



Citrin Deficiency School Leaflet

What is citrin deficiency?

Citrin deficiency is a hereditary condition which affects a person's metabolism in the liver, including energy production from carbohydrates and detoxication of alcohol. It is usually manageable by diet and no activity restriction is necessary.

Presentation

Typically, citrin deficiency patients have a preference for foods that are high in fats and protein like cheese and meat, over foods that are sweet or contain high carbohydrates such as bread, rice, and candy. Some patients may also experience other symptoms such as failure to thrive, fatigue, abdominal pain, dizziness, and others. Importantly, citrin deficiency affects individuals very differently depending on their physical and nutritional condition. Dietary imbalance especially from eating too many carbohydrates/sweets can lead to sickness.

Treatment

The existing treatment at the moment is diet management. Most of the time, patients have a natural tendency to meet their needs by selecting and avoiding certain foods. This is a key for them to stay energetic and healthy. There is also a need to eat frequently by having snacks between meals to have the continuous flow of energy intake.



Tips to support your students with citrin deficiency

- ★ Understand that their food preference is a bodily reaction for their well-being and not something to be corrected.
- ★ Help them eat what they wish to eat in the amount they wish.
- ★ Make snacking time available at school.
- ★ Inform doctors that the patient has citrin deficiency in the case of an emergency.
- ★ Help raise awareness and inspire compassion in other students by offering them resources that explain the condition.
- ★ Please make an effort to be inclusive during activities or events that may pose challenges for patients such as birthdays and field trips

When students with citrin deficiency get sick



It may sometimes take patients a longer time to fully recover from a general cold if they cannot eat enough during sickness. Please be understanding and allow for adjustments to homework deadlines or exams if they need time to recover.

When patients say they feel sick at school, please allow them to have what they wish to eat/drink regardless of the usual medical protocol. In case they need medical attention, please inform doctors that the patient has citrin deficiency. The use of GLYCEOL® is prohibited and high calorie infusion with glucose is not recommended as it may further exacerbate the condition of the patients. There is no issue with general infusion of glucose to treat hypoglycaemia, diarrhoea, or vomiting. But it is advisable to let patients consume the food they prefer after their appetite comes back for faster recovery.



School meals

In schools where lunch is provided, please be informed that the portion of each dish may need to be adjusted to fit the needs of patients. Typically, having more meat and dairy products (fat/protein) and consuming less rice/bread/pasta (carbohydrate) will be the right balance for them.

Please allow the patients to decide on what and how much they want to eat so their dietary needs on the day can be naturally fulfilled. It is different from being selfish or picky. It is also different to having an allergy. Too many carbohydrates and sweets tend to make the patients feel sick, but they may favor consuming small amounts of carbs and sweets if it is necessary. It may be more preferable if understanding from their classmates can be obtained in advance.



Seasoning

Some seasonings may taste sweet to patients which may cause them to avoid consuming the dish. If there is no alternative dish they can choose from, it may be necessary for them to bring lunch from home.



Alcohol content

Alcohol consumption may put the patient's life at risk. Also avoid fermented products or other products that may contain traces of alcohol. Fully evaporated cooking wine may not be a problem, but it may be safer to avoid it.

Supplementary food and drink

Energy supplementation between meals is suggested by doctors to respond to the metabolic condition. Parents may ask the school to keep supplementary food/drinks at hand if it is necessary. Please keep in mind that *typical children's snacks may not be their favourite*. Children with citrin deficiency do not enjoy sweets, candies, or juice as much as other kids. But especially younger children may have more than what their body can handle in a social environment. Please pay attention so they do not eat too much sugar/carbs.

Typical likes and dislikes

This is variable and may depend on what was consumed in previous meals or their condition.

Likes

Cheese, yogurt, sausage, bacon, beef jerky, salmon, tuna, chicken, tofu, egg, nuts, butter

Dislikes

Pasta, rice, bread, buns, jam, sweet beans, honey, candy, fruit juices, energy drinks