

Malnutrition & MCAS

Nourishing Health and Happiness with MCAS



Disclaimers

Trigger warning - this document is about food and contains images of food.

We recognise that many of the images in this guide contain foods that are restricted on low histamine diets. The images are from stock photos and do not exactly reflect a low histamine diet.

We have done our best to reduce references to high-histamine foods wherever possible.

Everyone with MCAS is different, and this is general information, not tailored to your individual needs. This resource is intended to be used alongside support from a qualified health professional. Please seek advice from your medical practitioner or dietitian for specific dietary guidance.

We hope you will be confident to adapt the guidance and recipes for your circumstances, and swap out foods that you are not able to tolerate for others that you are. This sheet is designed for adults with Mast Cell Activation Syndrome. The nutritional needs of children and teenagers will differ, and the nutritional needs of individuals with specific medical conditions will vary.

If your diet is very limited and you feel that you are struggling to get enough nutrients in your diet or have a specific medical condition that may have specific dietary needs, then please ensure you seek individualised dietary advice from a dietitian with experience in this area.

This resource is designed to support, not replace, tailored advice from your medical team.

For more information about low histamine diets and other dietary adjustments, please see our Self-Management Toolkit HERE



Introduction

Why Does Diet Matter?

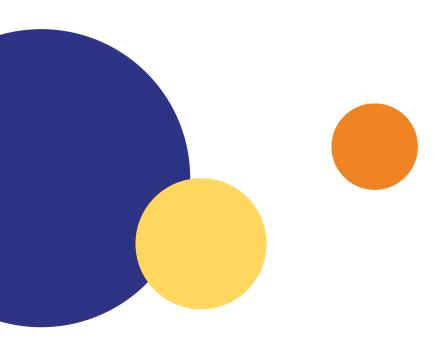
Diet plays a really important role in helping those with MCAS, but can also be one of the trickiest areas to navigate, as those with MCAS often have dietary triggers.

What you eat can directly influence mast cell behaviour and histamine levels in the body.

Common Dietary Challenges with MCAS

People with MCAS often face considerable challenges with food, including:

- Food sensitivities and intolerances: MCAS can cause reactivity to a wide range of foods.
- Variable and evolving triggers: Food triggers can change over time or vary based on other factors such as stress, hormone levels, illness, or environmental exposures.
- Digestive issues: Symptoms like bloating, nausea, abdominal pain, and altered bowel habits are common and may require additional dietary adjustments.
- Nutritional adequacy: Due to multiple food restrictions, maintaining a balanced, nutrient-rich diet can be difficult without careful planning.





We don't currently have specific statistics on how many people with MCAS experience unintentional weight loss or maintain a low body weight due to their symptoms. However, many healthcare professionals working with our community report seeing this challenge frequently.

In fact, our 2023 survey found that 41% of people with mast cell disorders limit their diet to 20 foods or fewer in an effort to manage their symptoms. (1)

How do I identify if I've become malnourished?

Malnutrition refers to deficiencies or excesses in nutrient intake, an imbalance of essential nutrients, or impaired nutrient utilization. (2)

In this section, we will be talking about deficiencies in nutrient intake, including protein, energy, and vitamins and minerals.

Common signs of malnutrition include:

- Unplanned weight loss
- Loss of appetite lack of interest in food and/or drinks
- Loss of muscle strength
- Tiredness
- Alterations in mood (3)

Why is it important to stop unintentional weight loss or improve body weight when it is low with MCAS?

Malnutrition can:

- increase the risk of illnesses and infection
- slow wound healing
- lead to low mood, reduce energy levels, and reduce quality of life
- reduce muscle strength

HELPFUL TIP

Create a shopping list of safe foods and ingredients to take shopping with you



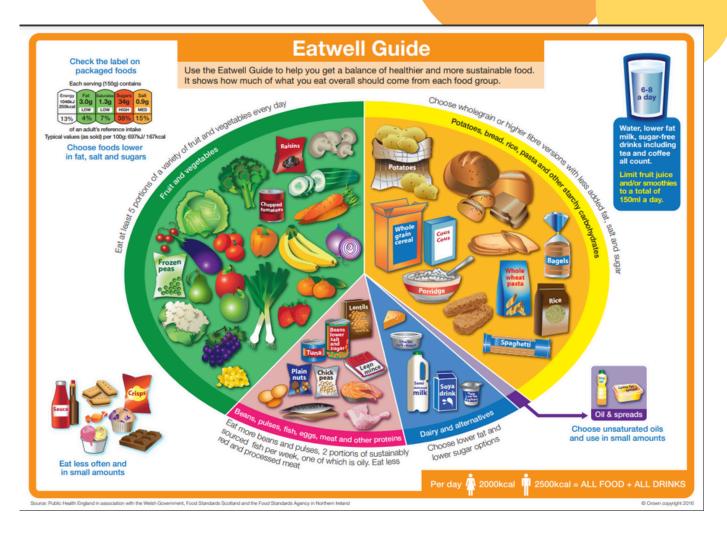
Studies have shown that malnutrition can make immune cells more active and increase inflammation in the body. For people with MCAS, this often means that the more malnourished they become, the more symptoms they may experience. (4)

In addition to that, some vitamins and minerals are needed to support the histamine breakdown pathways in our bodies, so if we become deficient in these we may not be able to break down the histamine in the food we eat as well as we could. (5, 6)

How to prevent malnutrition with MCAS

Try to aim for a balanced diet as shown in the Eatwell Guide. This may be more challenging depending on your dietary triggers. If you are struggling to achieve this, please consult a registered dietitian, who will be able to provide support.

Take opportunities to add in nutritious foods wherever you can - not just cutting foods out





What to do if you suspect that you are malnourished and have MCAS

If you suspect you may be malnourished, connecting with a registered health professional is a key step to getting appropriate help.

To gain weight, you need to consume more calories than your body uses. If your appetite is small, increasing portion sizes at meals can be challenging, so including energy-dense foods or drinks and eating smaller meals more frequently can be helpful.

Here are some tips on how to increase your energy and protein if your appetite is low:

- Try and eat every 2-3 hours.
- Have nourishing drinks between meals such as milkshakes (can be made with alternative milks if needed), smoothies, milky hot drinks, e.t.c
- Ready-to-drink build-up drinks can be purchased without a prescription and supply energy, protein, vitamins, and minerals.
- Add extra oils such as olive or rapeseed oil (or any that you tolerate) to foods such as salads and vegetables as a dressing.
- Add nuts and seeds (whole, ground, or as nut butters) to toasts, cereals, salads, or smoothies.
- Add cheese or plant-based alternatives to foods such as cooked meals, soups, and salads.
- Ensure that you have a protein source at each meal, such as meat, fish, nuts/seeds, or beans and pulses.



- If you can tolerate milk, then you could try making 'fortified milk': Add 2 to 4 tablespoons of skimmed milk powder to 1 pint of milk and whisk well. Use this milk in place of ordinary milk as a drink, in cooking, on cereals, and in hot drinks.
- Add extra oils such as olive or rapeseed oil (or any that you tolerate) to foods such as salads and vegetables as a dressing.
- Add nuts and seeds (whole, ground, or as nut butters) to toasts, cereals, salads, or smoothies.
- Add cheese or plant-based alternatives to foods such as cooked meals, soups, and salads.



MAST CELL ACTION

We recognise that each person with MCAS has unique triggers, and what works for one may not work for another. You might find that you're unable to follow some or all of the tips here. This sheet is intended as general guidance and does not replace personalised advice from a healthcare professional.

For additional tips, advice, and recipes on gaining weight while following elimination diets like low histamine or dairy-free, please see the dedicated sections in this pack.

- References
- 1. Jennings SV, Slee VM, Finnerty CC, Hempstead JB, Bowman AS. Symptoms of mast cell activation: The patient perspective. Ann Allergy Asthma Immunol. 2021;127(4):407-9.
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- 5. Hrubisko M, Danis R, Huorka M, Wawruch M. Histamine Intolerance-The More We Know the Less We Know, A Review, Nutrients, 2021:13(7). 6. Harris CI, Nasar B, Finnerty CC. Nutritional Implications of Mast Cell Diseases. J Acad Nutr Diet. 2024.



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