

Navigating MCAS together

Mast Cell Activation
Syndrome Support Guide
for Loved Ones



WELCOME

Welcome to "Navigating MCAS Together," a resource designed to provide you with guidance, and support if your loved-one is living with Mast Cell Activation Syndrome (MCAS). Whether you are new to supporting someone with MCAS, or you have been helping them for a while, we understand that caring about someone with MCAS can be both challenging and rewarding.

MCAS is a complex condition that affects many aspects of life, not just for those diagnosed, but for their loved-ones too.

This resource aims to equip you with the knowledge and tools to navigate the various challenges that may arise, while also offering practical advice to help you manage your own well-being.

Inside, you'll find clear explanations of what MCAS is, tips on supporting someone with this condition, and insights into becoming a formal carer, if that becomes necessary.

This guide is for those who are supporting an adult or child with MCAS, and includes advice on maintaining your own physical and emotional health, as well as practical guidance on how you can support your loved-one.

Our goal is to make this journey a little easier for you. With contributions from the community, and a wealth of useful contacts, this resource is designed to be not only informative but also uplifting. Remember, you are not alone—there is a community ready to support you every step of the way.

Please also refer to other resources on our website.



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What is MCAS?



What is MCAS?

Mast Cell Activation Syndrome (MCAS) is a condition which can develop in children or adults. Mast Cells are a type of blood cell found in all parts of the body. They are a key part of the immune system. Mast cells detect different types of triggers and tell other immune cells how to respond.

Mast cells are known as 'police officers' of the immune system' – spotting signs of trouble and calling for back-up when needed.

In a healthy state, mast cell mediators create a number of protective responses in the body to help fight infection and promote healing. In someone with MCAS, where these mediators are released too frequently, they can affect the body in multiple ways - causing multiple symptoms in different parts of the body at the same time.

Usual mast cell triggers include bacteria, parasites, viruses, stings and wounds. Additional triggers for many people with MCAS include food and environment.

In people affected by MCAS, mast cell mediators are released too frequently or abundantly, and/or in response to triggers that are not typically considered to be harmful, for example; foods or chemicals in the environment. This can lead to a wide range of symptoms that affect multiple parts of the body.

You can find out more about MCAS at www.mastcellaction.org.



Symptoms

MCAS symptoms can come and go and may often change over time within the same person. This can make it difficult to identify specific triggers, and the number of triggers and severity of symptoms may increase, or change, over time. Symptoms include:

Nasal-ocular (nose and eyes)

- Nose congestion
- Eye watering and itching

Respiratory (lungs & breathing)

- Sore throat
- Hoarseness
- Wheezing
- Shortness of breath
- Throat swelling

Musculoskeletal

- Joint & muscle pain
- Osteoporosis (brittle bones)
- Loss of bone mass

Genital and urinary

- Genital pain or swelling
- Pain when urinating
- Vaginal pain, discharge or itching
- Bladder urgency or loss of control

Dermographic (skin)

- Flushing/redness
- Hives or wheals
- Itching with or without a rash
- Swelling



General

- Extreme tiredness
- Anaphylaxis, which can be life threatening

Neurologic (brain and nerves)

- Headache
- Brain fog (memory and concentration difficulties)
- Numbness, pain or tingling skin
- Anxiety
- Behavioural issues, rages

Cardiovascular

- Chest pain
- Low blood pressure
- Fast heart rate
- Fainting or light-headedness

Gastrointestinal (digestive system)

- Bloating
- Stomach cramps or pain
- Reflux
- Feeling or being sick
- Diarrhoea
- Constipation
- Dumping syndrome
- Food allergies or intolerance

Triggers

Triggers and symptoms of MCAS vary greatly between individuals. Triggers can include fragrances, exercise, stress and changes in temperature.

While there are some common triggers, most people affected by MCAS struggle to identify all the triggers responsible for their episodes. And each individual has a unique set of triggers that cause their mast cells to overreact.

Common triggers include:



Telling others about MCAS

Telling others about MCAS can be difficult. It is a complex condition with lots of different components to understand.

You might find the explanation below useful in helping you simplify MCAS for others:

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Mast Cell Activation Syndrome (MCAS) is a condition where certain cells in your body, called mast cells, release too many chemicals too often.

Think of mast cells as tiny "guard" cells in your body that help defend against things like infections or allergens.

Usually, these cells release chemicals (like histamine) when they detect something harmful, such as an allergen. This helps your body react and protect itself.

In MCAS, these mast cells become overactive. They release too many chemicals even when there's no real danger. It's like your body's alarm system going off all the time for no good reason.

Because of this overreaction, you can have a lot of different symptoms. These might include itching, hives, stomach pain, headaches, or trouble breathing. The symptoms can vary a lot from person to person and can sometimes be mistaken for other conditions.

Different things can trigger these overactive responses, like certain foods, stress, temperature changes, or even strong smells.

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2 Supporting someone with MCAS



Supporting someone with MCAS

Caring for someone with MCAS can be a complex and demanding task.

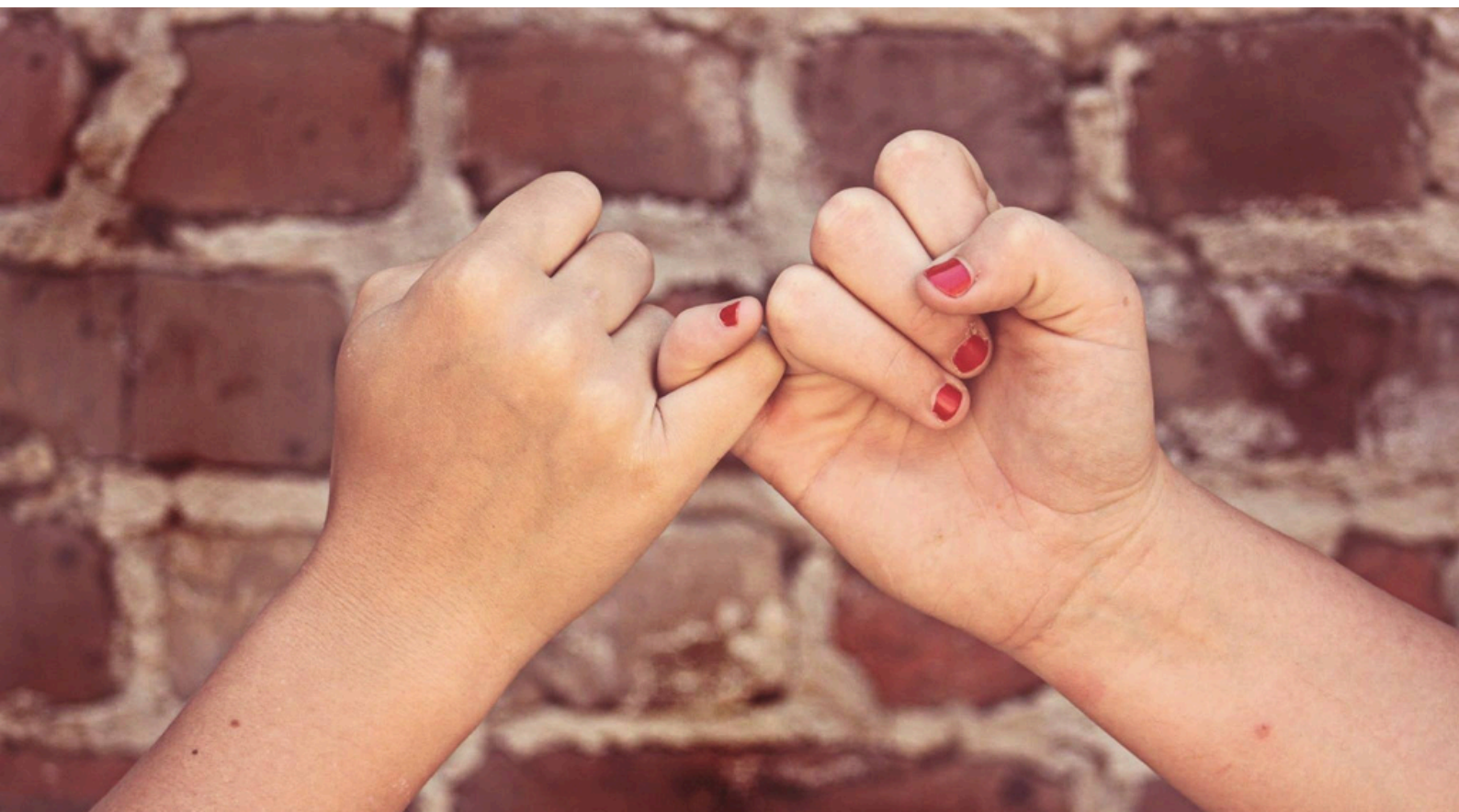
One of the most important aspects of caring for someone with MCAS is ensuring their environment is safe and free from common triggers. This might involve:

- **Eliminating Triggers:** Use safe products, keep the home well-ventilated, and avoid using strong fragrances or chemicals.
- **Supporting with Diet:** Help plan healthy meals that avoid potential triggers and help your loved-one to identify and avoid foods they need to eliminate in their diet.
- **Managing Stress:** Help your loved one manage stress through relaxation techniques, creating a calm environment, and ensuring they have time to rest.

Being Prepared for Emergencies

MCAS can sometimes lead to sudden and severe reactions. It's crucial to be prepared so that you can are ready to act in an urgent situation:

- Ensure that emergency medications, such as antihistamines or epinephrine injectors, are always easily accessible. Ensure your loved-one and you know how to use them and when to seek medical help.
- Keep a list of emergency contacts, including healthcare providers, on hand. Make sure you know the quickest route to the nearest medical facility.



Supporting someone with MCAS

Emotional Support

Living with MCAS can be isolating and overwhelming for your loved one. Providing emotional support is just as important as managing physical symptoms:

- Allow your loved one to express their feelings and frustrations. Listen without judgement and validate their experiences.
- Help them find activities that bring joy and relaxation. This might include light exercise, hobbies, or spending time with friends and family in safe environments.
- Encourage your loved one to connect with others who have MCAS. Online communities or support groups can be a valuable source of comfort and information.

Communication with Healthcare Providers

Effective communication with healthcare professionals is key to managing MCAS. The tips below might be helpful in supporting your loved-one at medical appointments:

- Keep a Symptom Diary: Help your loved-one to track symptoms, triggers, and reactions. This will help healthcare providers tailor their treatment plans more effectively.
- Don't be afraid to ask healthcare providers about your loved-one's treatment options, potential side effects, and any concerns you may have.
- Be your loved one's advocate, ensuring they receive the best possible care and support.

Supporting someone with MCAS is a journey that comes with challenges, but your care and understanding can bring comfort and strength and transform your loved-one's experience for the better.

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Navigating MCAS as a family has been challenging, but it's also strengthened our bond and taught us to advocate for each other.

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3

Advocating on behalf of someone with MCAS



Advocacy

Here at Mast Cell Action we are committed to empowering people living with MCAS or suspected MCAS, and those whose loved-ones have MCAS or suspected MCAS. We hope to empower you and your loved-one to advocate for yourselves.

We understand the challenges and complexities that often accompany life with MCAS, and we provide resources and support to help individuals advocate effectively.

Self-advocacy is being able to speak up for yourself, assert your needs, and actively participate in decision-making regarding your health and well-being.

For people living with MCAS, self-advocacy can be critical for managing their condition.

However, people who have MCAS can sometimes feel too unwell to advocate for themselves, or need support to be able to do this. At those times, help from loved-ones like you can be crucial in helping them make their voices heard.



Advocacy

Key Aspects of Being Able to Advocate for Someone Else

Education:

Knowledge is power. [Understanding MCAS](#), its [symptoms](#), [triggers](#), and treatment options is essential for effective advocacy.

We know that sometimes MCAS can be confusing and feel difficult to understand, and hard to explain. We provide as many [resources](#) as possible to empower individuals with MCAS to become 'patient experts' in their condition. You can use these resources too, to help you to understand your loved-one's health needs. Take time to explore these resources, and to become familiar with your loved-ones specific triggers and symptoms, so that you can help them to stay safe, and be their voice when they need help.

Communication:

Effective communication with healthcare providers, family members, employers, and educators is vital. People with MCAS often find it difficult to articulate their needs and make their voices heard so that they can receive the support they need.

Often, having a loved-one to communicate for them when they are in a flare can be helpful. Everyone will be different. It's important that you allow your loved-one to speak for themselves when they can, but also recognise that sometimes they may need your help. Discuss this with your loved-one and find out what support they feel they need. This can be especially helpful to talk about before hospital or other medical appointments.

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I've discovered that the most important thing I can do is listen and validate their experiences—it's made all the difference.

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Advocacy

Key Aspects of Being Able to Advocate for Someone Else

Self-Care:

Prioritising self-care is important for people with MCAS. This might include maintaining a healthy lifestyle, managing stress, getting adequate rest, and adhering to treatment plans where possible.

Often, people with MCAS find it hard to put their own needs first, so as their loved-one, your advocacy role could include helping your friend or family member to prioritise self-care, as well as helping to provide them with the resources and support they need for this. Perhaps you could enjoy some self-care together, as it's important for you too. Find out more in chapter 10.

Seeking Support:

No one should have to navigate MCAS alone, and supporting someone with MCAS can sometimes feel lonely. But you don't have to feel alone!

There may be times when your loved-one needs more support, in addition to what you can provide for them. Seeking support from peers, support groups, and advocacy organisations can provide invaluable emotional support, practical advice, and a sense of community, for you both.

Mast Cell Action serves as a hub for individuals to connect with others facing similar challenges. Talking to others who have experience of supporting people with MCAS can be really helpful and help us to feel less alone.



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Finding the right support services has been a lifeline, helping us understand MCAS and connect with others who truly get it. We now have the tools and confidence we need to navigate this condition.

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You are not alone

Advocacy is not just about speaking up—it's about reclaiming control, asserting your loved-ones rights, and advocating for the support and resources that they deserve. At Mast Cell Action, we stand alongside everyone with MCAS, and their carers and loved-ones, on their journey toward empowerment and self-advocacy.

By arming yourself with knowledge, you can learn how to effectively advocate for your loved-one - despite the challenges posed by MCAS. Remember, their voice matters, and so does yours. You both have the right to be heard and supported.

Together, we can amplify our voices, drive positive change, and create a world where people living with MCAS have the support they need.



How to Be Heard

Being heard and taken seriously by healthcare providers, educators, and others is essential for effectively managing MCAS and accessing the support your loved-one needs.

In order to help you advocate for them and help them make their voice heard, we have provided some strategies below which may be helpful.

- **Prepare for Appointments:** Use our guide on the next page to help your loved-one prepare for medical appointments.
- **Speak Up:** Don't be nervous about speaking up and sharing your loved-ones needs and preferences with others. Help them to clearly communicate their symptoms, treatment experiences, and any challenges they're facing. Be concise, specific, and confident in expressing yourself, and speaking up on behalf of your loved-one if you feel you need to.
- **Ask for Clarification:** If you don't understand something a healthcare provider says, don't hesitate to ask questions. It's important to fully understand your loved-one's condition, treatment options, and any accommodations or support they are being offered, and make sure it's right for both of you.
- **Seek Advocacy Support:** If you feel your loved-one is not being heard or is having difficulty accessing the support they need, you might find it helpful to seek advocacy support from trusted people, such as your wider circle of friends and family, counsellors or independent organisations. They can help you navigate challenging situations, communicate effectively with relevant parties, and advocate for your rights and needs. You can find out more about [advocacy](#) support here.



Preparing for Appointments

People with MCAS often find themselves navigating a complex healthcare landscape, and medical appointments may not be straightforward. To get the best out of your appointments, it's a good idea to do some preparation.

- **Before Appointments:** Prepare a list of questions, concerns, and goals. Use our ready-made [Doctor Visit Preparation form](#) to help. Being organised and informed shows that you are serious about managing your condition together and can help facilitate productive discussions and help you prioritise your appointment time to get the most from it. It is often reassuring for medical professionals to see that someone with MCAS has a support network around them, so don't be afraid to accompany your loved-one.
- **Research and Learn:** It can be helpful to understand the biology and terminology around MCAS, common symptoms, triggers, and available treatment options, as this may help facilitate understanding between you and the doctor. Reliable sources such as medical journals, reputable websites, and educational materials provided by organisations like ours can help you build a solid understanding.
- **Keep a Symptom Journal:** Support your loved-one to complete a [symptom journal](#) to track their experiences. Note down any symptoms they experience, potential triggers, and the effectiveness of different treatments or lifestyle changes. This information can be invaluable when discussing their condition with healthcare providers and helping to spot patterns and develop personalised management strategies for them. Take this to your appointment, with any records or test results.
- **Stay Informed about Your Rights:** Educate yourself about the rights your loved one has when living with a chronic health condition. Familiarise yourself with laws and regulations related to education, accommodations, and access to healthcare services. Become familiar with best practice care for MCAS, and also consult the NICE Guidelines for any other conditions your loved-one has. Knowing their rights empowers you to advocate effectively for the treatment they need.
- **Find Out What Works for Others:** Reach out to others who are living with MCAS and find out what helped them. Discuss this with your loved-one then talk about this with their medical team. Connect with others via our [online forums](#), social media groups, [Our Stories](#) webpage, and local support groups to hear about others' experiences.

Family

Because of the nature of MCAS, and the need to create a safe home environment and limit trigger exposure, when one person in the family has MCAS, it affects everyone in the home. People living with MCAS rely on the support and cooperation of those around them to manage their condition successfully and stay as well as possible. Having the right support can help people with MCAS to remain more stable. On the other hand, not having support in place can negatively impact their health. So supporting someone with MCAS can feel like a big responsibility.

When a family member is diagnosed with MCAS, it can bring significant changes and challenges. However, families often discover profound resilience and opportunities for growth during this journey.

Family members often discover new strengths and talents in themselves and each other. Whether it's mastering new medical knowledge, finding innovative ways to make daily life easier, or providing emotional support, these hidden strengths come to the fore. Recognising and celebrating these abilities can boost individual self-esteem and reinforce your family's collective resilience.

MCAS often leads to a greater appreciation for life's simple joys. Families may come to cherish moments of good health, celebrate small victories, and find joy in everyday activities.



4

Taking on a Caring Role



Becoming a Carer

Often, people find they have become a carer without really thinking about it. It is common for us to take on caring responsibilities for those we love as they start to need additional support. It can feel strange sometimes to realise that you might be a 'carer', and often people don't think of themselves this way. But whether this word resonates with you or not, if you are performing caring duties for a loved-one, it's important to also consider your needs, and recognise the impact on you.

Caring for someone with MCAS can be a challenging and emotionally taxing experience. It's important to acknowledge and address the emotional impact this role can have on you as a caregiver.

Some of the emotional challenges you might face are stress and anxiety. The unpredictability and varying severity of MCAS symptoms can keep you constantly on edge. Additionally, the complex and misunderstood nature of MCAS often leads to long diagnostic processes and uncertain treatment plans, causing anxiety about the future. These factors can create a significant amount of stress, making it difficult to relax or feel secure.

Feelings of helplessness are also common among caregivers. It can be incredibly frustrating and disheartening to see your loved one in distress and feel unable to help. This sense of powerlessness can erode your emotional well-being over time. Continuous care demands can lead to emotional fatigue and burnout. The constant need for support by your loved one can drain your own energy, affecting your overall well-being. Night-time symptoms or emergencies can disrupt your sleep, leading to physical and emotional exhaustion.



Guilt and resentment can also emerge over time. You might feel guilty about taking time for yourself, which can hinder your ability to engage in necessary self-care. Despite your deep love and commitment to the person you're caring for, the constant demands of caregiving can lead to feelings of resentment. Acknowledging these feelings is essential to prevent them from affecting your relationship and emotional health.

To cope with these emotional challenges, seeking support is crucial. Connecting with other caregivers through support groups, whether online or in-person, can provide a sense of community and shared understanding. Professional counselling can offer a safe space to express your feelings, develop coping strategies, and manage stress.

Prioritising your health is also essential. Ensure you get regular exercise, eat a balanced diet, and get adequate rest. Taking breaks and time for your personal interests is crucial for maintaining your well-being. Mindfulness and relaxation techniques, such as mindfulness meditation, yoga, or deep-breathing exercises, can help you manage stress and improve emotional resilience.

Educating yourself about MCAS can reduce anxiety and help you feel more in control. Stay informed about the latest research and treatment options, and work closely with healthcare providers to ensure the best care for your loved one. Don't hesitate to ask questions or seek second opinions when needed.

Building a support network can lighten your caregiving load. Involve family and friends, and don't be afraid to ask for help.

You are not alone, reach out to Mast Cell Action for support and to connect with others who understand.



5

Supporting Adults with MCAS



Supporting Adults with MCAS

Supporting an adult with a chronic illness like MCAS presents unique challenges that can deeply impact both the carer and the person being cared for. The unpredictable and often debilitating nature of MCAS symptoms can make daily activities difficult to plan, requiring constant flexibility. This can put a strain on personal relationships, as roles and dynamics shift to accommodate the needs of the person with MCAS.

For the person living with MCAS, needing help may lead to feelings of guilt, frustration, or a loss of independence, as they adjust to relying on someone else for tasks they once managed alone. These changes can affect their self-esteem and sense of identity, potentially leading to feelings of isolation or depression. This may manifest in irritability or withdrawal, which can be difficult for loved ones to understand.

For those giving support, the emotional toll of watching a loved one struggle, combined with the practical challenges of helping them, can be overwhelming. Both parties may grieve the loss of their previous relationship and lifestyle, making it crucial to prioritise open communication, emotional support, and self-care to navigate the complexities of this new reality together.

It is important to recognise that people with MCAS, and their loved ones, can lead happy and fulfilled lives, and symptoms can fluctuate and improve over time, and with careful management. Working together to adapt and create a new way of life which feels positive and fulfilling for both of you is, for many, a good way to face the future.



6 Supporting Children with MCAS



Supporting Children with MCAS

Caring for a child with MCAS can be emotionally and physically demanding, as the condition's unpredictable nature makes it difficult to plan and manage daily routines. For parents or carers, the challenge of balancing medical care, monitoring triggers, and managing your child's emotional needs can feel overwhelming.

MCAS often requires strict control over triggers such as environment, diet, and activities, often limiting your child's participation in everyday experiences, which can lead to frustration for both your child and you.

Your child may feel isolated or different from their peers, which can impact their self-esteem and emotional well-being. They might struggle to understand why they need extra care.

For you, as their parent or carer, this can create a sense of guilt and sadness, as the illness alters the typical parent-child relationship and introduces stress into what should be carefree moments. Despite the challenges, providing emotional support, helping your child feel empowered in managing their condition as it becomes appropriate, and maintaining open communication about their feelings can foster resilience in both your child and you as their carer.

It's important to remember that caring for a child with a chronic illness is not just about medical management—it's about helping them grow emotionally, feel secure, and maintain a sense of normalcy in their life where possible.

You are not alone, there is a whole community of people coping with MCAS. Reach out to find out how you can connect with others who understand.



Supporting Children with MCAS

Caring for a child with MCAS comes with unique emotional challenges, as your child may feel angry, frustrated, anxious, or isolated due to their condition, and this can cause emotional strain for you and them. Offering emotional support is key to helping them cope with the physical and emotional impact of MCAS. As a parent or caregiver, your role goes beyond just meeting their physical needs—you are their emotional anchor. By creating a safe space for open communication and showing that their feelings and opinions matter, you can help them build resilience and emotional intelligence.

Below are some tips for how you can emotionally support a child with MCAS:

Validate Their Feelings: Acknowledge your child's emotions, whether they're feeling scared, frustrated, or overwhelmed by their symptoms. Let them know it's okay to feel upset and that you're there to help them through it.

Encourage Open Communication: Regularly check in with your child about how they're feeling, both physically and emotionally. Create a safe space where they feel comfortable expressing concerns or fears without judgment.

Help Them Understand Their Condition: Age-appropriate explanations of MCAS can help reduce fear and confusion. Use simple language to explain why they experience certain symptoms and what they can do to manage them, empowering them to take control where possible.

Normalise Their Experience: It's important for children with MCAS to feel that they are not alone. Sharing stories of other kids who have similar challenges or connecting with support groups can help them feel less isolated and different from their peers. Order your free Casper the Chameleon Book by filling out this [form](#).



Supporting Children with MCAS

Offer Comfort During Difficult Times: When symptoms flare up or treatments feel overwhelming, be there to offer comfort - whether through physical affection, distraction, or simply being present. Reassurance during these moments can help your child to feel supported and less alone.

Promote Emotional Expression: Encourage your child to express their feelings through creative outlets like drawing, writing, or talking. These activities can help them process their emotions in a healthy way, especially when words are hard to find.

You can find a range of creative resources for children with MCAS on the [Mast Cell Action Casper](#) resources page.

Foster Resilience and Positivity: While it's important to acknowledge the challenges of living with MCAS, it's also helpful to highlight your child's strengths and celebrate their accomplishments. Reinforcing their resilience could help them feel more confident in handling difficult situations.

Take Care of You: It's important to take time to care for your own wellbeing, too, using some of the tools later in this guide, so that you can nurture your own reserves of resilience so you can be your best self for your child. Our [Parent Support Leaflet](#) has lots on information about taking care of yourself while looking after a child with MCAS.

Use our School Packs: We have a [Freedom Kit](#) to help Primary Schools care for children with MCAS and a [Supporting Safe Learning for Students](#) with MCAS pack to help your child at secondary school, for both teachers and students.

You can find a range of resources and information about supporting children with MCAS on our website, [here](#).



7 Young Carers



Young Carers

Young carers are people under the age of 18 who regularly provide a substantial amount of help to a family member, often a parent or sibling, who is living with a chronic illness, disability, mental health condition, or addiction. Those who have parents or siblings with MCAS may inevitably find that this impacts on them, and they may have to provide some caring duties.

This might involve help with physical care, medication management, medical appointments and hospital visits, or even dealing with medical emergencies like anaphylaxis. They may also have to help with cooking, cleaning and household chores if loved-ones are unable to perform these due to reactions and chemical sensitivities.

While caring for a loved one can be rewarding, it is especially challenging for young people and may cause them emotional strain, social isolation, and disruption to their education and personal development.

Young carers often demonstrate immense strength, compassion, and resilience in their daily lives.

While it can be difficult to balance their own needs with those of the person they care for, young carers often develop a deep sense of empathy, maturity, and problem-solving skills that set them apart from their peers.

If you are a young carer, remember you are never alone; see the next pages for resources and organisations that can provide guidance, encouragement, and help.



Young Carers

Sources of Support

- **Teachers.** If you are caring for someone at home, it's important to talk to your teachers about this. Teachers are there to help you to thrive at school. It's helpful to tell them about any problems you are having. If you're missing lessons to help look after someone at home, or struggling to get your work in on time, talk to a teacher so that they can understand what is happening and give you more help. There are lots of ways your school can help, so speak to your teachers to find out what support they might be able to offer. The school could also put you in touch with your local young carers service, or get a young carers worker to talk to you.
- **A GPs or nurses.** Those who are helping the person you look after can organise more support for them, to help you concentrate on school or college. Speaking to your GP or practice nurse can be a good idea.
- **Counsellors** often work in schools or hospitals and their job is to listen to you and provide emotional support that is completely confidential.
- **Social Workers.** A social worker from your local council has to visit, if you or your parents request this. Social workers may be asked to help a young carer's family if there are problems that the family members are finding hard to sort out on their own.
- **Local Authorities** have a duty to assess whether a young carer living in their area needs support.



Young Carers

Other Sources of Support

- [Meeting other young carers](#) is a great way to make new friends, have some fun and share some of your worries with people in a similar situation.
- [Young carers projects](#) can give you a break from home, and give you time to relax and make friends. Young carers projects may offer evening clubs, weekends away, days out and even holidays, as well as friendly advice and information for you and for your family.
- [The Children's Society](#) can help you find a young carer group in your local area. They also run the [Young Carers Festival](#).
- [Sense](#) run online and in-person activities for young carers under 18.
- [The Mix](#) has a weekly online support group for young carers up to the age of 25.
- [Carer's Trust](#) offers information and advice for young carers, and runs local support services.
- [Sidekick](#) by Action for Children is a text message and email support service for young carers.
- [Citizens Advice](#) has information on money, benefits and your rights.
- [The National Careers Service](#) has a helpline, webchat and email service about education and careers for teenagers. Support is also available up to the age of 25 for those who have learning difficulties or disabilities.



8

Mental Health and MCAS



Mental Health and MCAS

During an MCAS reaction, your loved one may experience mental health symptoms, like feeling anxiety, anger, weepiness, depression, or a feeling of 'impending doom.'

These are all common MCAS symptoms, as the chemicals being released by mast cells can affect the brain and the nervous system, causing emotional and mental changes. It may even be the case for some people that their main symptom is mood changes.

Your loved one may behave out of character during a reaction, for example by being angry, irritable, irrational, fearful, or even experiencing worryingly low moods.

Sometimes people with MCAS may not understand themselves why they are feeling these emotions. They may say things like 'It's not really me', or 'I don't know why I'm crying.' Children can also be affected by this, and you may notice behavioural changes.

These sudden emotional changes can be alarming and distressing for the person with MCAS, and also for their loved ones.

It can be helpful to recognise that this is a symptom of a reaction. This can be helpful to spot, so you can identify when someone you care about is reacting to something.

During these times, your loved one will need your support and understanding, and forgiveness if they behave out of turn. Giving them reassurance and being a stable, grounding presence for them while they are experiencing these reactions will help them through it.

People with MCAS experiencing mental distress can also ring The Samaritans on 116 123 or Text Shout to 85258 to talk to someone in confidence about how they are feeling.



9

Financial and Legal Help



Financial Support

If you are caring for someone with MCAS, you may be entitled to financial support, such as Carer's Allowance

To be eligible, the person you care for and the type of care you provide must meet certain criteria. You can find out more at gov.uk/carers-allowance

To be eligible, you will need to spend at least 35 hours a week caring for someone.

Among other things, this might include:

- Helping with washing and cooking
- Taking the person you care for to a doctor's appointment
- Helping with household tasks, like managing bills and shopping
- Supporting them with personal care and grooming

If you claim Carer's Allowance, this may affect any other benefits you get, and also the benefit received by the person you are caring for.

It's important to seek advice about benefits.

You can find out more about benefits for carers [here](#)

[Citizen's Advice](#) can also give advice about benefits and help you fill in the forms.



Legal Support

Managing your own life whilst caring for someone can be difficult. Remember that you have certain legal rights and entitlements.

As a Carer, you have rights under the 2014 Care Act, which sets out the responsibilities that local authorities have to you as an adult carer.

Under this legislation your local Council have a duty to offer you an assessment of your caring role and to provide you with the financial and practical support you might need.

You also have protections under The Equality Act 2010. Under the terms of this Act, a carer must not be discriminated against on the basis of their association with a disabled person, so you cannot be treated unfairly as a result of your caring duties.

Additionally, if you're a carer juggling work alongside your caring role, you also have employment rights. This includes the right to request flexible working and the right to take unpaid time off during emergencies without affecting your employment.

It is important to check your contract and your employer's compassionate leave policy, as each employer will offer different terms.

You can find out more about your legal rights as a Carer on the [Carer's UK](#) website. [Citizens Advice](#) can also give you advice about this.



10 Taking time for you



Taking time for you

Caring for someone with MCAS can be both rewarding and challenging. It's easy to become so focused on meeting their needs that you forget about your own. But taking time for yourself is not just a luxury—it's a necessity. By caring for yourself, you'll have more energy, patience, and resilience to support your loved one.

Prioritise Self-Care

Just as you schedule appointments and manage symptoms, schedule time for self-care, whether it's a quiet cup of coffee in the morning, a walk around the block, or a moment of meditation, these small breaks can help you recharge.

Set Boundaries

It's okay to say no. Setting boundaries is crucial to maintaining your own health and well-being. Communicate clearly with others about what you can and cannot do. Remember, it's not selfish—it's essential.

Ask for Help

You don't have to do it all on your own. Reach out to friends, family, or support groups. Whether it's someone to talk to, help with chores, or a few hours of respite care, accepting help can ease your load and give you time to focus on yourself.

Stay Connected

Maintaining social connections can help prevent feelings of isolation and burnout. Even if you can't meet in person, a phone call, text, or video chat with friends or family can provide much-needed support and a break from caregiving duties.



Taking time for you

Practice Mindfulness and Stress Management

Stress can take a toll on your physical and emotional health. Techniques like deep breathing, meditation, or journaling can help manage stress and keep you grounded. Taking a few minutes each day to centre yourself can make a big difference. You can find some Mindfulness resources and tools [here](#).

Don't Ignore Your Own Health

It's easy to neglect your own health when caring for someone else, but your well-being is just as important. Keep up with your own medical appointments, eat well, and get enough rest. You can't pour from an empty cup.

Celebrate Small Wins

Caregiving can be exhausting, but it's also filled with meaningful moments. Celebrate the small wins, both yours and your loved one's. Recognising these moments can help you stay positive and remind you of the impact of your care.

Beware of Burnout

Professor Marie Asberg, an expert on burnout, talks about the funnel of exhaustion. She found that, as soon as we feel like we don't have enough time or energy, it is the nourishing things that we drop first, such as eating well, exercising, doing hobbies, and socialising with friends. But these are the things that sustain us and enable us to keep going, filling up our own cup of energy. Dropping these self-care activities leads us into a negative downward spiral, the exhaustion funnel, that often begins with low mood and irritability, and ends with burnout and physical illness. This is particularly relevant for those who support others. It is important to become aware of when you are slipping into this downward funnel, and to notice if you have begun to drop your own self-care. Spend some time thinking about how can you build a little bit of self-nourishment back into your day.



Taking time for you

Self-Care

There can be a misconception about self-care that it has to be 'all or nothing', and that self-care means taking a whole hour, or even a whole day or a whole week 'off', to focus on yourself.

This often feels unachievable and then self-care can become another 'chore' that we struggle to fit into our already over-busy lives, and we can give up.

We can feel as though 'I don't have time for self-care'.

But actually, small, achievable actions, which can be done consistently every day have much more benefit than one full day of self-care once in a blue moon. Focusing on just 1 or 2 minutes of self-care activity every day feels much more achievable, and actually has much more benefit.

This is like 'putting the stress down' for just a few moments. If you take just 2 or 3 minutes a day to do a short self-care practice, you are in effect 'resetting' your nervous system, and allowing it to put down the stress for just a short period of time, a bit like a factory reset. Even taking one, single, deep, mindful breath has a calming and restorative effect, which allows us to then resume what we are doing holding less stress and tension in our nervous system. In the same way as putting down the heavy shopping bags gives our muscles a quick rest, 'putting down' our stress just for a few minutes allows us to then pick up and carry on. Over time, this adds up to help us stay in a much calmer state. The 'bucket' of stress never fills up to overflowing, because you are regularly lowering it during the day.



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Useful contacts



Support for Carers

Carers UK is a leading charity that offers advice, information, and support for people who care for family members or friends. They provide a helpline, online resources, and support for carers navigating the complexities of health and social care, including a directory of respite care centres. <https://www.carersuk.org>

Carers Line: 0808 808 7777 (Wed & Thurs 10am-12pm, 2-4pm) Email: info@carersuk.org

The Carers Trust is a UK-wide network of charities providing support to carers, including emotional support, advice, and practical assistance. They work with local organisations to offer services like respite care and peer support groups. <https://carers.org>

NHS Carers Direct is a government service offering information and advice to carers about health-related topics, such as managing medication, dealing with hospital visits, and accessing NHS services. <https://www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/>

The Princess Royal Trust for Carers offers services designed to support unpaid carers, including access to respite care, training, and emotional support. Many local Carer Centres are part of this network. <https://carers.org>



Useful contacts

Caring Together provides support to family carers of people with disabilities, dementia, or long-term health conditions. Their services include information, advice, and support groups. <https://www.caringtogether.org/>

Many areas in the UK have **Local Carers' Centres** which offer personalized advice and support tailored to carers in that area. These centres often provide practical services, emotional support, and respite options. Your local council or the organisations above can direct you to the nearest Carers' Centre.

Crossroads Together are a not for profit registered charity providing high quality care at home and support services for carers and people with care needs. <https://www.crossroadstogether.org.uk/about/>

Community Service Volunteers (CSV) recruits and trains volunteers to help individuals in need of support. information@csv.org.uk www.csv.org.uk

Caring for Older People

Age UK provides support for older carers, particularly those who are caring for older relatives. They offer advice, local services, and help with planning for the future. [Age UK](https://www.ageuk.org.uk)



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Other tools and resources

Other tools and resources

This section includes other tools and resources and links that may be useful for people living with a mast cell disorder. All resources are available to download for free from our website.

You can access our resources at:


mastcellaction.org/resources

These include:

- [MCAS Triggers](#)
- [MCAS Symptoms](#)
- [MCAS and Higher Education](#)
- [The Spoon Theory](#)
- [Feel Better Plan](#)
- [The Histamine Bucket Theory](#)
- [Travelling with MCAS](#)
- [Testing for MCAS](#)
- [Reasonable Adjustments in the Workplace](#)
- [Doctors Visit Preparation Form](#)
- [Mindfulness, Mindful Breathing and Mast Cells](#)
- [Self-Management Toolkit](#)


Visit our website at **mastcellaction.org** for further resources and information about Mast Cell Activation Syndrome

All resources are available to download for free from our website at www.mastcellaction.org/resources.



How to Handle the Sample

- Patients must be advised the test uses sensitive equipment.
- Patients should collect the sample correctly.
- On the day of the test, instruct the patient to wash their hands, trim their fingernails, and use nail polish remover, if any, for the sample.
- Please use the container with the following Prevalence from 2018 (by US state):
- Screen patients at least once, preferably a year.
- Place urine in the sample and the report will be in 10-15 minutes. Contact the lab directly for specific instructions on handling samples.
- Samples must be kept cool until they are sent to the lab.
- Samples must be kept in a cooler pack and not exposed to freezing temperatures and not exposed to heat.



Reading the Results

The simplest test result reader is a handheld positive result test – it is not a test that captures the DNA. It is high sensitive but not accurate. It is not a test that captures a negative result as well as a positive result.

Patients who are concerned should either use a test that is more accurate or have a sample sent to a laboratory.

| Sample type | Screening time |
|------------------------|----------------|
| Urine sample | 10-15 minutes |
| Saliva sample | 10-15 minutes |
| Penile sample | 10-15 minutes |
| Penile sample (in bag) | 10-15 minutes |
| Penile sample (in bag) | 10-15 minutes |
| Penile sample (in bag) | 10-15 minutes |

Prevalence from 2018 (by US state):

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A positive result is one that indicates a positive result. A negative result is one that indicates a negative result. A positive result is one that indicates a positive result. A negative result is one that indicates a negative result.


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
Testing For MCAS


The lab will also offer you several different tests. The lab will also offer you several different tests. The lab will also offer you several different tests.


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







































MAST CELL ACTION

The Histamine Bucket Theory

**ENVIRONMENT
HORMONES
ACTIVITIES
WEATHER
SMELLS
STRESS
DIET**

This histamine bucket theory is a useful visual aid in trying to understand the impact of factors contributing to histamine levels.

This theory can help us to understand the impact of different activities and situations on histamine levels and therefore, how to reduce this exposure where possible.

You could think of your body as an empty bucket.

Different foods and activities fill your histamine bucket at different speeds but combine to form the total level of histamine in your body.

If you can keep your bucket at a lower level, you may feel better because a fuller bucket could mean that you have more symptoms.

Managing triggers, reducing exposure to known triggers, and taking medication could all help to manage the level of your bucket.

For more supportive resources visit our website, www.mastcellaction.org

Charity No. 154610

Further support

If you have found the information in this pack to be useful and would like to access further information, support and resources, please visit: **www.mastcellaction.org**



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Make your legacy a lifeline for people with MCAS, leave a gift in your will to Mast Cell Action.

