Advocating for yourself on the NHS

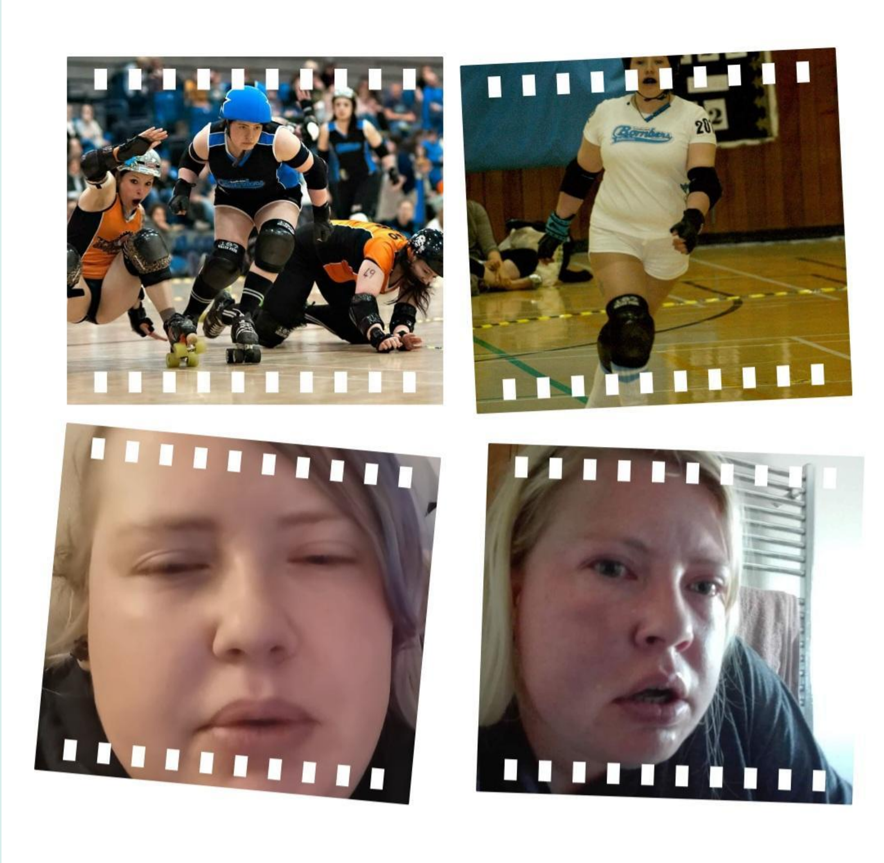
by Vicky Pearson, on behalf of MCAS Action

Introduction

- What we'll cover
- Key takeaways
- Questions

Vicky’s MCAS journey and experience - Symptoms & Struggles

- Lifelong symptoms, including migraines and stomach upsets.
- Previously an international competing athlete with a health focused diet. Was vegetarian, but found I had issues with it.
- Serious car accident in 2012 led to serious lifestyle restrictions.
- Medication mix up and misdiagnosis, led to medical complications and Serotonin syndrome in 2017. Misdiagnosed Fibromyalgia.
- Resulted in living in a day bed, unable to leave the house, daily regular vomiting and 'Migraines', skin sores, swelling around eyes. Despite not eating and being straw fed dietry milkshakes I was 18 stone.
- Had home carers employed by social services as I could no longer take care of myself.
- Ignored by Drs, told to eat less and go out for a walk despite not eating solid foods.



Vicky's MCAS journey and experience - Finding MCAS

- Was picked up by Jenn Brea, after a desperate call for help in a support group and added to one of her early research groups on MCAS, as the first Brit/international member.
- Researched and researched. Started video diaries on her suggestion. Moved GP practice and went into my new GP armed with evidence and research.
- Forced through an immunology referral, despite resistance.
- Immunologist denied MCAS was a real condition. I countered with my videos, photos and diaries. I informed him of the medication I needed (hs1 hs2 receptors, etc) and demanded that I trial the medication for changes. (The only way to get diagnosed at the moment)

Vicky’s MCAS journey and experience - Changes

- Lost 1 stone in swelling within 1 week of starting medication. Within a month I had lost 2 stone. Within 12 months I had lost 4 stone. I have now lost 6 stone in total of allergy reaction fluid from under my skin.
- Full video diary evidenced. Had to go through cancer screening, as the weight loss was so dramatic. I now have stretch marks, even on my face.
- Through process of elimination, I discovered a 'Severe!' Soy reaction. Plus milder gut reactions to all super processed foods, E numbers and ingredients.
- Discovered I have a heart condition, triggered by MCAS flares that causes Pulmonary Edema and a 'Very High' BPM. I can now monitor an MCAS flare by checking my BPM rises.
- My migraines were not migraines, but anaphylaxis. I managed to photograph myself in anaphylaxis to prove it was real. Found asprin instantly relieved neck pain, I had assumed was associated with my car accident injury, but was heart related.

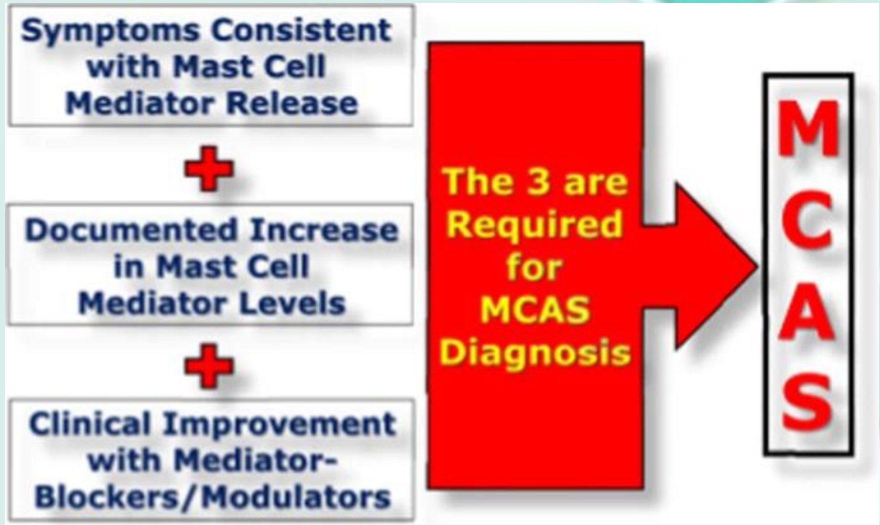
Vicky’s MCAS journey and experience -Now

- My immunologist in December 2023, confirmed that he believes I have MCAS as the results from the medication trials were astonishing. It was the first diagnosis he has confirmed and his attitude towards MCAS and my situation, changed immensely.
- I am still in recovery, I am still losing swelling and have discovered after the swelling reduced, that I have EDS symptoms that were hidden previously.
- I am finally rebuilding my career and accessing society again, after 12 years of decline.
- I am working with a business partner, to develop a diagnostic assistance tool, for chronically ill patients, to take greater ownership of their own health in an accessible way. We are hoping to build this to work alongside and with the NHS as a support.

She Roars
MARKETING

NHS attitude toward MCAS and how it impacts patients

- No NICE guidelines for the NHS on MCAS.
- MCAS is listed on the CDC in America and the National Organisation for Rare Diseases.
- There are currently no NHS funded MCAS testing facilities in the UK.
- MCAS can be mistaken as a mental health issue, by some Dr's.
- Proving you have MCAS on the NHS, requires a lot of evidencing and a long testing period on MCAS medication, to be accepted.



Symptoms Consistent with Mast Cell Mediator Release

+

Documented Increase in Mast Cell Mediator Levels

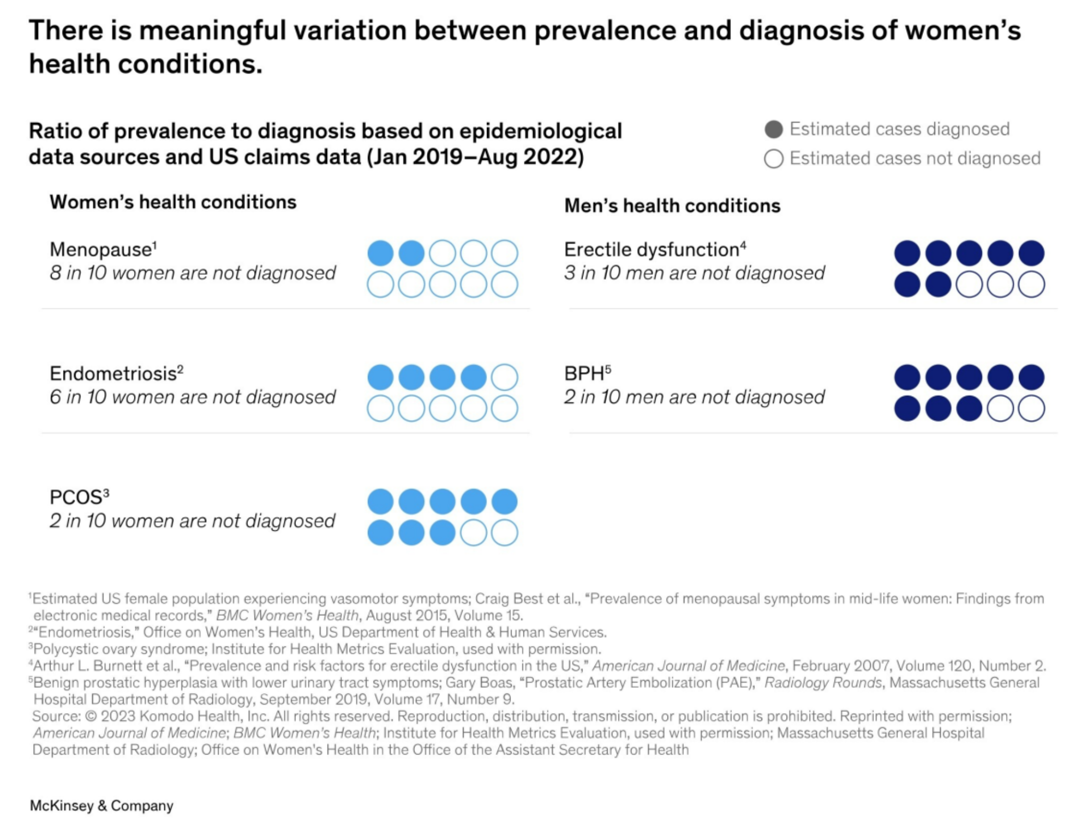
+

Clinical Improvement with Mediator-Blockers/Modulators

The 3 are Required for MCAS Diagnosis

MCAS

How gender bias may impact your experience



There is meaningful variation between prevalence and diagnosis of women's health conditions.

Ratio of prevalence to diagnosis based on epidemiological data sources and US claims data (Jan 2019–Aug 2022)

● Estimated cases diagnosed
○ Estimated cases not diagnosed

Women's health conditions

Menopause[1]
8 in 10 women are not diagnosed

Endometriosis[2]
6 in 10 women are not diagnosed

PCOS[3]
2 in 10 women are not diagnosed

Men's health conditions

Erectile dysfunction[4]
3 in 10 men are not diagnosed

BPH[5]
2 in 10 men are not diagnosed

[1] Estimated US female population experiencing vasomotor symptoms; Craig Best et al., "Prevalence of menopausal symptoms in mid-life women: Findings from electronic medical records," *BMC Women's Health*, August 2015, Volume 15.
[2] "Endometriosis," Office on Women's Health, US Department of Health & Human Services.
[3] Polycystic ovary syndrome; Institute for Health Metrics Evaluation, used with permission.
[4] Arthur L. Burnett et al., "Prevalence and risk factors for erectile dysfunction in the US," *American Journal of Medicine*, February 2007, Volume 120, Number 2.
[5] Benign prostatic hyperplasia with lower urinary tract symptoms; Gary Boas, "Prostatic Artery Embolization (PAE)," *Radiology Rounds*, Massachusetts General Hospital Department of Radiology, September 2019, Volume 17, Number 9.

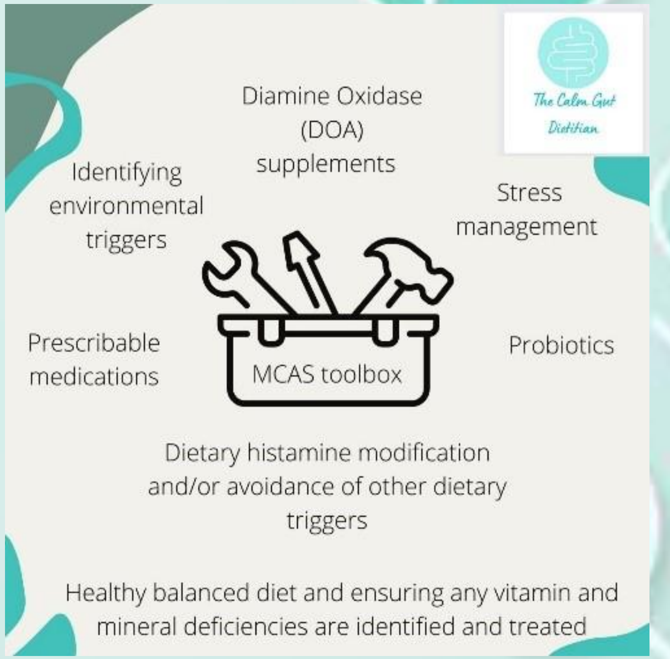
Source: © 2023 Komodo Health, Inc. All rights reserved. Reproduction, distribution, transmission, or publication is prohibited. Reprinted with permission; *American Journal of Medicine*; *BMC Women's Health*; Institute for Health Metrics Evaluation, used with permission; Massachusetts General Hospital Department of Radiology; Office on Women's Health in the Office of the Assistant Secretary for Health

McKinsey & Company

- Medical Gender Bias affects us all.
- Lack of Womens Health Research
- 'Womens Conditions' are less researched and funded.
- Bias towards down playing women's experiences/symptoms
- Womens experiences often dismissed as psychosomatic.

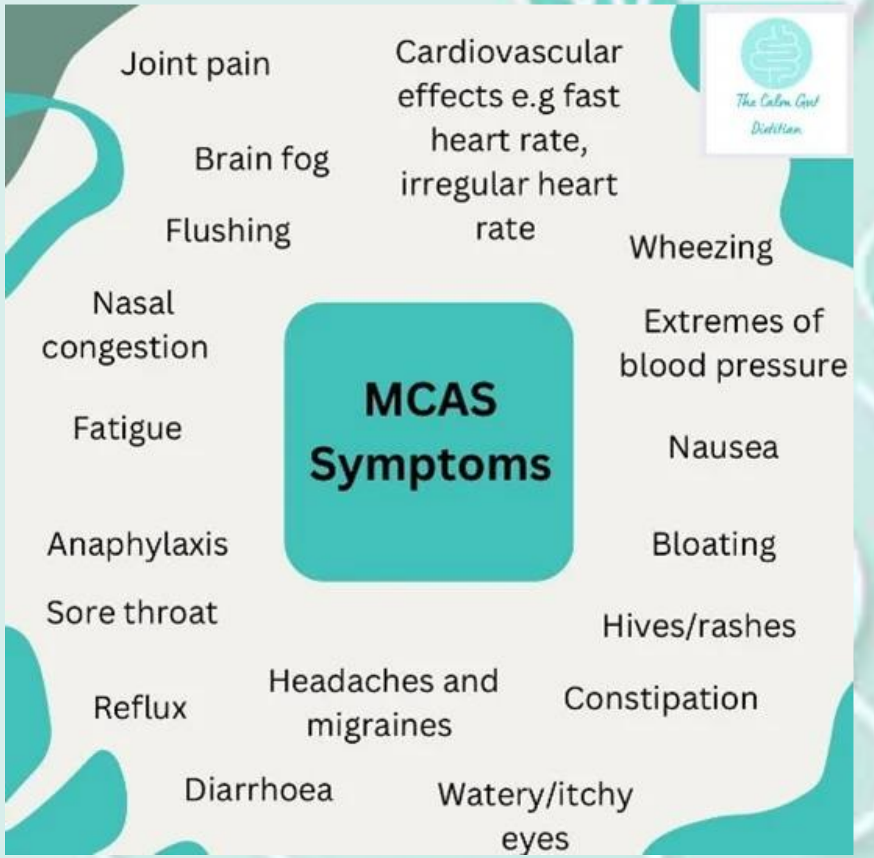
The importance of arming yourself with knowledge

- NHS GP's will likely have no accurate knowledge of this condition.
- Only an Immunologist on the NHS can provide a diagnostic pathway.
- By understanding the process, you can navigate this hole in our care system.
- Right to Choose and your rights.
- Be assertive with your health needs.
- Keeping your symptoms focused onto those that are recordable, measurable and evidencable.
- Research MCAS medication, to ensure you have all receptors and inhibitors, covered.
- Understanding your body, your reactions and your needs.
- Research natural histamine levels in foods. Test and record your reactions.



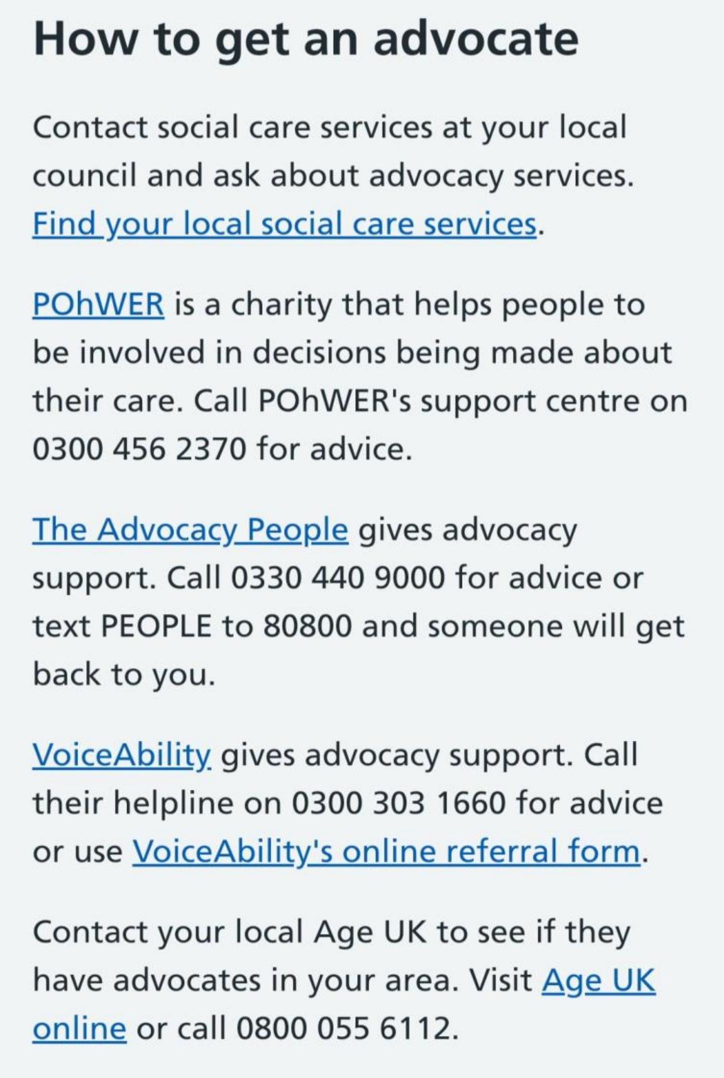
Evidencing and recording your symptoms – my advice from my experience.

- Keep a food diary! - paper, video, photographs.
- Monitor your health reactions before and after potential triggers.
- Break your food right down to basics and re-build and evidence!
- Photograph and video your reactions.
- Create diaries/video diaries of your health, at regular intervals, especially after starting medication.
- Start to monitor your bpm, alongside MCAS reactions.
- Apps available for various services above.



How can I advocate for myself, when I'm feeling so ill?

- Get help from friends and family if you can. For Appointments and monitoring.
- Request an advocate.
- Request an Adult Home Care Assessment from your local Adult Social Services. - Request Direct Payments.
- Write down what you need to say, if speaking is hard.
- Videos and pictures.



How to get an advocate

Contact social care services at your local council and ask about advocacy services. Find your local social care services.

POhWER is a charity that helps people to be involved in decisions being made about their care. Call POhWER's support centre on 0300 456 2370 for advice.

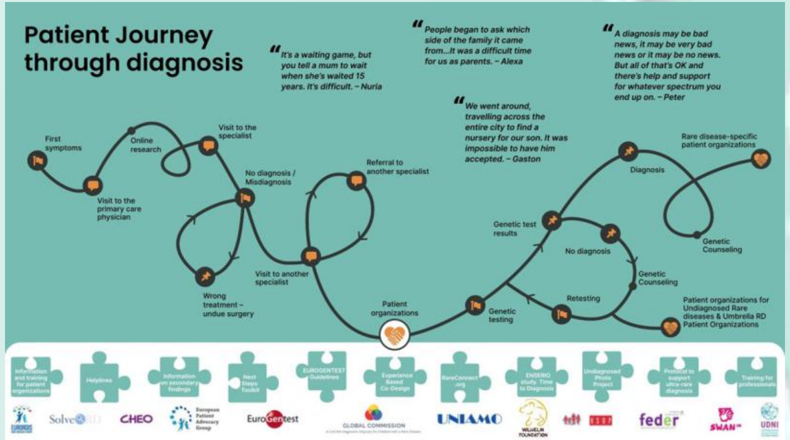
The Advocacy People gives advocacy support. Call 0330 440 9000 for advice or text PEOPLE to 80800 and someone will get back to you.

VoiceAbility gives advocacy support. Call their helpline on 0300 303 1660 for advice or use VoiceAbility's online referral form.

Contact your local Age UK to see if they have advocates in your area. Visit Age UK online or call 0800 055 6112.

Right to choose and pushing through testing requests

- Right to Choose – What is it? - A contingency on the NHS
- insist any refusals are noted.
- You have a right to request a new GP, medical professional or clinic referral.
- Back up all your requests with evidence and records of your health.
- Use the NHS app.



“It's a waiting game, but you tell a mum to wait when she's waited 15 years. It's difficult. – Nuria

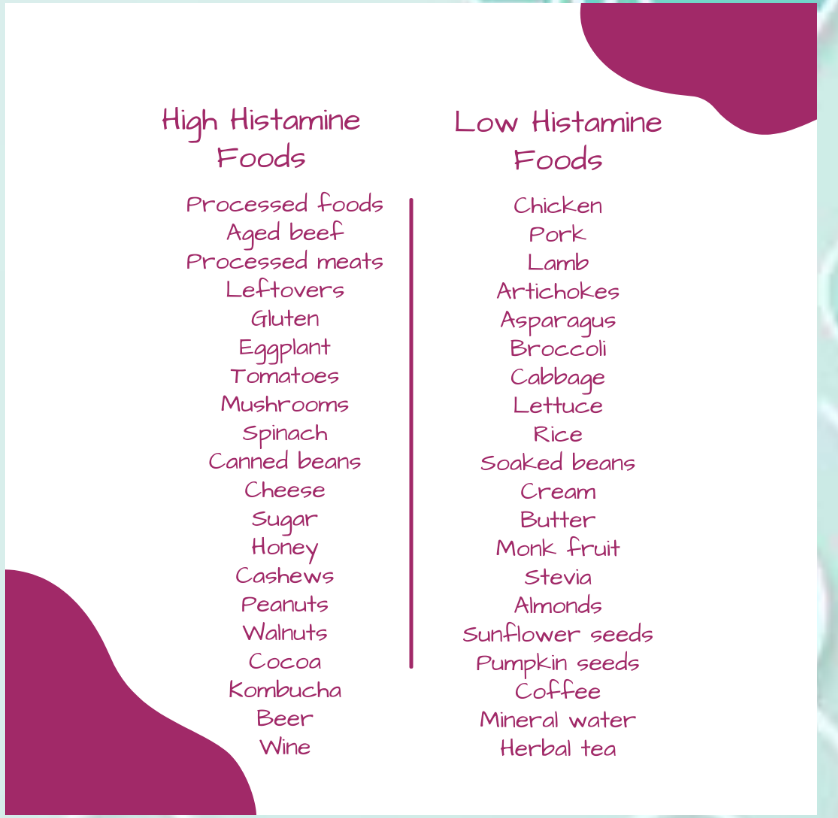
“People began to ask which side of the family it came from...It was a difficult time for us as parents. – Alexa

“We went around, travelling across the entire city to find a nursery for our son. It was impossible to have him accepted. – Gaston

“A diagnosis may be bad news, it may be very bad news or it may be no news. But all of that's OK and there's help and support for whatever spectrum you end up on. – Peter

My experience with my diet and lifestyle

- Taking micro control over environment and diet.
- One size does not fit all, in terms of identifying triggers.
- This is a lifestyle change, not a fad diet.
- Diaries will be essential in tracing back your potential triggers.
- Medication is only one aspect of treatment.
- Without diet change, you will not feel a long lasting recovery.



High Histamine Foods	Low Histamine Foods
Processed foods	Chicken
Aged beef	Pork
Processed meats	Lamb
Leftovers	Artichokes
Gluten	Asparagus
Eggplant	Broccoli
Tomatoes	Cabbage
Mushrooms	Lettuce
Spinach	Rice
Canned beans	Soaked beans
Cheese	Cream
Sugar	Butter
Honey	Monk fruit
Cashews	Stevia
Peanuts	Almonds
Walnuts	Sunflower seeds
Cocoa	Pumpkin seeds
Kombucha	Coffee
Beer	Mineral water
Wine	Herbal tea

Working together with your medical team, moving forwards - my advice

- Although medical professionals will want to help you, many will not have heard of this condition, or had training on it.
- Take control of your own health and medical research.
- Use your diaries and tools to illustrate your situation.
- Be polite but firm with your needs.
- Try to work with your medical team.
- We need to take more ownership of our own medical care and use the NHS as a tool, to assist us.

Did you know? BMA

GPs and their teams are exhausted and losing morale.

No matter how many hours we work, we still can't see all the patients that need our care.

This is why you struggle to see your GP

General Practice is being broken.
We know you deserve better than this.
GPs Are On Your Side.

Thank you!
Any questions?