

Diet Guidelines for people taking Miglustat

Can Miglustat cause gastrointestinal disturbances?

Diarrhea, gas, bloating, abdominal pain or discomfort, nausea and vomiting are symptoms often reported by people taking Miglustat. These symptoms are usually mild or moderate and generally decrease over time. Side effects are the worst in the first weeks/months of being on the drug and usually get better after about 3 months.

What is the cause of these symptoms?

Miglustat stops the intestinal enzymes that break down disaccharides (mainly sucrose, maltose, and to a lesser amount lactose) from working. These disaccharides (sugars) are not digested and absorbed properly, and stay in the gut. This can cause diarrhea. These sugars are also “food” for the bacteria in your gut and are fermented, producing gas. This also means your body doesn’t absorb these sugars and you aren’t getting the calories from them.

What can I do to minimize these symptoms?

- Take Miglustat separately from meals (e.g. 2 hours before or after meals)
- Start dietary changes at least 3 days (up to 2 weeks) before you start taking Miglustat
- Consider gradually increasing your dose (as recommended by your doctor)
- Eat a diet low in disaccharides (sucrose, maltose, and to a lesser extent lactose)

**Miglustat absorption is not affected if you have diarrhea as it is rapidly absorbed in the gut after it is taken

What is a disaccharide?

Disaccharides are two monosaccharides (single sugars) joined together.

Examples of disaccharides:

- Sucrose (table sugar) is made up of glucose and fructose joined together.
- Maltose is glucose and glucose joined together.
- Lactose (or milk sugar) is a galactose and glucose joined together.

What is a low disaccharide diet?

It is a diet low in sucrose, maltose, and lactose.

Reduce disaccharides to <5g per meal. Look at the sugars on the nutrition label and the ingredient list to get an idea of how much disaccharide is in a food.

Avoid eating foods high in disaccharides (sucrose and maltose)

Desserts: cookies/biscuits, cakes, pies, puddings, custard, ice cream, sweetened yogurt

Certain fruits: bananas, dates, peaches, apricots, pineapples, mangos, tangerines, dried fruits

Additives/condiments: molasses, sugar, chocolate, jam, marmalade, honey, Nutella, sugar-based syrup

Avoid high-carbohydrate drinks such as naturally sweetened soft-drinks, sweetened fruit juices, and alcohol-containing drinks (beer/wine). Fructose-containing food and fruit drinks, and artificially sweetened soft drinks may be consumed.

Reduce dairy intake (milk, cream, yogurt, cream cheese)

- Lactose-free and soy based products can be used to replace milk and yogurt
- Unsweetened and/or soy based yogurts allowed
- Ensure you are meeting your calcium and Vitamin D requirements from diet and/or supplements

Reduce intake of starchy foods as the body naturally produces maltose (a disaccharide) as it digests foods such as bread, breakfast cereals, legumes, potatoes, corn, rice, beans, pasta and other grains.

- Avoid large servings starchy foods at one time
- Spread out your intake of starchy foods over the day

If GI symptoms continue, intake of starchy foods may need to be more severely reduced, and then slowly re-introduced one-by-one over several weeks/months.

Will I always have to be this strict with my diet?

As your gut adapts to miglustat therapy and symptoms improve, you may be able to slowly re-introduce foods back into the diet. This would be done slowly and would be based on your tolerance.

What about eating out/special occasions?

For parties or social occasions where it is hard to avoid high disaccharide foods (e.g. birthday cake) consider taking Imodium. Imodium increases the amount of time that food remains in the gut, improving carbohydrate digestion and absorption. This may limit diarrhea and abdominal pain.

Will I lose weight?

Ideally we do not want you to lose weight on Miglustat (assuming you are at a healthy weight to start with). It is very important that you maintain an adequate calorie intake while taking Miglustat.

If you are getting less calories from carbohydrates, then you will need to get these calories from protein and fats.

Protein Sources: non-breaded meat/fish, eggs, tofu, nuts and seeds

Fat Sources: oils, margarine, and avocado

You may need to snack more often.

Monitor your weight regularly (e.g. at least once a month). Let your doctor, nurse or dietitian know if you are losing weight.

Can probiotics help with my symptoms?

Probiotics (e.g. live cultures in yogurt) may help. There has not been a lot of research done about this. Taking probiotics, which deliver helpful bacteria to the gut, might help with symptoms while on Miglustat.

Probiotics that break down disaccharides seem to be helpful. One study showed Tilactase and Lactobacillus reuteri improved symptoms related to eating lactose people who were lactose intolerant.

References:

1. Belmatoug, N. et al. Gastrointestinal disturbances and their management in miglustat-treated patients. JIMD (2011) 34:991-1001.
2. Helping yourself with healthy choices – Zavesca.