Dear Alice,

After many years of confusion, I have been diagnosed with trimethylaminuria. It is an awful disease that has caused much emotional pain in my life. I was hoping that if the disease was discussed on your site that people's awareness may increase and perhaps people would not be quite so quick to judge others. I would appreciate it if you could post my message for this reason. Also, if the disease is caused by the lack of a certain hormone in my body, then would an injection of this hormone be a possible solution? In all of my research, I have not seen this discussed.

Answer

Dear Reader,

Dealing with trimethylaminuria certainly has its difficulties, but you aren’t alone. For those who are unfamiliar, this genetic condition occurs when the body isn’t able to break down trimethylamine (a naturally occurring dietary compound) and causes individuals to give off a fishy odor. Many people with this disorder experience depression as a result of disruptions to their social life, relationships, or career. Though there’s currently no cure or treatment (such as a pill or injection), there are some strategies for minimizing trimethylamine in the system, thereby reducing the symptoms. Seeking assistance from a health care provider and mental health professional may help to manage this condition and feelings of isolation and embarrassment often associated with it.

First, a little more background on trimethylaminuria: this condition is thought to be caused by mutations in the FMO3 [2] gene, which normally produces an enzyme that converts fishy-smelling trimethylamine into an odorless molecule. It’s believed that the condition is inherited, meaning both parents are carriers of the altered FMO3 gene and pass it along. When the FMO3 gene isn’t working properly and trimethylamine isn’t processed, it has the potential to accumulate and cause the body, breath, sweat, and urine to smell strongly of fish. Trimethylaminuria seems to be more common among individuals assigned female at birth. In fact, there’s evidence to suggest that it’s linked to the levels of progesterone and estrogen in the body as the condition worsens around puberty, before and during menstrual periods, while taking oral contraceptives, and during menopause — all times when these particular hormones levels are higher. Both the type
of FMO3 mutation and lifestyle factors such as stress and diet seem to influence the duration and severity of symptoms.

To help manage these symptoms, you might consider talking with your health care provider about trying these management strategies to mitigate symptoms:

- Avoiding foods containing trimethylamine and its precursors such as:
  - Milk obtained from wheat-fed cows
  - Eggs
  - Liver
  - Kidney
  - Peas
  - Beans
  - Peanuts
  - Soy products
  - Brassicas (e.g., Brussels sprouts, broccoli, cabbage, and cauliflower)
  - Lecithin and lecithin-containing fish oil supplements
  - Seafood (freshwater fish have less trimethylamine N-oxide)
- Taking low doses of antibiotics or using laxatives to reduce the amount of trimethylamine produced in your gut
- Taking activated charcoal or other supplements to decrease the concentration of trimethylamine in your pee
- Using body soaps with a moderate pH (between 5.5 and 6.5)
- Taking riboflavin (vitamin B2) supplements to enhance FMO3 enzyme activity (recommended intake is 30 to 40 milligrams taken three to five times per day with food)
- Avoiding activities and conditions that might make you sweat (e.g., physical activity and stress)

List adapted from the National Human Genome Research Institute [3].

Although the condition is caused largely by a missing enzyme, at this time, replacement therapy for FMO3 isn’t an approved treatment. The good news is that you don’t have to manage trimethylaminuria on your own — it’s wise to partner up with a health care provider. This is because mixing medications and supplements may have undesirable or unintended results and dietary restrictions may result in nutritional deficits. Further, it’s recommended that those with this condition who are pregnant or breastfeeding consult with their medical professional before making any dietary changes. Dealing with the symptoms of this disorder may also be emotionally challenging, but working with a mental health professional may provide some support in this way for folks living with this condition. You may find Types of therapists [4] and How to find a therapist [5] in the Go Ask Alice! Emotional Health [6] archives to be helpful if you’re looking for more information about navigating mental health resources. Thank you for bringing more awareness of this condition to others!

All the best going forward,

Alice!

Category: