or margarine, jam and honey.



5

Low Protein Prescribed Foods

There are specially manufactured foods, available on prescription. These provide replacement for foods that naturally contain protein including low protein bread, low protein pasta, low protein milk and low protein rice.



What Can I do as a Teacher?

Support your Pupil to Take Their Synthetic Protein Supplement

- Your pupil may need to take their synthetic protein supplement in school as it is best spread throughout the day
- Maintain a positive attitude towards the supplement. It is a vital part of the diet
- Some children can struggle with their supplement, but it is important if all adults around them provided a consistent message and praise the child's efforts
- If your pupil does not finish their supplement, or refuses to take it please inform their parent or guardian

Maintain Good Communication with Parents

We know that as a teacher you have an entire classroom of children to monitor. Accidents can happen when children swap or sneak food. If you know or suspect this has occurred please inform the parents.

If your pupil does not eat all their lunch or finish their synthetic protein supplement please send it back home with them and make sure the parents or guardian know what has not been consumed. This helps them keep track of their child's protein intake for the day as they may need to make adjustments for the rest of the day.



Always let the parents/guardian know if a child has taken a food they should not have or if the child has not taken their supplement

Lunchtime

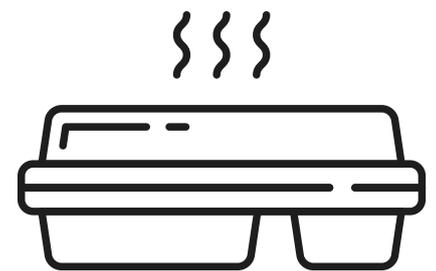
Packed Lunches

Foods should not be swapped with other children. You may already have some class rules about food and sharing of food. Having class rules prevents your pupil from feeling isolated or 'different'. Leftover food should be sent home in their lunchbox.



Hot School Meals

Many schools are now part of the hot school meals programme. Currently there may not be suitable options for these pupils. If parents are able to provide a low protein meal alternative, please allow access to a microwave where possible. If you need further advice please contact the metabolic dietitians at the National Centre for Inherited Metabolic Disorders.



What if My Pupil Asks For a Food They Cannot Have?

Sometimes, it is easy to think that a little of a restricted food will not do any harm. But, many children with inherited metabolic protein disorders can only tolerate a very small amount of protein. Also, gaining a taste for higher protein foods that they cannot have will make it harder for them to stick to their diet in the long run. One of the most important factors in managing the diet is **being consistent**. It is important you discuss with the parents about the answer you all give so that the child gets the same message from everyone who takes care of them.

What Can I do if My Pupil Eats Something They are Not Allowed?

Do not panic! However, it is important that the parent must be told. The parent can make changes and cut down on exchanges later on that day and will be able to explain any raised blood levels to the dietitian.



Common Scenarios in School



Parties and Treats

There are a number of sweets which are protein free and allowed in the diet and these can be used for treat days or parties. The majority of fruit is protein free. If treats are to be given at school, check with the parents and have some suitable foods available for them that can be shared with the whole class. Lists of some suitable sweets are available on our website www.metabolic.ie

Children with the metabolic conditions **PKU** and **TYR** must **avoid the artificial sweetener aspartame or E951/E962**. This can be used in sweets, diet drinks and squashes. The parents will let you know if this applies to their child. Please double check labels if this is the case for your pupil

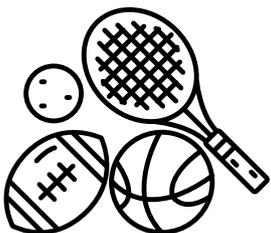
Baking and Cooking in School

If the class is learning about food or cooking, recipes may be adapted to low protein versions. Talk to the parents as they will be able to help you with ideas or alternatively you can check out the selection of low protein recipes on metabolic.ie or contact the National Centre for Inherited Metabolic Disorders for further help by emailing the dietitians on metabolic.dietitians@childrenshealthireland.ie.



School Trips/Tours

There is no reason why pupils with metabolic protein disorders cannot participate in school trips along with everyone else in their class. It is important to liaise with parents/guardians in advance of the trip to ensure their dietary requirements will be catered for.



Sports

Pupils with a metabolic protein disorder can play sports in the same way as everyone else as their synthetic protein supplement provides them with all the energy they need to do so. If they play a lot of sport, maybe playing for a club or school team, their dietitian will be able to provide suitable advice. Resources on sports nutrition for those on a low protein diet are available on www.metabolic.ie

Educational Attainment

Most children with metabolic protein disorders will have the same educational attainment as their peers. Young people with metabolic disorders may have a developmental assessment as a part of their care, completed by the psychologist in the National Centre for Inherited Metabolic Disorders. They may also have additional assessments, such as a cognitive, psychological or neuropsychological assessment, if any specific concerns arise from parents or school about learning ability or overall school difficulties.

What Can I do If I Have Concerns?

If you have any concerns regarding the child's educational ability, or about issues such as behaviour or attention, talk to the child's parents, who will pass on the concerns to the psychologist working in the National Centre for Inherited Metabolic Disorders.

Where Can I Find Out More Information?



Our website www.metabolic.ie, under the 'Family and Patient Information' heading, contains information on the specific metabolic protein disorder your pupil has as well as general information on following a low protein diet.





National Centre for Inherited Metabolic Disorders



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