#### Mast Cell Action



# Mast Cells and The Mind



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#### **QUALIFICATIONS:**

- Naturopathic Nutrition and Health Coaching: Diploma-College of Naturopathic Medicine (CNM)
- Hypnotherapy and Psychotherapy: Mindworks
- ✓ Mindfulness Teacher: Teach 10 Institute
- ✓ IEMT Practitioner

#### **MEMBERSHIPS:**

- ✓ National Council for Integrative Psychotherapists (NCIP)
- ✓ UK & International Health Coaching Association(UKIHCA)
- ✓ The Association of Naturopathic Practitioners (ANP)
- ✓ Association of IEMT Practitioners



Socials: Live Well With Chronic Illness Email: <u>livewellwithchronicillness@outlook.com</u> Website: https://livewellwithchronicillness.co.uk Specialist in Lyme Disease, MCAS, Dysautonomia and Chronic Pain



#### Mental Wellbeing NOT Mental Illness

NOT implying, in any way, that MCAS is a mental, or psychosomatic, illness.

I know that many of you will have experienced disbelief from medical professionals, as I have done.

This is all about how we can look after our mental wellbeing while living with MCAS, and how supporting our mental wellbeing can be beneficial for us.

It is NOT suggesting that MCAS can be 'cured' by 'thinking differently' or doing mindfulness etc.

I know that talking about mental wellbeing and mental health can still feel difficult I want you all to know that this is a safe space, you are safe here, and there is no judgement here.

If any of this still feels difficult for you, please feel free to switch off your camera, talk about it afterwards, or to leave the call if it's too triggering. I won't be offended, and no one will judge you. Do what you need to do to feel safe and to feel well.

Questions - at the end. Can put into chat, or ask at the end.



### Disclaimer

- We're all in different places, we all need different things.
- Especially with MCAS, everyone experiences it differently
- Everyone here will be affected differently by their MCAS, and will experience different symptoms
- I want to say that, I'm going to share some ideas and thoughts that I have come across through my own research, things that have helped me, things that make sense of some of my own symptoms.
- Some of these things might be things you already know
- Some of these ideas might be new, some might be challenging. Not all of them may resonate with you
- What works for one person, won't work for another
- Take what 'lands' for you take what you feel is helpful, and feel free to use it to help you on your MCAS journey.
- Leave the rest! It's fine to disagree, or to feel differently.
- If it doesn't feel right, or helpful for you, then don't worry about it.
- Only do what feels right for you.
- REVISIT



#### Topics we will Cover

- Anxiety and MCAS
- Stress and MCAS
- Mast Cells and The Nervous System



- Some of the ways we can use our minds to support us when we live with MCAS Feeding Safety into our System
  - Some tips for helping us stay mentally well with MCAS

Booklet Download
 <u>https://www.mastcellaction.org/assets/\_/2023/07/04/674c4d7f-dc2d-48c0-ac10-</u>
 <u>d82d4d481bfd/mast-cells-and-the-mind-pdf.pdf?v=1</u>



### Opening your mind to new ways of thinking can be the greatest lifeline in difficult situations



Image by <u>Amy Z</u> from <u>Pixabay</u>







Image by Joe from Pixabay

#### Questions

How do you feel about your own mental health?

Do you feel your MCAS impacts on your mental wellbeing?

Do you suffer with anxiety or depression because of your MCAS?

How do you take care of your mental wellbeing with MCAS?

How do you make time for self-care?





### Anxiety and MCAS

Having a reaction to something can be very unpleasant experience

It can be very scary

It is normal to feel anxious about having MCAS, and it's normal to feel anxious about reacting.

We shouldn't 'beat ourselves up' about this.

It's ok to recognise that you might feel anxious because of your MCAS sometimes.

It's understandable to become anxious about foods, or going places, or being exposed to something that might make you ill.

Anyone would feel like that. Important to validate how we feel and acknowledge that.

Plan coping strategies in advance.



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#### Anxiety and MCAS

Anxiety can be a <u>symptom</u> of an MCAS reaction Histamine is a powerful neurotransmitter, and it stimulates the nervous system

Mast cells are closely linked to neurons, or nervous cells, and they are paired with one another all over the body

Depending on where your mast cells are reacting, and if they are producing histamine, you might notice that, as part of your reactions, you feel 'wired' or less able to cope with stress than usual.

This can be a symptom of too much histamine in your nervous system. It can be quite normal for many of us to feel this way during a reaction.

It is not a 'mental health issue'.

Mast Cell 360 has some good resources on this





<u>References</u> <u>https://www.ncbi.nlm.nih.gov/pmc</u> /articles/PMC2584714/

https://mastcell360.com/nervoussystem-balance-is-essential-inmast-cell-activation-syndrome-andhistamine-intolerance/

#### Stress and Mast Cells

• How many of you notice that you feel less able to deal with stress when your mast cells are flaring?



- Conversely.....
- How many of you notice that stress is a trigger for you, and that when you experience stress, it can cause a flare?



#### Mast Cells and The Nervous System

Mast Cells and Neurons talk to one another!

On neurons there are receptors for mast cell mediators On Mast Cells, there are receptors for the neurotransmitters. They are always 'sensing' how the other one is doing.

When our nervous system is sending out 'danger' signals, our mast cells respond to this

Our nervous system is constantly sensing whether we are safe or not. It is constantly monitoring for signs of danger, and sending signals of safety or danger through our bodies.

Mast Cells are part of our 'defence' mechanism - the mast cells are receiving signals from our nervous system about how safe we are.

If they receive messages of danger, it can trigger them to degranulate, in response to perceived threat.



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References https://www.ncbi.nlm.nih.gov/pmc/articles/PMC75 30006/ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC64 35484/ https://www.sciencedirect.com/science/article/abs/ pii/S0149763417300295 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC43 74437/ https://pubmed.ncbi.nlm.nih.gov/16110169



#### Mast Cells and The Nervous System

That is why stress can be a trigger for us!

You are not imagining it!!

This happens outside of our control, we are not to 'blame' for this!

It can be really helpful to understand this relationship, and why we react to stress

It's our body's natural defence mechanism



# Ways we can use this to our advantage



Once we understand the way that our nervous system and our mast cells are 'talking' to each other, we can use this to our advantage and help us to manage our MCAS better

Mast cells can also respond to positive chemicals like oxytocin and dopamine

Getting stressed can make mast cell reactions worse Staying calm/feeling positive emotions can encourage mast cells to stop reacting sooner

Sending signals of safety into our nervous system can help our mast cells stay calmer

https://www.nature.com/articles /s41419-022-04695-y

https://www.ncbi.nlm.nih.gov/pmc/ar ticles/PMC4990927/



#### The State of Safety

According to the work of Dr Stephen Porges, known as Polyvagal Theory, Our vagus nerve operates in 3 states:

Rest and Digest - Parasympathetic (ventral vagal) Fight of Flight - Sympathetic Freeze - Dorsal vagal

Rest and Digest state To be optimally healthy, and for our cells, and our immune system, to work at its best, we need to be in rest and digest and not in fight or flight.

The more often we can keep ourselves in the 'rest and digest' state, the better our bodies function.

References

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3108032/ https://www.sciencedirect.com/science/article/abs/pii/B978012386525000 0676





#### Fight or Flight Vs Rest and Digest

- When we are in Fight or Flight
- Our bodies produce cortisol and adrenaline
- We are under stress
- Our heart is under extra pressure
- Our immune systems don't function properly
- We don't produce antibodies and are more likely to catch 'bugs'
- We don't digest our food properly, our stomachs stop working, we don't extract all the goodness that we need from our food
- We stop eliminating toxins and detoxing properly
- Our cells stop repairing and regenerating



**References** 

- <u>https://www.ncbi.nlm.nih.gov/pmc/articles/P</u> <u>MC2679852/</u>
- <u>https://www.health.harvard.edu/staying-</u> <u>healthy/understanding-the-stress-response</u>
- <u>https://www.ncbi.nlm.nih.gov/pmc/articles/P</u> <u>MC7219460/</u>
- <u>https://www.ncbi.nlm.nih.gov/pmc/articles/P</u> <u>MC3582394/</u>
- <u>https://psycnet.apa.org/record/1996-98420-</u> 013
- <u>https://www.ncbi.nlm.nih.gov/books/NBK538</u>
  <u>516/</u>
- <a href="https://pubmed.ncbi.nlm.nih.gov/7752515/">https://pubmed.ncbi.nlm.nih.gov/7752515/</a>

#### Fight or Flight Vs Rest and Digest

- When we are in 'rest and digest'
- We produce positive neurotransmitters like serotonin, oxytocin, GABA
- We produce nitric oxide (Self-Compassion, heart health, Mast Cell regulator)
- Our heart is protected
- Our immune systems work better and protect us properly
- We digest food and extract nutrients for our bodies to function
- We detox chemicals and hormones like histamine properly so they don't build up
- Our cells undertake repair and regeneration work
- 'Healing State'



<u>References</u> <u>https://pubmed.ncbi.nlm.nih.</u> <u>gov/12100016/</u>

https://pubmed.ncbi.nlm.nih. gov/25457445/

## Safety in Chronic Illness

- One of the most important things we can do, when we live with chronic illness is to consistently and regularly feed in signals of 'safety' into our nervous system
- This puts our bodies into a 'healing state'
- It switches off the 'fight of flight' state
- It switches on the 'rest and digest' state
- Safety is also crucial for mental wellbeing we feel mentally well when our brains perceive that we are safe.



References https://www.ncbi.nlm.nih.gov/pmc/ar ticles/PMC9131189/

https://www.livescience.com/parasym pathetic-nervous-system-rest-anddigest



#### Maslow's Hierarchy of Need

Safety is crucial - at the bottom of all wellbeing is the sense of being safe.

It becomes difficult for us to feel safe - our sense of safety can be very badly compromised by living with MCAS

Not feeling safe in our own bodies, not feeling safe in our environment Not being able to eat safely.

Very difficult for us

That badly affects our wellbeing and our mental health

Making a conscious effort to feed safety into our system







om/course/view.php?id=5

# Some of the things we can do to send signals of safety

- Staying calm
- Thinking calming thoughts
- Breathing exercises
- Mindfulness tools
- Tai Chi/Qigong
- Restorative Yoga (Yoga Nidra)
- Affirmations
- Noticing joyful moments
- Noticing things to be grateful for
- Being Kind to Ourselves self compassion



#### Thoughts

Our minds, and our nervous systems, can't tell the difference between imagined thoughts, and reality. They respond to both as 'real and present danger'.

It's why we cry at sad films, or get goosebumps when reading a thriller

We can control what 'state' we are in, and what signals our nervous system is sending to our bodies by what we choose to think about.

Whether we are operating in a predominantly 'danger' state or a 'safety' state





### Biology - not Mythology

NOT Saying that if you think happy thoughts, your mast cells won't react. This is not true - it's not a mental health condition

NOT saying that you should feel happy that you have MCAS, or say 'how marvellous, I'm so pleased!' Not about 'Pollyanna Syndrome' - trying to 'fake' being happy Not about manifesting etc.



Analogy of a fire. The fire is burning, we have MCAS, we can't stop that with our thoughts. However, we can choose to calmly sit next to the fire and wait for it to burn out

OR we can throw petrol on the flames and make it an inferno







True or not true?

It is true that living with MCAS can be awful. It is often very difficult. It can be frightening. It can be worrying. It can be stressful. It can be frustrating. It feels cruel, and unfair.

It's entirely understandable for us to think about how difficult things are for us, how miserable we feel. To worry about the future, to feel anxious about our situations This is normal and anyone could feel this way.

Is it helpful or unhelpful?

It is TRUE to think 'I might have a reaction tomorrow, it might be awful'. Is it HELPFUL to think that? Triggering stress hormones in our bodies, triggering 'danger signals' in our nervous system and signalling danger our mast cells. Possibly making it more likely that we will have a reaction.

Not possible to stop thinking these thoughts!! But become more aware of them, and choosing to reduce the time we spend 'throwing matches at ourselves'

Become more aware of the amount of time we spend thinking these 'unhelpful' types of thoughts, and 'feeding' danger into our bodies instead of safety.



#### Thinking Helpful Thoughts

It's important to notice these thoughts and try to replace those 'unhelpful' thoughts with helpful ones.

- By becoming aware of our thoughts
- Noticing when we are focussing on negative, worrying thoughts
- Don't beat ourselves up for that acknowledge this is difficult and it's ok to find it hard
- See if we can gently encourage ourselves away from that thought
- By deliberately choosing to think more helpful thoughts when we can

Thinking about good things, things we enjoy, things that make us happy, as often as possible.

We are feeding in a sense of safety into our nervous system

We are helping our bodies to stay in a 'healing state'

We are reducing the 'danger' signals that are being sent to our Mast Cells through our nervous system

This is NOT about beating ourselves up for feeling bad when things are bad! It's ok to acknowledge that things are difficult, and some days this will be harder than others, and that's ok. It's a process. Don't blame yourself for feeling anxious or worried, just try again later.





# Some other things we can do to send signals of safety

- Breathing exercises
- Mindfulness tools
- Affirmations
- Noticing joyful moments
- Noticing things to be grateful for
- Being kind to ourselves
  - Not beating ourselves up
  - Cultivating a sense of self-worth
  - Taking proactive steps towards our own wellbeing
  - Taking action for ourselves cultivating a sense of control





#### **Breathing Exercises**

In Breath is the stress breath Out breath is the breath of relaxation

Sending signals of safety or danger to the vagus nerve

Involuntary - but can also be voluntary!

By focussing on making the out breath longer than the in breath, you are switching on the parasympathetic system.

7-11 breathing

In for 7, out for 11

4,6,8 - in for 4, hold for 6, out for 8

IF that works for you. Don't force it!



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#### **Mindfulness Practice**

Mindfulness is the act of becoming aware of our present moment experience and welcoming what we find with a kind and open heart.

Staying present in this moment

Not being drawn into the past or the future

Noticing our thoughts - observing them, not 'being' them

Using the breath to ground us in the present moment Using our 5 senses to ground us into the present moment Using Movement to ground us in the present moment

Mindful awareness of the breath - observing the breath, not trying to force it or change it. Observation of the breath, as it comes, without judgement.

Mindful Meditation Recording on MCA Website





#### Affirmations

Not thinking excessively about unhelpful thoughts is one thing, but actively thinking 'helpful' thoughts instead has proven benefits.

Helpful to have on standby for when we find ourselves thinking 'unhelpful' thoughts. Create something that resonates with you - a statement in the positive. I AM..... (not I am NOT)

Affirmations - I am ok, I am safe, I am calm, I am healing, every day I am becoming x

Sending signals into our nervous system of safety - nervous system is hearing 'good things are happening' instead of 'danger'.

Builds new neural pathways in our brains - the more we think about something helpful, the easier it is to 'walk those pathways' in our minds and the easier it becomes to focus less on the unhelpful stuff. (Desire lines)





References https://positivepsy chology.com/dailyaffirmations/

#### Joy and Gratitude

Difficult for us!

What have I got to be grateful for?! What is there to be joyful about?!

There is a lot of talk about 'Gratitude Journals' etc This can all feel very inaccessible to us when our lives are so difficult.

The science behind it: It is impossible to feel joy and fear at the same time It is impossible to feel gratitude and fear at the same time.

Whenever we genuinely experience feelings of either joy or gratitude, we are automatically signalling to our nervous system (and our mast cells!) that we are safe!





#### Joy and Gratitude

#### Try to look out for one thing each day to feel joyful about

A small thing - a flower, a phone call from a friend, a blue sky, a letter

Try to do something each day that brings you joy - look at the stars, read a book, have a bath, watch your favourite TV show. Notice the joy and savour it - don't take it for granted, FEEL it Good things still exist in the midst of suffering - duality

#### Try to look out for one thing each day to feel grateful for

A small thing - a favour, a smile, a soft blanket, your favourite song, a loved-one.

Notice the gratitude - savour it! Allow yourself to feel the gratitude - it's the physical sensation that counts.

Write these things down - it compounds the benefits and strengthens the effect. Read back through them and 're-live' the joy and the gratitude when things are difficult remind yourself of that feeling.



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#### Being Kind to ourselves!

Not Beating Ourselves Up!

Also difficult for us!

- Who finds it hard to be kind to themselves?
- Who finds themselves blaming themselves for being ill?
- Who beats themselves up regularly?
- When we do this, we are sending signals of danger into our nervous system, releasing lots of stress hormones
- The best thing we can do for ourselves it so be kind to ourselves. (nitric oxide)
- Recognise that things are hard, this is difficult, and offer yourself some kindness Treat yourself how you would treat a friend, or a small child, who was suffering.
- Acknowledge the suffering, and offer yourself kindness
- If you feel you have done something that was unhelpful acknowledge that that might not have been helpful, be kind to yourself, and try to do better next time!



#### Being Kind to Ourselves!

Cultivating a sense of your own self-worth outside of your illness

Remind yourself often of your achievements, of what you CAN do Think about your talents, own them. Appreciate yourself for who you are. Think about your values, your attributes. Make a list, and revisit it often

Being sick doesn't take any of that away from you You have value and worth outside of your illness Remind yourself of that daily

Being ill gives us so many reasons to beat ourselves up and feel sh\*t about ourselves.

We have to make a conscious effort to focus on the good stuff and cultivate a sense of our own value and worth as a person, in spite of illness



#### Being Kind to Ourselves!

Taking proactive, positive steps towards your own wellbeing

Taking small steps towards making your situation as good as it can be, whatever that looks like for you.

Learning and researching - empowering yourself Gives you a sense of control, and safety Identify your triggers The more you can learn for yourself about your illness, the more you can help yourself the better - the more in control you feel

Advocate for yourself - with friends, family and healthcare professionals - believe that you know your own needs best. Don't be afraid to speak.

Hope! Always believe that there is hope for a better future, and that you can get better than you are today.

'Action is hope, but there is no hope without action' (Ray Bradbury)



#### Purpose

Having a sense of purpose is linked to longevity, better health and wellbeing, physically and mentally. A feeling that we are contributing to something greater than ourselves- that our lives have value.

When we become ill, we can sometimes lose our sense of purpose, particularly if we become too unwell to work.

Finding small ways that you can feel a sense of purpose and meaning in your life is crucial to our mental and physical wellbeing.

Depending on your situation - doesn't have to be huge

Feeding the birds Doing a small task for someone Volunteering Helping someone else Offering support on a forum or illness group





### 10 Top Tips

1. Do not beat yourself up. About MCAS, or anything else. Take control of your thoughts!

2. Stay in present, don't think about past or future too much - Consider a Mindful Meditation practice. (free downloads)

- 3. Avoid watching stressful, violent films, TV.
- 4. Look for joy, deliberately include things in your daily life that make you happy.
- 5. Look for reasons to be grateful, even if it feels difficult.
- 6. Build up a sense of your own self-worth outside of illness.

7. Take proactive steps towards your own wellbeing, however small.

8. Advocate for yourself and your wellbeing, research, educate and empower yourself as much as possible.

- 9. Find small ways that you can feel a sense of purpose.
- 10. Remain hopeful for the future.



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### Keep in Touch!

#### Contacts





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# Any Questions?



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# Resources

https://www.webmd.com/balance/ss/slideshow-what-happens-when-relax

https://www.sciencedirect.com/topics/medicine-and-dentistry/psychoneuroimmunology

Book - Altered Traits: Science Reveals How Meditation Changes Your Mind, Brain and Body. By Daniel Goleman & Richard Davidson.

Explaining the Default Mode Network: <u>https://mpfi.org/how-does-mindfulness-change-the-brain-a-neurobiologists-perspective-on-mindfulness-meditation/</u>

https://www.gene.com/stories/a-mindful-approach-to-chronic-disease

https://positivepsychology.com/mindful-breathing/

https://www.apa.org/monitor/2017/01/ce-corner

https://self-compassion.org/

https://chriskresser.com/finding-joy-in-the-midst-of-illness-pain-and-difficulty/

Neuroscience of gratitude: <u>https://positivepsychology.com/neuroscience-of-gratitude/</u>



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