

All questions answered by Wendy Busse, except where indicated.

## Q: Can you help script a response for people to use when patients are in a social setting and declining to eat the food provided?

A: Thank you very much, but I'm going to pass. I tend to have strong food sensitives, so I try to eat before I come to functions. It seems a better idea then disrupting your wonderful party with an EpiPen and an ambulance. © [Use a question or statement to shift the conversation to something else. e.g. You must have spent days preparing all of this!]

A: Everything looks lovely, but I think I'll refrain. I'm prone to food sensitivities and sometimes there's hidden culprits in the places you least expect them. I ate before I came so I'm good, thanks. [Use a question or statement to shift the conversation to something else. E.g. Gosh, I haven't seen Lisa in ages!]

A: Thank you, I sure wish I could. I tend to have sensitivities to certain foods so I think I'll play it safe, join the conversation and leave the delicious food to you guys. [Use a question or statement to shift the conversation to something else.]

Answered by MSC.

## Q: How would you recommend reintroducing foods that have been out of your diet for a long time? i.e. gluten, dairy

A: Everyone is a little different and needs an individualized plan. Here's a few tips:

- 1. Introduce foods systematically. Haphazard reintroductions usually do not go well.
- 2. Start with a small amount and work up slowly.
- 3. Consider a rotation reintroduction if food reactions seem to build up for you. For example, eat the new food once every three or four days.

If you need further help, consider <u>booking an appointment with me</u>. I develop individualized reintroduction plans for clients and support them through the process.



Q: After identifying food triggers and eliminating them from my diet for two years, I am now able to tolerate small amounts of previously identified triggers. Why does this happen? Is it temporary or can I count on safely adding them back in?

A: One possibility is that introducing the food very slowly helped your body develop tolerance. When I help clients reintroduce foods, we always start with small amounts and work up. I would suggest continuing to eat the new food and gradually increase the portion size. For many people, food is better tolerated if they eat it a few times per week, rather than every day

Q: If a food seems to have triggered an intense reaction when ingesting a small amount, would you recommend trying to reintroduce it? If so, how would you go about doing this? I haven't consumed it in a couple of years.

A: I would strongly suggest talking with your allergist or mast cell disease specialist about a medically supervised food challenge. If that is not possible, talk with your physician about doing a food challenge in a hospital cafeteria. Bring a book and hang out for a few hours. If an epinephrine autoinjector has been prescribed, bring it with you. You will most likely tolerate the food, but it is good to be safe!

Q: Do you have any advice on how I can maintain a balanced diet when I have to eat a gluten free, egg free, low histamine and low salicylate? Any supplement recommendations? (These foods, especially salicylates, have been proven to trigger my symptoms and also produce high blood levels of Tryptase).

A: A multivitamin and mineral supplement is a good idea for everyone, especially when you are on a restricted diet. You may have already done this, but explore the many alternative foods, such as wholesome gluten-free grains. Consider making an appointment with a registered dietitian to review your diet.



Q: How do I get over the fear of trialing a food? My reactions are mostly respiratory, and involve rescue meds and possibly a trip to the ER. I can't try new foods when I'm home alone, but when my family is here they aren't keen for me to try because they worry. So, I end up eating the same things.

A: Fear is understandable when you have experienced severe reactions. If your physician has not prescribed an epinephrine autoinjector, you may want to check into this. Please see the answer above about reintroducing food. If you decide not to try new foods, you can make your limited diet more interesting with creative preparation.

## Q: How do I help family and friends accept my food intolerances and not feel fearful of sharing food with me?

A: That's a difficult question to answer without knowing more about your situation! If your physician has prescribed an epinephrine autoinjector, make sure you have it available. Your family may be more comfortable if they can practice with a training device.

Q: Do you have any good strategies when going out to eat? It can be very embarrassing to ask so many questions of the host or the waiter/waitress. It can make everyone feel tense, yet I can't risk a severe reaction.

A: I would suggest calling the restaurant and speaking with the manager or chef that will be working when you arrive. If you call between meal rushes, they usually have time to talk, and you can decide what you will have. When you arrive, discretely confirm your order with the manager.



## Q: Will you be sharing a list of low histamine foods? Or high histamine foods to avoid?

A: The low histamine diet is a guideline, not an exact science. More information is available from https://wendybusse.com/hit-and-mcd/

# Q: In your presentation, you asked us if we research reputable websites for information on mast cell disease. Which websites would be considered reputable?

A: The following websites are great resources when seeking information:

- Mastocytosis Society Canada, of course! (www.mastocytosis.ca)
- The Mastocytosis Society (<a href="https://tmsforacure.org/">https://tmsforacure.org/</a>)
- My website (<a href="https://wendybusse.com/hit-and-mcd/">https://wendybusse.com/hit-and-mcd/</a>) Note: I will be updating this section at the end of March.
- MastAttack by Lisa Klimas (https://www.mastattack.org/)

Answered by MSC.

## Q. Are there specific dietary or supplement recommendations for those of us who also have Autism & ADHD?

A: Neuroprotek is promoted for mental health aspects of mast cell disease, but like all supplements, the research is limited. When you trial new supplements, make one change at a time, so you know what is working.

Q: In dealing with the loss of food as a source of pleasure, how do you suggest dealing with others/societal pressures to eat? I find so much of our culture is focused on eating it's very difficult to join in group activities that are focused around food.

A: Please see my blog post - Holiday Eating with Food Sensitivity.



Q: Are there any current research studies to better understand the how food acts as a trigger in mast cell disease?

A: I am not aware of any research in this area. Hopefully, there will be some in the future.

#### Q: Which lab conduct testing for mast cell disease?

A: Labs that conduct testing such as Serum Tryptase, 24 Hour N-Methylhistamine Urine and others vary from province to province. MSC has not yet put together a comprehensive list of which tests are available at the various labs. This initiative is on our long-term plan for MSC.

However, in the upcoming months, mast cell experts from across North and South America will convene to discuss Mast Cell Centres of Excellence. I'm hopeful information on mast cell testing will be a topic and plans to standardize testing are discussed.

Answered by MSC.