# Standing on Shifting Sands:

## MCAS, Immune Systems and Long Covid

*by Sara Waymont*

Rumi said that before you speak, you should let your words pass through three gates. At the first gate, you should ask yourself "Is it true?". At the second gate, you should ask "Is it necessary?" and at the third gate, you should ask "Is it kind?". When Norman asked me to write an article on living with a compromised immune system during this time of pandemic, my first attempt at the endeavour passed through only one of those gates. Everything that I wrote was certainly true, but probably not necessary and definitely not kind. This second writing is an attempt to rectify that and to offer something that the yoga community and wider community might find useful in the ongoing struggle against Covid-19.

Once upon a time, I was fit and healthy. The type of person who took her strength and ability for granted. I lived a very full life. I was the Head of Latin at a preparatory school, an RAF Reservist, an artist and I volunteered for a military charity. I ran every night, swam, rode and practised yoga, but slowly, insidiously, things began to change. My body stopped functioning as well as it once did. I couldn't quite keep up with myself, but I pushed and pushed until I literally broke.

In late 2014, I herniated two discs in my lower back. I don't even remember how I did it but this injury really was the proverbial straw. I became deconditioned as a result of my injury and I began to suffer from recurrent joint dislocations in my knees as well as a racing heartbeat and spells of dizziness and fainting.

I began to feel as though I had been cut adrift from myself, as though I were at sea in my own body.

As my physical health declined, so too did my work performance and my mental health. By the end of 2015, I was unable to work and taking the anti-depressant fluoxetine daily. I had no idea what was happening to my body or my mind.

She who has health has hope and she who has hope has everything.

At that point in my life, I was feeling pretty hopeless.

## When You Hear Hoofbeats...

In 2016, after long, painful months spent visiting consultants and undergoing tests, I was diagnosed with Hypermobile Ehlers Danlos Syndrome (hEDS) and PoTS (Postural tachycardia syndrome). As it turns out, I have lived with both conditions all my life. hEDS is a genetic connective tissue disorder that affects the collagen throughout my body.[1] This means that my joints are hypermobile and very unstable, leading to repeated dislocations and subluxations, which form a background of pain and increasing disability. Whilst flexibility is often lauded in the yoga world, in hEDS, this extra range of

[1] For more details on this cause of hypermobility, see https://www.ehlers-danlos.org/.

movement is more of a curse than blessing. I count myself lucky that I'm still able to walk with minimal pain and am not yet confined to a wheelchair. I know others with hEDS in a very different position.

This collagen defect does not just affect my joints, but, as the anatomists among you will have realised already, pretty much every single part of my body. My digestive system doesn't work properly. I have hyper-stretchy veins and arteries, which has contributed to my having PoTS, a condition where I am constantly tachycardic (an extremely fast heart rate (over 100 beats/minute)), even at rest; my exercising heart rate can easily reach 250bpm (at least it did back in the days when I was able to exercise). PoTS leads to feelings of dizziness and actual fainting. An episode of PoTS can leave me feeling nauseous, brain-fogged and absolutely wiped out. I also have Raynaud's disease (limited circulation, often in extremities) and regularly experience blistering of my hands and feet due to the problems I have with circulation. But the worst consequence of my having a collagen defect has been the development of Mast Cell Activation Syndrome (MCAS), where the person experiences repeated episodes of the symptoms of anaphylaxis.[2]

In 2018, I woke to find myself covered from head to foot in a mysterious rash that felt like I had been burned in a chemical spill. In the days and weeks that followed, my face began to swell. My eye sockets filled with fluid, as though I'd gone several rounds with Mike Tyson, my lips began to swell and my airway became compromised. After being turned away by the receptionists at my local GP surgery, I drove myself to A&E and was put on steroids and antihistamines whilst they inserted a cannula, drew blood and kept me in for observation. I was issued epi-pens and sent home with a course of steroids to try to control the reactions, but no answers.

## Never Bet Against Occam

Unfortunately, living with hEDS, you quickly learn that you have to become your own advocate and you usually know far more about your condition than the physicians treating you.[3] I had already worked out that the likely cause of my reactions was MCAS (approximately 60% of those with hEDS and PoTS also have MCAS, in some kind of unholy trinity of disease).[4] I asked my GP to refer me for MCAS testing and was told that the waiting times were 6–12 months.

I'll just reiterate that for you: 6–12 months.

6–12 months of waking up every day with a swollen face, burning rash and feeling like I'd been hit by a bus whilst simultaneously trying to nurse the world's worst hangover. I'd also be simultaneously battling with tinnitus, heart palpitations, dizziness and fainting, brain fog, insomnia and crippling joint pain. All I was offered during this time were repeated courses of steroids, which only kept the reactions at bay until I came off them, and some antihistamines at doses way below what is required to tackle the histamine produced by MCAS.

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[2] For more details on Mast Cell Activation Syndrome (MCAS), visit https://www.mastcellaction.org/.

[3] EDS is considered a rare disease and little attention is given to it at medical school. Read, for instance, Gemma H's story https://www.ehlers-danlos.com/gemmah/.

[4] Ingrid Cheung and Peter Vadas. 2015. 'A New Disease Cluster: Mast Cell Activation Syndrome, Postural Orthostatic Tachycardia Syndrome, and Ehlers-Danos Syndrome'. *Journal of Allergy and Clinical Immunology* 135(2). Presentation https://slideplayer.com/slide/14377303/ .

As with my other conditions, I was once again forced to seek diagnosis in the private health care sector. I'm not rich and I've been fortunate to have had most of my treatment funded by Benenden Healthcare, a type of insurance my mum has paid for since I was very small. In total, my private diagnoses and consultations would have cost me in excess of £10,000 had I had to foot the bill myself and all because my conditions are so poorly recognised and provided for by the NHS. This is a tale that many in the EDS community will be familiar with.

So, in the year whilst I waited to be seen by an NHS specialist, I visited private allergy and immunology clinics for testing, saw several experts in food-related allergy and mast cell diseases and was finally given the chance to try mast cell stabilising drugs about 9 months after my first episode. I was also allowed to increase my antihistamine dosage to try to control the symptoms.

During this period, I had gone from my completely vegan diet to only being able to eat meat, dairy and eggs without triggering a huge MCAS reaction. Even then I wasn't symptom free, but at least I wasn't waking up with filled eye-sockets every single day, perhaps only every other day, and the rash was still there, but not covering my entire body any more. It is probably unsurprising that my mental health deteriorated during this time. I already had some issues due to previous trauma, but my state of mind declined to the point where I knew that I would take my own life if no long-term management strategy could be found.

I was just so tired. I was exhausted from living with the chronic pain and symptoms of hEDS as well as the debilitating effects of PoTS and now the horrific unpredictability of MCAS reactions day-in and day-out. My sleep was poor and my nutrition was terrible. I had a flare up of the anorexia that I'd worked for years to control, because I was now terrified of eating and the MCAS reaction that it would induce. I was still, somehow, managing to maintain employment throughout all this but I had had enough.

People talk about trauma being created by living in an environment that isn't safe, but what do you do when your body itself is compromised? How do you live when you have no idea what your body is going to do from one hour to the next, let alone day-to-day? Since my hEDS diagnosis in 2016, it's been like standing on shifting sands. Just when I think I've got a handle on what my body is about, something else comes along and completely obliterates that understanding. MCAS was very nearly the end for me.

When my NHS appointment finally came through, it was only just in time. The first time I saw the specialists, my suspicions were confirmed and I was diagnosed with some type of Mast Cell Activation. My antihistamine dose was increased, as were my mast cell stabilisers and I was also prescribed Montelukast, which has been something of a game-changer for me. I currently take 23 tablets a day in order to be able to eat and function without catastrophic mast cell reactions. I still have to be very careful about what I eat, am exercise intolerant and still have days when I'll have an MCAS episode (fortunately, these are now fewer and further in between). I'm still triggered by stress, strong fragrances and fatigue and have to be very careful about how I manage my days. I've also now been diagnosed with several comorbid mental health conditions, which add to the challenge of going about my daily life. To say that my spoons are limited would be a massive understatement.[5]

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[5] For those of you unfamiliar with Spoon Theory, check out https://www.healthline.com/health/spoon-theory-chronic-illness-explained-like-never-before#1.

## 'Sometimes Even to Live is an Act of Courage'

That's been a very long introduction to this article, but it feels important to have told some of my story, because the number of people suffering from chronic ill health is increasing daily, thanks largely to the ongoing pandemic. Seneca said that sometimes even to live can be an act of courage and this is particularly true for those of us who live with a long-term health condition. Covid-19 has changed a lot of things and those who are living with long Covid have been given an unwelcome invitation into the world of invisible disability that people with EDS, dysautonomia (dysfunction of the autonomic nervous system) and MCAS have dwelt in for years.

When I first wrote this article, it was with an unempathetic undertone of 'welcome to my world'. This is what happens when we respond from a place of pain. Norman had asked me to describe what it was like living with a different immune system during the pandemic and my response was rather snarky. Life during the pandemic has been easier for me than it had been in several years: I can work from home, everyone has no social life, not just me, and everyone is scared and feeling their own mortality. I feel like the playing field has been levelled and that you are all now experiencing at least some of the daily horror of life for people living in compromised bodies. This is my honest response to what has been a huge crisis for so many of you.

But, whilst this is my *honest* response, it's not kind and it's probably not necessary. Rumi would not approve.

So now, perhaps, I can do something to redress that. I've learned a lot over the last few years about how the body works. I've also developed a greater understanding about the connections between the immune system, nervous system and endocrine system. For many people, this is purely academic research, but for me this is essential to understanding my own life. For those of you now suffering from long Covid or for those of you who might know someone who is, I'd like to share some of my insights and direct you towards experts who might be able to give you some answers.[6]

## Mast Cells, Covid and Long Covid

There are few specialists in MCAS, but one of the leading doctors, Dr Lawrence Afrin, has been increasingly asked to give his input into the role that mast cells are playing in Covid and long Covid.[7] Mast cells are a type of white blood cell found in the connective tissues of the body (hence the link between connective tissue diseases and MCAS). Mast cells are most often known for their role in allergy symptoms. When mast cells degranulate (typically part of an immune reaction), they release a whole host of chemical mediators that travel throughout the body and cause the symptoms that we frequently associate with an allergic reaction. Mediators include, but aren't limited to, histamine, natural proteases, proteoglycans and cytokines. Cytokines are particularly interesting, as they are what

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[6] By way of a disclaimer, I'm not a doctor or medical specialist, just someone with extensive lived experience of MCAS and dysautonomia who has become familiar with the literature and specialists in this field. For introductory reading on mast cells and MCAS, see Lawrence B. Afrin M.D. 2016. *Never Bet Against Occam: Mast Cell Activation Disease and the Modern Epidemics of Chronic Illness and Medical Complexity.* Sisters Media.

[7] LB Afrin, LB Weinstock and GJ Molderings. 'Covid-19 hyperinflammation and post Covid-19 illness may be rooted in mast cell activation syndrome'. Nov 2020. *International Journal of Infectious Diseases* 100: 327–32 (https://www.sciencedirect.com/science/article/pii/S1201971220307323) and 'Coronavirus and MCAS, A Letter from Dr Afrin' May 1, 2020. DrTaniaDempsey.com. (https://www.drtaniadempsey.com/post/mast-cell-activation-syndrome-mcas-covid-19-coronavirus).

cause the phenomenon known as 'cytokine storm' that many Covid patients are experiencing, which hugely compromises their lungs.[8]

In MCAS, these mediators lead to a whole host of unpleasant side effects, including rashes, dizziness, hives, shortness of breath, brain fog, heart palpitations, difficulty sleeping, fatigue, joint pain, depression and anxiety, tinnitus and digestive problems. For long Covid patients, the list of symptoms is identical, except with the addition of a loss or change of smell and taste.[9] Unsurprisingly, Dr Afrin ascribes many of the symptoms seen in those with long Covid to the activation of mast cells and the production of mast cell mediators during degranulation.[10]

Another curious side effect for those with long Covid has been the sudden development of diabetes,[11] which seems completely bizarre until you understand the role that mast cells play in inflammation and metabolic disorders.[12] It has even been seen that diabetes patients show beneficial effects when treated with mast cell stabilisers.[13]

What about the psychological symptoms of long Covid? Brain fog, insomnia, depression and anxiety can all be attributed to mast cell activation and the chemical mediators that they produce. An article in *Psychology Today* entitled '*Mast Cell Activation Syndrome: An Alert to Psychiatrists*' describes how mast cell activation can present as depression, anxiety and brain fog.[14]

Mast cells are also known drivers of dysautonomia.[15] My own PoTS dramatically improved once I was medicated for MCAS and I now only have my worst flare ups during an episode of mast cell activation. Similarly, I can now predict an MCAS flare up by the state of my gastro-intestinal system. When I feel my guts are misbehaving, I know that I'm going to experience a mast cell reaction shortly after. This makes perfect sense when you consider the following.

> It is known that mast cells interact closely with nerves. Mast cells have been observed degranulating adjacent to nerve synapses and increased numbers of activated mast cells have been documented in the mucosal tissues in "functional" gastrointestinal (GI) disorders that often coexist with dysautonomia. It therefore makes sense that abnormal mast cell mediator release may be a driving force behind nervous system disorders that involve the ANS and that may lead to GI symptoms. The ANS is made up of three parts: the sympathetic nervous

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[8] Duraisamy Kempura et al. Jul 2020.'Covid-19, Mast Cells, Cytokine Storm, Psychological Stress, and Neuroinflammation'. *The Neuroscientist* 26(56) (https://journals.sagepub.com/doi/full/10.1177/1073858420941476) and Randy Q Cron. Feb 2021. 'COVID-19 cytokine storm: targeting the appropriate cytokine'. *The Lancet* 3(4). https://www.thelancet.com/journals/lanrhe/article/PIIS2665-9913(21)00011-4/fulltext).

[9] 'Long term effects of coronavirus (long Covid)'. NHS.uk (https://www.nhs.uk/conditions/coronavirus-covid-19/long-term-effects-of-coronavirus-long-covid/).

[10] 'The Role of MCAS in Long Covid: With World Leading Specialist Dr Lawrence Afrin'. Video. 9 Feb 2020. https://www.youtube.com/watch?v=OaNXiEUrpIc).

[11] 'COVID-19 found to trigger diabetes in healthy people'. 17th June 2020. Diabetes.co.uk. (https://www.diabetes.co.uk/news/2020/june/covid-19-found-to-trigger-diabetes-in-healthy-people.html).

[12] Duraisamy Kempura et al. 2016. 'Are mast cells important in diabetes?'. *Polish Journal of Pathology* 67(3): 199–206 (https://pubmed.ncbi.nlm.nih.gov/28155967/).

[13] Michael A Shi and Guo-Ping Shi. 2012. 'Different Roles of Mast Cells in Obesity and Diabetes: Lessons from Experimental Animals and Humans'. *Frontiers in Immunology* 3: 7 (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3341969/).

[14] Judy Tsafrir. July 23, 2019. (https://www.psychologytoday.com/gb/blog/holistic-psychiatry/201907/mast-cell-activation-syndrome-alert-psychiatrists ).

[15] Matthew J Hamilton and Kelly Freeman. 2014. 'Mast Cell Activation'. TheDysautonomiaProject.org. (https://thedysautonomiaproject.org/mast-cell-activation/) .

> system, the parasympathetic nervous system and the enteric nervous system (ENS). Much of the current study of dysautonomia focuses on the roles of the sympathetic and parasympathetic nervous systems, however there has been little emphasis on the ENS. The ENS is comprised of a fabric-like system of neurons that are located in the smooth muscle linings of the intestines (see figure below) and plays an important role in many GI functions. It stands to reason that dysautonomia affecting the ENS leads to GI symptoms.[16]

If you live with MCAS or know someone who does, all of the seemingly unconnected side-effects of long Covid make perfect sense. If we can hope for anything good to come out of this pandemic, it's that doctors will begin to pay more attention to mast cells and the role that they play in causing symptoms for long Covid sufferers, as well as the rest of us who are already part of the MCAS/ dysautonomia community.

## How Can Yoga Teachers Help?

A good place to start is with understanding the community of people who present with connective tissue disorders. It has long been known that hypermobile people are over-represented in the yoga world. Despite our hypermobility, we often feel stiff and love to stretch. We also do much better in movement than we do in sitting still. Those of us with PoTS/ dysautonomia find standing a challenge and those of us with hEDS find sitting a challenge, so combining the two can make life very complicated indeed. Movement is often the only time that we can feel any sense of 'normality' within our bodies, even with all the proprioceptive challenges this brings. I thoroughly recommend the recent work of Jess Glenny *Hypermobility on the Yoga Mat* and also Isobel Knight's *A Guide to Living with Ehlers-Danlos Syndrome (Hypermobility Type)* for a better understanding of the issues that yoga students and practitioners with connective tissue disorders can face.[17]

But aside from becoming better informed, yoga teachers can offer practices that focus on activating the parasympathetic nervous system and working with the breath. It's unfortunate that those of us with dysautonomia live in sympathetic dominance.[18] A slower, more meditative practice is good for encouraging the activation of the parasympathetic nervous system, so yin yoga may be a particularly valuable practice.[19] Yin yoga also has the benefits of being accessible for those with chronic fatigue and doesn't require lots of head-down to head-up transitions, which can be particularly triggering for those with dysautonomia. A word of caution, however, is that those with connective tissue disorders will likely require lots of props for a safe yin yoga practice, ensuring that they stay well within their range of movement, rather than pushing beyond it and causing harm[20]. Restorative yoga is, therefore, a good alternative to a yin practice.

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[16] See note 13.

[17] Jess Glenny. 2021. *Hypermobility on the Yoga Mat*. Singing Dragon and Isobel Knight. 2015. *A Guide to Living Well With Ehlers Danlos Syndrome (Hypermobility Type): Bending Without Breaking*. Singing Dragon.

[18] Michael J Reichgott. 1990. 'Clinical Evidence of Dysautonomia'. In HK Walker, WD Hall and JW Hurst (eds). *Clinical Methods*. 3rd edn. Butterworths, 389–97 (https://www.ncbi.nlm.nih.gov/books/NBK400/) and 'Determing the Cause(s) of Dysautonomia, Vagopathy, and Autonomic Nervous System Imbalances'. CaringMedical.com (https://www.caringmedical.com/determining-causes-dysautonomia-vagopathy-autonomic-nervous-system-imbalances).

[19] Bernie Clark. March 20, 2020. 'Yin Yoga Will Not Trigger The Parasympathetic Nervous System'. Yinyoga.com (https://yinyoga.com/yin-yoga-will-not-trigger-the-parasympathetic-nervous-system/).

[20] See Jess Glenny's book (note 15) and Norman Blair. 2015. 'Being Flexible about Flexibility'. Yogawithnorman.co.uk (https://www.yogawithnorman.co.uk/space/1ff1de774005f8da13f42943881c655f/pdfs/Being_Flexible_about_Flexibility_FINAL2.pdf ).

Another way to help support those with MCAS and long Covid is to work with the breath. Research has shown that focused breathing practices can improve vagal tone, which has a direct effect on the autonomic nervous system.[21] Particularly useful are the 7:11 breath and the 6:6 breath (so 7 seconds inhale, 11 seconds exhale or 6 seconds inhale, 6 seconds exhale).

Finally, facilitating practices that encourage meditation and relaxation can be deeply supportive to anyone experiencing mast cell activation, dysautonomia and the trauma of living in a compromised body. Learning to live with the difficulties that come from chronic ill health and disability is no easy feat. As yogis, we talk a lot about 'acceptance' and how we ourselves are responsible for suffering in the face of pain (the two arrows). However, I challenge any able-bodied person to live just one day with the combination of hEDS, PoTS and MCAS and find acceptance at the end of it. The trauma of living in a body that is neither predictable nor safe makes acceptance and the avoidance of suffering almost impossible. Meditation and relaxation practices help, but they don't make the problem go away. They can provide perspective, though, and help to make the suffering just a little less. I personally find meditating on the breath and yoga nidra incredibly valuable, both for reducing stress (and thus reducing flare ups) and putting a bit of distance between myself and my body.[22]

## 'Never Lose Hope, Miracles Dwell in the Invisible'

I began this article with a quote from Rumi and that's how I'm going to end it. MCAS and hEDS are known as invisible disabilities, because most of the time it's not that obvious that we are suffering. In the world pre-pandemic, our invisible was unseen, under-recognised and uncared for. Post-pandemic, there are going to be many, many more people living with invisible disability. In the UK alone, it is estimated that 1.1 million people are living with the after-effects of long Covid.[23]

It's my hope that this will lead to a miracle of sorts; that clinicians, family, friends and the wider population will begin to see our invisible. It's my hope that we will learn from this period of suffering and that the world will become a kinder place as a result of enduring this collective trauma. Covid-19 has offered us many lessons; long Covid is just one of them. I hope that we, as a society, can learn. I hope that post-Covid we can all live in a fairer and more equitable society, whether we're able-bodied or not. Part of this learning is the responsibility of researchers and clinicians, the rest is the duty of everyone else, to educate themselves on what it means to be disabled or chronically ill and to offer support to those who have need of it. Sometimes that support is as simple as letting a disabled or chronically ill person know that they aren't invisible, that they are seen.

The first arrow is pain….We're all collectively responsible for the shooting of the second.

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[21] 'Beginner's Guide'. Rhythmofregulation.com (https://www.rhythmofregulation.com/resources/Beginner's%20Guide.pdf); Norman Blair. 2021. '*Nervous Systems, Nerves and More'*. Yogawithnorman.co.uk (https://www.yogawithnorman.co.uk/blog/nervous-systems-nerves-and-more) and Herbert Benson.1992, *The Relaxation Response*. Wings Books.

[22] See Jon Kabat-Zinn. 2020 (orig 1990). *Full Catastrophe Living: How to Cope with Stress, Pain and Illness Using Mindfulness Meditation*. Piatkus, and Sara Waymont. 2018. *Yoga, PTSD and Me*. Sway Arts.

[23] 'COVID-19: 1.1 million in the UK recently reported having long COVID'. 1 April 2021. News.sky.com (https://news.sky.com/story/covid-19-11-million-in-the-uk-have-long-covid-latest-estimate-shows-12262530).