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Histamine Intolerance (HIT), Mast Cell Activation Syndrome (MCAS) and Long Covid (LC)

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Key messages:

The prevalence of Mast Cell Activation Syndrome (which causes Histamine Intolerance symptoms) is estimated at 17% of the population.¹

This means that we are all seeing many of these patients every day in general practice, A&E departments, and OPDs.

They generally present with, or are labelled as ME, fibromyalgia, acid reflux, IBS, POTS, EDS, food intolerances, urticaria, vestibular migraine, eczema, asthma, rosacea, chronic migraine, facial pain, dysautonomia, severe anxiety, panic attacks, insomnia, rashes, poor reaction to anaesthetics, intolerance to various drugs, interstitial cystitis etc. This list is not exhaustive.²

Patients usually have completely normal tests and investigations and therefore remain mostly untreated - often being labelled as 'unexplained symptoms'. The symptoms are mostly caused by inflammation.² The condition can be 'triggered' or made much worse by a severe infection - ebstein-barr virus, food poisoning, chicken pox, lyme disease, coronavirus.

The treatment is simple, but not easy for the patient, and consists of a low histamine diet, type 1 and type 2 antihistamines, various vitamins and minerals to help support their metabolic processes and possibly a mast cell stabiliser. There are other treatments that may also be helpful. It isn't a quick fix.

Methylation and folate pathways seem to be affected in all of my patients in whom we have carried out genetic testing, as well as their histamine pathways. We use a company called LifecodeGx to calculate the pathways.

Most MCAS patients remain undiagnosed and untreated, and therefore their dysfunctional mast cells, whether causing mild or severe illness, are uncontrolled and may react inappropriately to SARS-CoV-2. This particular virus seems to cause excessive disruption of the mast cells as it can enter the mast cell through the ACE2 receptors.³

Long Covid (LC):

I have been diagnosing and treating patients with MCAS and HIT for the last 5 years (on average 4-6 per week).

I have now analysed the symptom profile of nearly 2000 Long Covid sufferers and their profiles are strikingly similar to patients with MCAS and Histamine Intolerance. The average number of symptoms they present with is 7.

From early November 2020 I started seeing LC patients in my clinic and so far, they all have a history suggestive of MCAS and HIT.

Their dysfunctional mast cells appear to have become super-sensitised, constantly releasing over 1000 different mediators, including histamine, heparin and elastase 2.

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Why is this condition so seldom diagnosed?

It is a recently described syndrome (1980s) named in the 1990s, and it wasn't until 2007 that the first publications started to appear (3 case studies). As a result the majority of doctors have not been taught about it and most are certainly unaware of its common prevalence. This makes it a very new area of investigation.

MCAS is extraordinarily complex and heterogenous in its clinical behaviour and so much remains undiscovered about the underlying biology and pathology of the condition.

References and supporting evidence

1. Covid-19 hyperinflammation and post-Covid-19 illness may be rooted in mast cell activation syndrome

Written by Dr Lawrence Afrin who works at the Department of Mast Cell Research in New York, published in the International Journal of Infectious Diseases, 10th September 2020. This would fit with my thoughts and observations. It includes recommended treatments.

[https://www.ijidonline.com/article/S1201-9712\(20\)30732-3/fulltext](https://www.ijidonline.com/article/S1201-9712(20)30732-3/fulltext)

Highlights:

- Much of COVID-19 hyperinflammation is consistent with mast-cell-driven inflammation.
- Prevalence of severe COVID-19 is similar to that of mast cell activation syndrome (MCAS).
- Drugs inhibiting mast cells (MCs) and their mediators show promise in COVID-19.
- None of the authors (or my) currently treated MCAS patients with COVID-19 had severe forms or mortality.
- The dysfunctional MCs of MCAS may underlie severe acute and chronic COVID-19 illness.

Conclusions:

- Hyperinflammatory cytokine storms in many severely symptomatic COVID-19 patients may be rooted in an atypical response to SARS-CoV-2 by the dysfunctional MCs of MCAS rather than a normal response by normal MCs.
- If proven, this theory has significant therapeutic and prognostic implications.

2. Diagnosis of mast cell activation syndrome: a global “consensus-2”

A paper by key opinion leaders in the field of Mast Cell Activation Syndrome.

<https://www.degruyter.com/view/journals/dx/ahead-of-print/article-10.1515-dx-2020-0005/article-10.1515-dx-2020-0005.xml?>

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3. Evolution of Antibody Immunity to SARS-CoV-2

An observational study into the persistence of the SARS-CoV-2 virus in the small intestine of infected patients.

<https://www.biorxiv.org/content/10.1101/2020.11.03.367391v1>

4. Mast Cell Action

A website explaining Mast Cell Activation Syndrome.

<https://www.mastcellaction.org/about-mcas>

5. Is this what's causing Long Covid? Viral Persistence at 4 Months - New Study

A video explaining and referencing current studies attempting to understand the pathology of Long Covid.

<https://www.youtube.com/watch?v=94ZYVxtdNHY>

6. Online lectures on MCAS

Two lectures presented by Dr Andrew Maxwell, Consultant Paediatric Cardiologist, at the ILS annual conference 2019. Dr Maxwell explains that the mast cell activation is at the core of the pentad of syndromes he describes.

<http://www.youtube.com/watch?v=2mlzE2X9OJk>

<http://www.youtube.com/watch?v=8wdVMvBFLCs>