Mast Cell Disease & Food Trauma

Bonnie Nasar RDN
Registered Dietitian Nutritionist

www.nasarnutrition.com
I have Ehlers Danlos Syndrome (hEDS) and Postural Orthostatic Tachycardia Syndrome (POTS)
I have 4 children, 2 of which have Cutaneous Mastocytosis
Specializing in nutrition management of Mast Cell Disease, EDS, POTS, and Gastroparesis is my passion in life
Fear of Food and Food Trauma
Fear of Food

- Avoiding food because it might make a person feel sick
- Previous encounters with food caused symptoms
- Losing interest in eating
- Feeling sick just looking at food
Food Aversions

- A strong dislike of a particular food
- The site, taste, or smell of the food makes you have a gut reaction
- This is a physiologic reaction of your brain to a specific food
What does this look like in real life?

- Skipping meals
- Avoiding going to dinners or parties with friends and family
- Eating alone
- Having on a few foods considered “safe” to eat
ARFID

- Avoidant Restrictive Food Intake Disorder
- Avoiding many foods or entire food groups in the absence of body dysmorphia
- Considered an Eating Disorder
- Three types:
  - Sensory sensitivity- avoiding specific textures
  - Fear of adverse consequences - vomiting, gagging, etc
  - Lack of interest in eating
OSFED

- Other Specified Feeding or Eating Disorder
- When a person does not fit other criteria for disordered eating, but has an symptoms or signs of issues with eating
Food Trauma

- What category of disorder is fear of food because it ACTUALLY makes you sick fall into?
  - none that I am aware of
  - Food Trauma- when your brain is telling you that your stomach doesn’t want something because it hurt you at some point before
Brain and Gut Connection

Your brain and your gut communicate!
Why we need food

- Gut microbiota
- Eliminating large groups of foods can negatively impact gut bacteria
- This results in less SCFAs being made in the gut
- SCFAs help to inhibit mast cell activation
- Limiting diet can actually lead to an increase of symptoms
Mast Cell Bucket

When too many triggers happen in one day, our buckets can fill up and spill out.
Mast Cell Bucket

On good days, you can keep your bucket from overflowing, and even include “sometimes” food items!
Where do you begin?

- Food and Symptom Diary for 1-2 weeks
- If using an app, what nutrients appear to be missing?
- What food groups seem underrepresented?
- What foods do you miss the most?
What tools do you need?

- An app for tracking or a notebook
- A list of foods you are most willing or wanting to try
- A device for checking your heart rate
- A mental health care worker for support
- A dietitian for support
How do I try a new food?
Just kidding! Do not copy cookie monster!

1. Decide what food you would like to try

2. Check resting heart rate

3. Put new food on your plate with the rest of your meal

4. Look at the new food and note any heart rate change

5. If heart rate increases over 10 points, your body is talking to you!

6. If heart rate is not changed, try new food
Three day rule

- At minimum, try one new food item every 3 days as long as no negative effects
- Keep a food and symptom diary to watch for any symptoms
- First day, try a small amount- a spoonful or whatever amount does not invoke any food trauma or anxiety. If it needs to be the size of a pea, start with that
- Increase the amount each day (if no negative effects) until you reach a full portion
Progression

- Keep a list of foods you are wanting or willing to try
- Make a list of the foods you have tried and were successful with
- The more you progress, the easier it will get
- Move at a pace that is comfortable for you
- If you are having a bad day, whether mentally or physically, it is okay to halt progress and wait
- If you find it difficult, reach out for help from family, friends, or a professional
Things to keep in mind:

- If you are trying a new medication, it is not the right time to try new foods too.
- If you cannot bring yourself to even try a pea-sized amount, it may be time to bring a licensed mental health care and registered dietitian on board to help.
- Look at other things, besides food, that can be causing reactions. Environment, cleaning agents, soaps, etc.
Fear of food is real

- You are heard
- You are validated
- It can be scary

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Fear of food is real

- You deserve to eat happily
- Your body needs a variety of nutrient dense foods for optimal health
- A colorful Mediterranean diet is ideal
Thank You!

I could not be doing all that I do without the love and support from my husband and children.