



Mast Cells and The Mind

By Deborah Bircham

Mental well-being, not mental illness

To start with, I want to be very clear that, by talking about mental wellbeing with MCAS, we are 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. I know that suggesting somehow that MCAS is linked to your mental health might be very triggering for you, as it is for me.

So, I want to make it very clear, from the start, that this information is all about how we can look after our mental well-being while living with MCAS, and how supporting our mental well-being 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 well-being 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.

Deborah



Disclaimer

We're all in different places and we all need different things at different times on our health journey. Everyone reading this will be affected differently by their MCAS and will experience different symptoms.

In this document, I share some ideas and thoughts that have resonated with me through my own research, things that have helped me on my own health journey, and 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.

My advice to the people I work with is always 'take what 'lands' for you – take what you feel is helpful, and feel free to use it to help you on your MCAS journey, and leave the rest. It's fine to disagree or to feel differently, and if it doesn't feel right, or helpful for you, then don't worry about it. Only do what feels right for you. Wellbeing is not a 'static' thing, it fluctuates and changes with time. Some of these ideas might be worth revisiting later on in your health journey, as they may become relevant for you as your situation changes.

The content provided here is for information and educational purposes only, and Mast Cell Action and Live Well With Chronic Illness cannot take any responsibility for your use of it. It is not a substitute for therapy or medication. Always consult with a medical professional before undertaking any wellbeing practice, especially if you have any diagnosed mental or physical health problems, and particularly if you are working with a health practitioner.



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- 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



Thinking points

These are some questions that you might want to think about before reading this document and continue to ponder whilst reading it.

It might be valuable to revisit them again after you have read the document and consider whether your answers have changed.

How do you currently feel about your own mental health?

Do you feel your MCAS impacts on your mental wellbeing?

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

How do you support your mental wellbeing?

What does self-care look like for you? How do you take care of yourself?

What steps can you take to promote your own wellbeing, on a daily basis?



Anxiety and MCAS

Having a reaction to something can be a very unpleasant experience, causing distress and discomfort. It is completely understandable that having a reaction can be very scary, as it can bring about feelings of fear and uncertainty.

It is normal to feel anxious about having Mast Cell Activation Syndrome (MCAS), as well as feeling anxious about potentially reacting to triggers.

It is important not to be too hard on ourselves in these situations. We shouldn't blame ourselves or feel guilty about experiencing anxiety related to MCAS.

It's perfectly okay to recognise and acknowledge that sometimes we may feel anxious because of our MCAS. It is a natural response to the challenges we face.

It's completely understandable to become anxious about certain foods, going to certain places, or being exposed to substances that may potentially trigger a reaction and make us ill.

It's important to remember that others in a similar situation may feel the same way, as the fear and concern are valid and understandable.

It is crucial to validate our emotions and acknowledge how we feel, as this helps us to cope and navigate our mental health in a healthy way.



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Anxiety and MCAS

Anxiety can manifest as a symptom of a Mast Cell Activation Syndrome (MCAS) reaction, contributing to feelings of unease and distress.

Histamine, a potent neurotransmitter, has the ability to stimulate the nervous system, potentially leading to various physiological and psychological responses.

Mast cells, which are closely connected to neurons or nervous cells, are found throughout the body in close association with one another.

Depending on the location of mast cell reactions and their histamine production, you may experience a sense of feeling "wired" or less capable of managing stress as part of your reactions.



Feeling this way, characterised by heightened sensitivity and difficulty coping with stress, can be a result of excessive histamine in your nervous system.

It is common for many individuals to experience such symptoms during a reaction.

It is important to understand that this experience is not indicative of a mental health issue, but rather a physiological response related to histamine and MCAS.

Check out mastcell360.com for some good resources on this.

Mast Cells and the Nervous System

Mast cells and neurons communicate with each other.

There are receptors for mast cell mediators on nervous system cells and there are receptors for the neurotransmitters on mast cells. They are always 'sensing' how the other one is doing.

When our nervous system perceives a threat or danger, it releases signals to communicate this information. In response to these "danger" signals, mast cells react and initiate various physiological processes within our bodies.

Our nervous system serves as a vigilant guardian, always assessing whether we are in a state of safety or potential harm. It continually monitors our surroundings, internal and external cues, and alerts us through signals of safety or danger.

Mast cells play a vital role in our body's defence system. They receive signals from the nervous system, acting as messengers that inform them about the perceived level of safety.

If mast cells receive messages indicating a potential danger or threat, it can trigger a process known as degranulation, where the mast cells release inflammatory mediators. This response is their way of preparing the body to defend itself.

This intricate connection between mast cells and our nervous system explains why stress can often act as a trigger for individuals with MCAS.

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Stress and Mast Cells

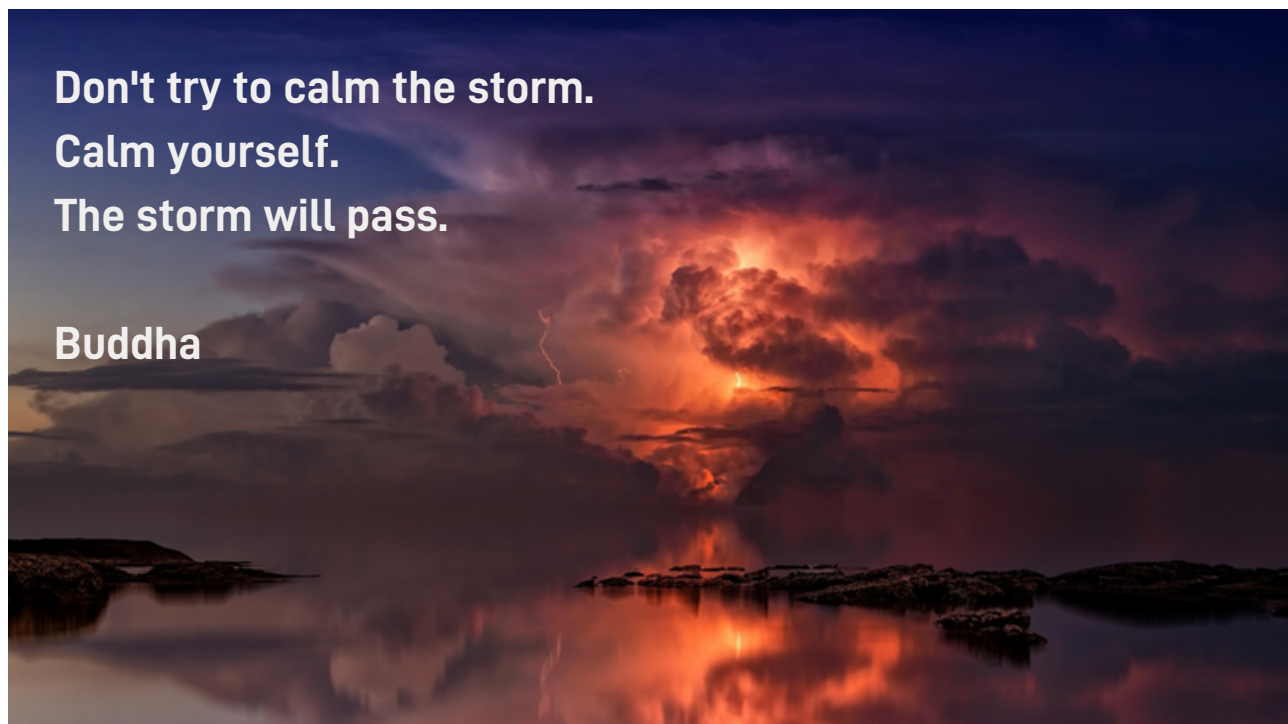
How many of you notice that you feel less able to deal with stress when your mast cells are flaring?

Conversely...

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

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.



References

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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 as it can help us to support the management of our MCAS.

We know that getting stressed isn't good for our overall health and can also make mast cell reactions worse. We know that staying calm can encourage mast cells to stop reacting sooner.

So by sending signals of safety into our nervous system, we can help our mast cells stay calmer.



The State of Safety

According to the work of Dr Stephen Porges, known as Polyvagal Theory, Our nervous system has 3 states:

- Rest and Digest – Parasympathetic
- 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 a state of fight or flight.

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

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Fight of 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
- Our cells stop repairing and regenerating
- We stop eliminating toxins and detoxing properly

When we are in 'rest and digest'

- We produce nitric oxide, serotonin, oxytocin, GABA
- Our heart is protected
- Our immune systems work better and protect us properly
- We digest food and extract nutrients for our bodies to function
- Our cells undertake repair and regeneration work
- We detox chemicals and hormones like histamine properly so they don't build up



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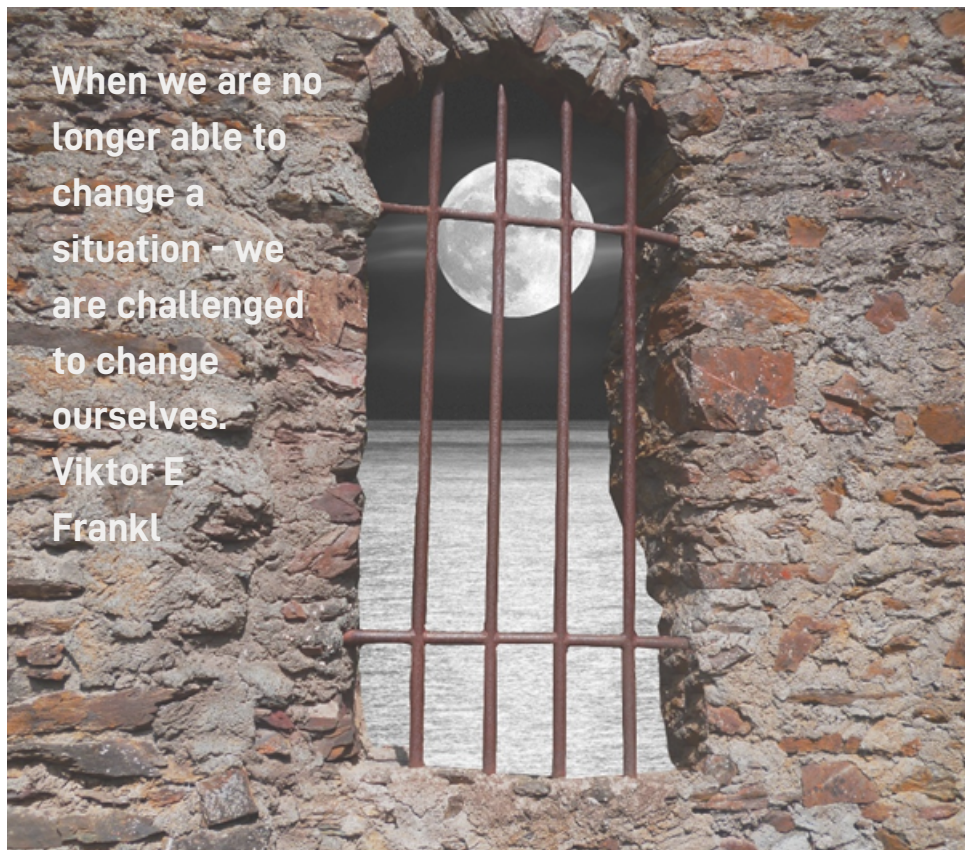
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Safety in Chronic Illness

- 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.

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- livescience.com/parasympathetic-nervous-system-rest-and-digest



Maslow's Hierarchy of Need

Safety is of utmost importance as it forms the foundation of overall well-being. Feeling safe is essential for our mental and emotional health.

Living with Mast Cell Activation Syndrome (MCAS) can significantly undermine our sense of safety, making it challenging for us to feel secure and protected.

This can result in not feeling safe within our own bodies and environment, as the unpredictable nature of MCAS can create a constant state of vulnerability.

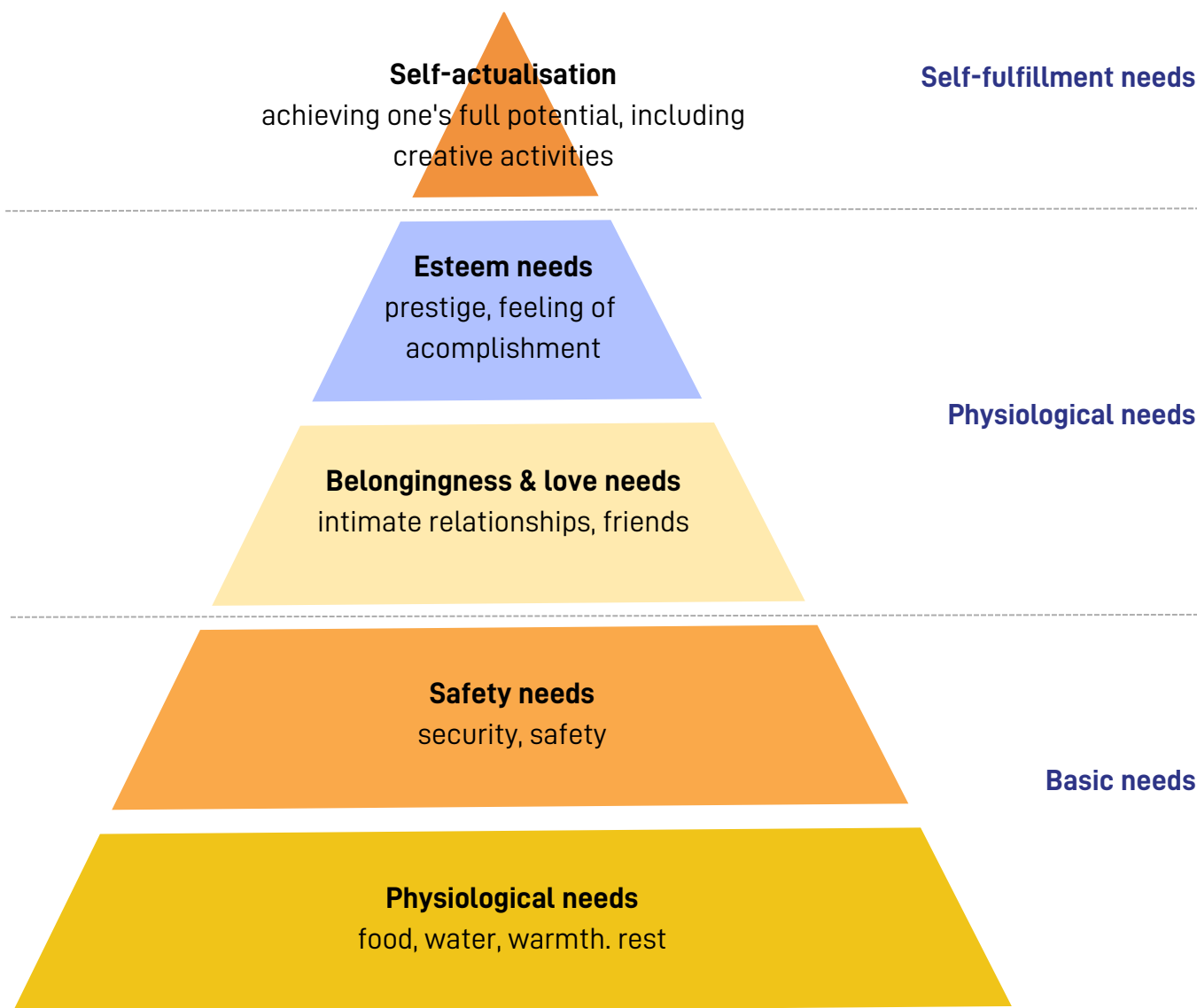
Being unable to eat safely adds to the difficulties often faced by those with MCAS, as it can erode our sense of security and impact our overall well-being.

These challenges have a profound effect on our well-being and mental health, as the constant feeling of being unsafe can contribute to heightened anxiety and stress.

It is crucial to consciously prioritise and incorporate safety measures into our daily lives, taking proactive steps to promote a sense of safety and security within ourselves and our surroundings.



Maslow's Hierarchy of Need



Some 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

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

It is important to clarify that we are not saying that thinking happy thoughts prevents mast cell reactions. It is not a mental health condition but a physiological response.

We are not suggesting that you should feel happy about having Mast Cell Activation Syndrome (MCAS) or pretend to be thrilled about it. This is not about adopting a "Pollyanna Syndrome" approach and trying to fake happiness despite the challenges. It is not related to any ideas of manifesting outcomes through thoughts.

Instead, this is about understanding the biochemistry involved and the chemicals released within our bodies during MCAS reactions.

An analogy can be drawn to a fire: If we consider MCAS to be like a fire burning within us, we know that our thoughts alone cannot extinguish it. However, we have a choice in how we respond. We can calmly sit next to the fire and patiently wait for it to burn out naturally.

Alternatively, we can metaphorically pour petrol on the flames and intensify the inferno by dwelling on negative thoughts and emotions.

How we utilise our thoughts and mindset can have a significant impact on our overall well-being, affecting our ability to cope and navigate through the challenges of MCAS.



Thoughts

True or not true? It is a fact that living with Mast Cell Activation Syndrome (MCAS) can be an incredibly challenging experience. It often brings fear, worry, stress, and frustration, and can bring an overall sense of cruelty and unfairness.

It is entirely understandable for us to think about the difficulties we face, the misery we may feel, and to be concerned about the future, causing anxiety about our situations.

This is a normal response, and anyone in similar circumstances could feel the same way. But, is it helpful or unhelpful? It is true to think, "I might have a reaction tomorrow, and it might be awful." However, it is worth considering whether thinking in this way is helpful. Such thoughts can trigger stress hormones in our bodies, activate "danger signals" in our nervous system, and signal danger to our mast cells, potentially increasing the likelihood of a reaction.

It is important to acknowledge that it is not possible to completely stop these thoughts from occurring. However, we can become more aware of them and make a conscious choice to reduce the time we spend "throwing matches at ourselves" with these thoughts.

By becoming more aware of the amount of time we spend dwelling on these "unhelpful" thoughts and consciously choosing to focus on safety rather than danger, we can help minimise the impact on our bodies and overall well-being.

Thinking helpful thoughts

It is important to notice our thoughts and make an effort to replace unhelpful thoughts with more helpful ones.

By becoming aware of our thoughts and recognising when we are fixating on negative and worrying thoughts, we can take steps to address them. It is important not to be too hard on ourselves in this process. We should acknowledge that it is challenging and perfectly normal to find it difficult.

We can gently encourage ourselves to shift away from unhelpful thoughts and deliberately choose more helpful ones whenever possible.

One way to do this is by intentionally focusing on positive things, things we enjoy, and things that bring us happiness as frequently as we can. By doing so, we are nurturing a sense of safety within our nervous system, promoting a healing state in our bodies, and reducing the "danger" signals being sent to our mast cells through the nervous system.

This is not about blaming ourselves for feeling bad when things are tough. It is okay to acknowledge that things are difficult, and some days may be more challenging than others. It is a process, and it's important not to blame ourselves for feeling anxious or worried. We can simply try again later.



Sending Signals of Safety

- Incorporate breathing exercises into your daily routine as they can help promote relaxation and reduce stress levels.
- Utilise mindfulness tools such as meditation or grounding techniques to bring your attention to the present moment and cultivate a sense of calm and clarity.
- Practice affirmations by repeating positive statements about yourself and your abilities, which can help boost self-confidence and promote a positive mindset.
- Take time to notice and appreciate joyful moments in your life, no matter how small, as they can bring a sense of happiness and positivity.
- Cultivate gratitude by actively noticing and acknowledging the things you are grateful for, which can shift your focus towards the positive aspects of your life.
- Be kind to yourself and practice self-compassion, treating yourself with the same kindness and understanding you would offer to a friend.
- Avoid beating yourself up over perceived shortcomings or mistakes, and instead, learn from them and practice self-forgiveness.
- Work on cultivating a sense of self-worth by recognising your inherent value and focusing on your strengths and accomplishments.
- Take proactive steps towards your own well-being, such as engaging in activities that bring you joy, seeking support when needed, and prioritising self-care practices.
- Take action for yourself and cultivate a sense of control by setting goals, making decisions that align with your values, and taking responsibility for your own happiness and fulfilment.



Breathing Exercises

The breath is a powerful tool for managing stress. Inhaling represents the breath of stress, while exhaling symbolizes the breath of relaxation.

By directing your focus on intentionally making the 'out' breath longer than the 'in' breath, you activate the parasympathetic system, which is responsible for inducing a state of calm and relaxation. Try the breathing techniques below to see if they feel comfortable for you.

The 7-11 breathing method

- Inhale for a count of 7
- Exhale for a count of 11

This prolonged exhalation helps promote a deeper state of relaxation.

The 4, 6, 8 breathing pattern

- Inhale for a count of 4
- Hold your breath for a count of 6
- Exhale for a count of 8.

This pattern helps regulate breathing and promotes a sense of tranquillity.

It's important to note that these techniques may not work for everyone, and that's perfectly okay. It's crucial not to force yourself to follow a specific breathing pattern if it doesn't feel comfortable or natural to you.

Remember, the goal is to find a breathing technique that works best for you and supports your relaxation and stress management.



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.

To practice mindfulness, try the following:

- Stay present in this moment, focusing your attention on the here and now, instead of being drawn into thoughts about the past or worries about the future.
- Notice your thoughts, observing them as an outside observer, rather than fully identifying with them and letting them consume you.
- Utilise your five senses as a way to anchor yourself in the present moment. Pay attention to what you can see, hear, touch, taste, and smell, allowing these sensory experiences to ground you in the present.
- Use the breath as a powerful tool for grounding yourself in the present moment.
 - Mindfully bring your awareness to the sensation of your breath, observing it as it naturally flows in and out, without trying to force or change it.
 - Practice mindful awareness of the breath, focusing on observing the breath without judgment. Allow the breath to be as it is, simply noticing its rhythm and flow without attaching any labels or evaluations to it.



Affirmations

It is one thing to refrain from excessively dwelling on unhelpful thoughts, but actively replacing them with "helpful" thoughts has also been shown to have significant benefits. Having a set of "helpful" thoughts ready to deploy can be beneficial when we catch ourselves entertaining unhelpful thoughts.

Try creating a personalised statement that resonates with you, focusing on the positive. Instead of using "I am NOT," embrace affirmations like "I AM..." to affirm safety, calmness, and the temporary nature of the situation.

By repeating these affirmations, we send signals of safety into our nervous system, effectively replacing the "danger" signals. This process helps build new neural pathways in our brains. The more we focus on helpful thoughts, the easier it becomes to traverse these pathways, gradually reducing our focus on unhelpful thoughts. Think of it as creating desire lines in our minds.

By actively cultivating and embracing helpful thoughts, we can rewire our thinking patterns and foster a greater sense of well-being and positivity.

References

- <https://positivepsychology.com/daily-affirmations/>



Joy and gratitude

It can be difficult for us to feel a sense of joy and gratitude when our lives are often challenging and overwhelming.

At times, we may find ourselves questioning what we have to be grateful for or what there is to feel joyful about given our circumstances.

There is often mention of "Gratitude Journals" and similar practices, but these may feel inaccessible to us when we are facing significant difficulties in our lives.

However, there is scientific evidence behind the power of joy and gratitude: It is impossible to experience both joy and fear simultaneously. When we genuinely feel joy, we automatically signal to our nervous system and mast cells that we are safe and in a positive state.

Similarly, it is impossible to feel gratitude and fear at the same time. Genuine feelings of gratitude also communicate safety to our nervous system and mast cells.

By embracing moments of joy and gratitude, even in the midst of challenges, we are actively signaling to our body that we are in a safe environment.

Remember, joy and gratitude can be found in even the smallest of moments, and acknowledging them can positively impact our well-being, providing a sense of safety and comfort in difficult times.

Top tips for joy and gratitude

- Make an effort to seek out and identify at least one thing each day that brings you a sense of joy. It can be something small—a blooming flower, a phone call from a friend, a clear blue sky, or a heartfelt letter.
- Incorporate activities into your daily routine that bring you joy and uplift your spirits. It could be stargazing, reading a book, taking a relaxing bath, or indulging in your favourite TV show.
- When you experience moments of joy, take the time to truly notice and appreciate them. Don't take them for granted. Allow yourself to fully feel and savour the joy they bring.
- Strive to find one thing each day that you are grateful for. It can be a small act of kindness, a warm smile, the comfort of a soft blanket, your favourite song, or the presence of a loved one.
- Take notice of this feeling of gratitude and allow yourself to fully experience it.
- Consider writing down these moments of joy and gratitude. By recording them, you compound the benefits and strengthen their impact on your well-being.
- During challenging times, revisit these written entries. Take the opportunity to read back through them, reliving the feelings of joy and gratitude. Remind yourself of the positive emotions you have experienced in the past to help uplift your spirits in difficult moments.
- By actively seeking joy, cultivating gratitude, and preserving these experiences, you can read back through them and 're-live' the joy and gratitude when things are more difficult, reminding yourself of that feeling.

Being kind to ourselves - not beating ourselves up

It can be challenging for many of us to be kind to ourselves, especially when we are facing the difficulties often associated with living with MCAS.

Sometimes we may struggle with self-compassion and may blame ourselves for our illness or 'beat ourselves up' on a regular basis.

Engaging in self-blame and self-criticism sends signals of danger to our nervous system, triggering the release of stress hormones that further impact our well-being.

The most beneficial thing we can do for ourselves is to practice kindness and self-compassion, recognise that the challenges we face are hard and difficult, and offer ourselves the same kindness and understanding we would extend to a friend who is suffering.



If you feel you have done something that was unhelpful, instead of berating yourself, acknowledge that it may not have been helpful, be kind to yourself, and strive to do better next time.

By embracing self-kindness and letting go of self-blame, we can create a nurturing and supportive environment within ourselves, fostering a sense of well-being and healing.

Being kind to ourselves - Cultivating a sense of self-worth

It is important to cultivate a sense of self-worth outside of having MCAS because it helps us to recognise our inherent value, strengths, and accomplishments beyond our health condition, fostering a positive self-perception and supporting our overall well-being.

Top tips for cultivating a sense of self-worth

- Take time to reflect on your accomplishments and remind yourself of what you have achieved and are capable of, despite the challenges of your illness.
- Recognise and embrace your unique talents and skills, owning them as part of your identity.
- Practice self-appreciation for who you are as a person, acknowledging your worth beyond your health condition.
- Consider your values and personal attributes that make you special and valuable, and reflect on how they contribute to your overall sense of self-worth.
- Create a list of your positive qualities and revisit it regularly, reminding yourself of your inherent value as an individual.
- Remember that being ill does not diminish your worth as a person; it is essential to separate your self-worth from your health challenges.
- Make a daily habit of reminding yourself of your value and worth outside of your illness, reinforcing a positive and healthy self-perception.
- Acknowledge that having an illness can sometimes lead us to criticise ourselves and feel negative about who we are, but it is crucial to consciously shift our focus to be more positive and cultivate a strong sense of our own value and worth, despite the presence of illness.

Being kind to ourselves - Taking proactive, positive steps

Focusing on taking proactive, positive steps towards your own well-being can help you to take control where possible.

Top tips for taking positive steps towards your own well-being

- Take small steps towards making your situation as good as it can be, whatever that looks like for you.
- Engage in learning and research about MCAS, empowering yourself with knowledge and understanding.
- By doing so, you gain a sense of control and safety, knowing that you are actively working towards managing your condition.
- The more you learn about your illness, the more equipped you become to help yourself, leading to better self-care and management.
- Advocate for yourself with friends, family, and healthcare professionals, believing in your ability to understand your own needs and expressing them confidently.
- Maintain a sense of hope, always believing that there is the potential for a better future and that you have the capacity to improve your health beyond your current state.

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



Purpose

Having a sense of purpose is linked to longevity and better physical and mental health and well-being.

Feeling a sense of contribution to something greater than ourselves, where our lives hold value, is important for our overall well-being. When we experience illness, especially if it hinders our ability to work, we can lose our sense of purpose.

Finding small ways that bring purpose and meaning into our lives can significantly impact our mental and physical well-being.

Depending on our situation, we can engage in activities such as:

- Feeding the birds
- Performing small acts of kindness for others
- Volunteering
- Helping someone else
- Offering support in online forums

These actions can help us to regain a sense of purpose and positively impact our well-being.



Top 10 Tips

1. Do not beat yourself up. About MCAS, or anything else!
2. Stay in the present, don't think about the past or future too much - Consider a 'Mindful Meditation' practice
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 well-being, however small.
8. Advocate for yourself and your well-being, 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.



Resources

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- Neuroscience of gratitude: [positivepsychology.com/neuroscience-of-gratitude/](https://www.positivepsychology.com/neuroscience-of-gratitude/)
- Explaining the Default Mode Network: [mpfi.org/how-does-mindfulness-change-the-brain-a-neurobiologists-perspective-on-mindfulness-meditation/](https://www.mpfi.org/how-does-mindfulness-change-the-brain-a-neurobiologists-perspective-on-mindfulness-meditation/)
- Book - Altered Traits: Science Reveals How Meditation Changes Your Mind, Brain and Body. By Daniel Goleman & Richard Davidson.



About me - the author

My name is Deborah Bircham, and I am the founder of Live Well With Chronic Illness.

I have a Diploma in Hypnotherapy and Psychotherapy and am a member of National Council for Integrative Psychotherapists. I specialise in teaching chronic pain-management techniques.

I trained in Mindfulness with the Teach 10 Institute, and I am also a member of the Association of Naturopathic Practitioners and the UK International Health Coaching Association. I specialise in teaching mindfulness for Chronic Illness and also practice as a Holistic and Naturopathic Wellness Coach, offering bespoke support for those living with Chronic Illness.

I have a particular interest in supporting people with Lyme Disease, MCAS, and Dysautonomia as a result of my own experiences with these health conditions. For 2 years I worked for a small national charity supporting people with chronic illness to return to work, and now I volunteer for Mast Cell Action as a Community Champion.

Using my skills and my lived experience to support others living with long-term health conditions is my vocation and has helped me regain a sense of purpose and direction in my own healing journey, and now my work focuses on supporting others to find their own path to wellness; mental, emotional and physical.

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