

# EDUCATOR'S GUIDE TO SEVERE MTHFR

(SEVERE METHYLENE TETRAHYDROFOLATE REDUCTASE)



## What is Severe MTHFR?

Severe MTHFR is a very rare genetic condition and it occurs when the body is unable to process certain amino acids (building blocks of protein) properly. Severe MTHFR causes a buildup of the Homocysteine (HCY) and a deficiency in the amino acid, methionine. In severe MTHFR, the enzyme methylene tetrahydrofolate reductase does not work at all. This is one of the disorders known as a remethylation defect since the conversion of HCY to methionine requires vitamin B12 (cobalamin) and conversion of the vitamin folate to methylfolate (which is the actual role of the enzyme methylene tetrahydrofolate reductase in this process).

There are two common variations of MTHFR which, in most populations, at least 30% of people have. It has made the news since at one time it was associated with many diseases. In most cases, the common variants of MTHFR do not cause problems (if they did, we would see these problems much more commonly given that so many people have these variants or in this case polymorphisms). Rarely do people with the common variants have problems with higher HCY, but usually this is due to vitamin B12 deficiency or folate deficiency and so supplementation can help.

## How can I help?

**Teach** your student as you would anyone else. Your student with Severe MTHFR may need additional time or attention to keep pace with the classroom. Some may have visual impairment and need visual support.

**Help** to ensure that your student takes their medication(s). Peer pressure may cause children to struggle to take their medication, or avoid it.

**Communicate** with parents and ask questions. Since you spend a fair amount of time with your student, you may be the first to notice issues related to HCU. Successful HCU management will rely on both parents and school staff communicating with each other.

## How can HCU affect the body?

The buildup of homocysteine levels can have **dangerous** and **life-threatening** impacts.

High homocysteine levels may cause:

- Feeding Difficulties, Vision Problems
- Seizures
- Poor Muscle Tone and Coordination
- Developmental Delay, Microcephaly
- Cerebral Atrophy, Neurological disorders
- Blood clots or strokes



Treat them the same as your other students. Your student is not sick and shouldn't be treated as such. If they follow their medication regimen they can be just as successful as their classmates

Patients **can't** feel when their HCY levels are high (unlike a diabetic who can feel when their insulin is low/high). Regular blood draws are required to manage medication and mitigate negative effects. Symptoms usually occur after a prolonged period of high homocysteine levels. Levels increase gradually, they do not spike suddenly.



Individuals with severe MTHFR can have strokes. If you are concerned that your student is actively having a stroke (symptoms include but this is not an extensive list: sudden confusion, loss of skills, difficulty communicating, one-sided weakness or facial droop), please seek immediate medical attention. If you feel that your student has had a stroke (in the recent or not so recent past), promptly discuss this with their parent.



# EDUCATIONAL ACCOMMODATIONS



Children with Severe MTHFR *may* experience challenges at school. It is important to meet with the student and their family prior to the beginning of the school year to discuss what, if any, accommodations may be needed to ensure the student's educational success. These accommodations may be in the form of a 504 plan, IHP or IEP, depending on the student and their needs.

**Severe MTHFR impacts the whole body. Some students may need additional services.**

- Vision Itinerant
- Reading Help
- Speech, OT or PT
- Counseling
- Occupational Therapy
- Protection from bullying



Ensure that ALL teachers and staff members are aware of the students' condition and accommodations. (related arts, school nurse, administrators, cafeteria staff, etc)



If the student rides a bus, you may need to make the accommodations available to their bus driver.

# CLASSROOM ACCOMMODATIONS

- Preferential seating
- Modified textbooks or audio-visual materials
- Oral test and visual aids
- Low vision Accommodations
- Easy access to bathroom and/or nurse
- Accommodations for fine and gross motor activities
- Assisting with self-help skills
- Access to assistive technology

# OTHER ACCOMMODATIONS TO CONSIDER



- ✱ Your student may need to establish a time during the school day to go to the school nurse for medication.
- ✱ If necessary, please allow your student to consume an approved snack before taking medication as it helps alleviate nausea and stomach pain.

**Even though Severe MTHFR is a metabolic disorder, your student should not need a special diet. Check with your students guardian to make sure snacks given out during parties are okay.**

**Communication is key!** 

Don't hesitate to ask questions and reach out to your student's parents should you notice anything that seems 'off' with your student.

