MAST CELL
ACTION

Navigating MCAS together

Mast Cell Activation Syndrome Support Guide for Loved Ones

Registered Charity
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WELCOME

Welcome to "Caring with confidence," a resource designed to provide you with the essential information, guidance, and support needed as you care for someone with Mast Cell Activation Syndrome (MCAS). Whether you are new to this role or have been caring for a while, we understand that looking after 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 carers 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 carer. We've included information on accessing financial support, understanding your legal rights, and finding time for self-care, which is just as important as caring for your loved one.

We also recognise the unique challenges faced by those caring for adults, children, or even as young carers themselves. This guide includes sections tailored to these specific situations, as well as advice on maintaining physical health, accessing emotional support, and planning breaks to recharge.

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.

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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 continue to increase as the condition progresses. Symptoms include:

Nasal-ocular (nose and eyes)

- Nose congestion
- Eye watering and itching

Respiratory (lungs & breathing)

- Sore throat
- Hoarsness
- 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

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

General

- Extreme tiredness
- Anaphylaxis, which can be life threatening

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:

- **Temperature changes**
- **Other 'typical' allergens**
- **Exercise/ exertion**
- **Medications**
- **Stress/ anxiety**
- **Fragrances**
- **Specific foods/drinks**

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:

> **“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 allergies.**
>
> **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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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 Allergens: Use hypoallergenic products, keep the home well-ventilated, and avoid using strong fragrances or chemicals.
- Monitoring Diet: Work closely with healthcare professionals to identify safe foods, and help plan meals that avoid potential triggers.
- 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. 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 judgment 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 as you attend appointments with healthcare providers:

- Keep a Symptom Diary: Track your loved one's symptoms, triggers, and reactions. This will help healthcare providers tailor their treatment plans more effectively.
- Ask Questions: Don't be afraid to ask healthcare providers about treatment options, potential side effects, and any concerns you may have.
- Advocate: Be your loved one's advocate, ensuring they receive the best possible care and support.
- Caring for someone with MCAS can be challenging, but with the right knowledge and support, you can make a significant positive impact on your loved one's life.

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Advocating on behalf of someone with MCAS

Self-Advocacy

Here at Mast Cell Action, we are committed to empowering people living with MCAS or suspected MCAS and those caring for people with MCAS or suspected MCAS through self-advocacy.

We understand the challenges and complexities that accompany living with MCAS, and we hope to provide resources, support, and a platform for individuals to advocate for themselves 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 a crucial tool for navigating the complexities of managing their condition.

Key Aspects of Self-Advocacy

- Education: Knowledge is power. Understanding MCAS, its symptoms, triggers, and treatment options is essential for effective self-advocacy. We provide as many resources and as much information as possible to empower individuals to become experts in their own health and will continue to develop further information and resources to support you in your journey.
- Communication: Effective communication with healthcare providers, family members, employers, and educators is vital. People with MCAS often find it helpful to clearly articulate their needs and concerns to help them to receive the support and accommodations necessary for managing their condition.
- 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. Self-advocacy involves advocating for the resources and support needed to prioritise self-care.
- Seeking Support: No one should have to navigate MCAS alone, and you don't have to! Seeking support from peers, support groups, and advocacy organisations can provide invaluable emotional support, practical advice, and a sense of community. Mast Cell Action serves as a hub for individuals to connect with others facing similar challenges.

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 you need.

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

- Prepare for Appointments: Before meeting with healthcare providers, educators, or other relevant individuals, prepare a list of questions, concerns, and goals. You can use our ready-made Doctor Visit Preparation form to help. Bring along your symptom journal and any relevant medical records or test results. Being organised and informed shows that you are serious about managing your condition and can help facilitate productive discussions. It can also help you to prioritise your appointment time in order to get the most from it.
- Speak Up: Don't be afraid to speak up and share your needs and preferences. Clearly communicate your symptoms, treatment experiences, and any challenges you're facing. Be concise, specific, and confident in expressing yourself.
- Ask for Clarification: If you don't understand something a healthcare provider or educator says, don't hesitate to ask for clarification. It's important to fully understand your condition, treatment options, and any accommodations or support being offered.
- Seek Advocacy Support: If you feel you're not being heard or are having difficulty accessing the support you need, don't hesitate to seek advocacy support from trusted people, such as your 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.

Arm Yourself with Knowledge

People with MCAS often find themselves navigating a complex healthcare landscape while also managing school, work, social activities, and everyday life. Empowering yourself with knowledge is the first step towards effectively managing your condition and advocating for your needs.

- Research and Learn: Learn about MCAS. Understand the biology behind the condition, common symptoms, triggers, and available treatment options. 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: Start a symptom journal to track your experiences. Note down any symptoms you experience, potential triggers, and the effectiveness of different treatments or lifestyle changes. This information can be invaluable when discussing your condition with healthcare providers and developing personalised management strategies.
- Stay Informed about Your Rights: Educate yourself about your rights as someone living with a chronic health condition. Familiarise yourself with laws and regulations related to education, accommodations, and access to healthcare services. Knowing your rights empowers you to advocate effectively for the support and accommodations you need at school or work and in other settings.
- Connect with Peers: Reach out to others who are living with MCAS. Connecting with peers who understand what you're going through can provide invaluable support, practical advice, and a sense of belonging. Our online forums, social media groups, and local support groups are great places to find like-minded individuals and share experiences.

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community
quote

You are not alone

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

By arming yourself with knowledge, you can learn how to effectively advocate for yourself - despite the challenges posed by MCAS. Remember, your voice matters, and you 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 can thrive.

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Becoming a carer

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.

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.

One of the primary emotional challenges you might face is stress and anxiety. The unpredictability and varying severity of MCAS symptoms can keep you constantly on edge. Additionally, the complex and rare 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 care and attention can drain your 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.

Family

When a family member is diagnosed with MCAS, it brings significant changes and challenges. However, families often discover profound strengths 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.

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Financial Support

Financial Support for you as a Carer

Carer's allowance

You could get £81.90 a week if you care for someone at least 35 hours a week and they get certain benefits.

- You do not have to be related to, or live with, the person you care for.
- You do not get paid extra if you care for more than one person.
- If someone else also cares for the same person as you, only one of you can claim Carer's Allowance.
- Carer's Allowance can affect the other benefits that you and the person you care for get. You have to pay tax on it if your income is over the personal allowance.
- You can choose to be paid weekly or every 4weeks into your bank account.
- For each week you get carer's allowance you'll automatically get national insurance credits.

Financial Support for you as a Carer

You may also be able to apply for:

- support from your local council
- a Council Tax Reduction
- Universal Credit if you're on a low income or out of work.
- Pension Credit if you're over working age.
- grants and bursaries to help pay for courses and training.

Eligibility

You may be eligible for Carer's Allowance if you, the person you care for and the type of care you provide meets certain criteria.

- The person you care for must already get one of these benefits:
- Personal Independence Payment - daily living component
- Disability Living Allowance - the middle or highest care rate
- Attendance Allowance
- Constant Attendance Allowance at or above the normal maximum rate with an Industrial Injuries Disablement Benefit
- Constant Attendance Allowance at the basic (full day) rate with a War Disablement Pension
- Armed Forces Independence Payment
- Child Disability Payment - the middle or highest care rate
- Adult Disability Payment - daily living component at the standard or enhanced rate

Financial Support for you as a Carer

If you care for someone along with others, you cannot get Carer's Allowance if you share the care of someone and the other carer is already claiming:

- Carer's Allowance for that person
- Carer Support Payment for that person
- The extra amount of Universal Credit for caring for someone who gets a disability-related benefit for that person.

If the other carer does not want to claim, you can still apply for Carer's Allowance.

The Department for Work and Pensions (DWP) will decide who should receive the benefit.

The type of care you provide

You 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

Financial Support for you as a Carer

Your eligibility

All of the following must apply:

- You're 16 or over
- You spend at least 35 hours a week caring for someone.
- You've been in England, Scotland or Wales for at least 2 of the last 3 years (this does not apply if you're a refugee or have humanitarian protection status)
- You normally live in England, Scotland or Wales, or you live abroad as a member of the armed forces (you might still be eligible if you're moving to or already living in an EEA country or Switzerland)
- You're not in full-time education.
- You're not studying for 21 hours a week or more.
- You're not subject to immigration control
- Your earnings are £151 or less a week after tax, National Insurance and expenses. If your earnings are sometimes more than £151 a week you might still be eligible for Carer's Allowance. Your average earnings may be calculated to work out if you're eligible.

If you get State Pension

You cannot get the full amount of both Carer's Allowance and your State Pension at the same time. If your pension is £81.90 a week or more, you will not get a Carer's Allowance payment. If your pension is less than £81.90 a week, you'll get a Carer's Allowance payment to make up the difference.

If you get Pension Credit

If your State Pension is more than £81.90 a week, you will not get a Carer's Allowance payment but your Pension Credit payments will increase instead.
If you're not eligible, you might be eligible for Carer's Credit.

Financial Support for you as a Carer

Effect on the benefits of the person you care for

When you get Carer's Allowance, the person you care for will usually stop getting:

- A severe disability premium paid with their benefits
- An extra amount for severe disability paid with Pension Credit

You can check if their severe disability payment will stop by contacting whoever pays this benefit. This is usually Jobcentre Plus, their local council, the Pension Service Helpline or Universal Credit. They might also stop getting reductions on their Council Tax bill. Contact their local council to find out if this affects them and if so, how.

Effect on your benefits

When you claim Carer's Allowance your other benefit payments may change, but your total benefit payments will usually either go up or stay the same.
You should not be affected by the benefit cap. Use a benefits calculator such as entitledto or turn2us to work out how your other benefits will be affected.

If you get Universal Credit

Your Universal Credit payment will be reduced by an amount equal to your Carer's Allowance payment. You may get an extra amount of Universal Credit for caring for someone who gets a disability-related benefit (whether you get Carer's Allowance or not).

Which benefits you get will affect which National Insurance credits you're eligible for.

If you get Carer's Allowance payments, you get Class 1 National Insurance credits, which help you qualify for some other benefits and State Pension.

If you get Universal Credit, you will get Class 3 National Insurance credits, which count towards your State Pension only.

Disability Living Allowance for children

This is an allowance to help with the extra costs of looking after a child under 16 years old with a disability. It's a payment between £28.70 and £184.30 a week. You are entitled to it if you're the parent or carer of a disabled child.

Financial Support for you as a Carer

Financial Support for the person you care for

The person or child you care for could be entitled to any of the following benefits:

PIP

PIP is a benefit for people aged 16 to State Pension age who need help with extra costs if they have a long-term physical or mental health condition or disability. You can apply by phone or post. An assessment might be required.
0800 917 2222.
gov.uk/pip

Attendance Allowance

Attendance Allowance is for people over State Pension age who need help with personal care or supervision due to a disability or illness. Application is via post. Forms can be requested online or by phone.
800 731 0122.
ov.uk/attendance-allowance

Carer's Breaks funds

This benefit provides funds for carers to take a break from their caring responsibilities. Availability and eligibility criteria vary by local authority. Contact your local council or carers' organisation for information and application processes.
nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/carer-breaks-and-respite-care

Universal Credit

Universal Credit is a benefit for people of working age on a low income or out of work. It replaces six previous benefits, including Jobseeker's Allowance and Housing Benefit. Applications are made online. You may need to attend an interview at your local Jobcentre Plus.
0800 328 5644.
gov.uk/universal-credit

Financial Support for you as a Carer

Carer's assessments

If you care for someone, you can have an assessment to see what might help make your life easier. This is called a carer's assessment.

It might recommend things like:
- Someone to take over caring so you can take a break
- Gym membership and exercise classes to relieve stress
- Help with taxi fares if you don't drive
- Help with gardening and housework
- Training, such as how to lift safely
- Putting you in touch with local support groups so you have people to talk to
- Advice about benefits for carers

A carer's assessment is free and anyone over 18 can ask for one.

It's separate from the needs assessment the person you care for might have, but you can ask to have them both done at the same time.

How to get a carer's assessment

Contact adult social services at your local council and ask for a carer's assessment.

If you're a parent or carer of a child, contact the children with disabilities department.

Financial Support for you as a Carer

What happens in the carer's assessment

Someone from the council, or an organisation the council works with, will ask how you're coping with caring. This includes how it affects your physical and mental health, work, free time and relationships. The assessment is usually face to face. Some councils can do it over the phone or online. Assessments usually last at least an hour.

How to prepare for your carer's assessment

You'll need:

- Your NHS number
- Your GP's name, address and phone number
- The contact details of anyone who's coming to the assessment with you
- The name, address, date of birth and NHS number of the person you care for
- Your email address

Give as much detail as you can about the impact caring for someone is having on your life. This will help make sure you get all the help and support you need.

It can help if you have someone with you during the assessment. This could be the person you care for, a friend or relative. You could also use an advocate. Advocates are people who speak up on your behalf. They can help you fill in forms and sit with you in meetings and assessments. They're often free.

The local council will tell you the results of the assessment. If you qualify for help from the council, they'll write a care and support plan with you that sets out how they can help.

If you're told you don't qualify for help and support, your council should give you free advice about where you can get help in your community.

Useful contacts

- Your local council's adult social services department can be found online
- Carers UK's free helpline on 0808 808 7777
- Age UK's free helpline on 0800 678 1602
- Independent Age's free helpline on 0800 319 6789
- Contact's free helpline for families with disabled children on 0808 808 3555

Financial Support for you as a Carer

How to tell if you're a carer

You're a carer if you're looking after someone regularly because they're ill, they're an older person or they're disabled – including family members.

Among other things, Carers help with:
- Washing, dressing or taking medicines
- Getting out and about and travelling to doctors' appointments
- Shopping, cleaning and laundry
- Paying bills and organising finances

They can also give emotional support by:
- Sitting with someone to keep them company
- Watching over someone if they can't be left alone

Financial Support for you as a Carer

Carers breaks

Respite care means taking a break from caring, while the person you care for is looked after by someone else. It lets you take time out to look after yourself and helps stop you becoming exhausted and run down. There are lots of respite care options. They range from getting a volunteer to sit with the person you look after for a few hours, to a short stay in a care home so you can go on holiday.

The person you look after could go to a daycare centre. Or, a paid carer could visit them at their home to look after them. Your local council or local carers' centre can give you information about local support. Local councils will only fund respite care for people that they have assessed as needing it. Carer's should have a carer's assessment. The person you're looking after should have a needs assessment.

Types of respite care

- Day care centres offer a chance for people who find it difficult to get out and about to socialise, make friends and take part in activities.
- Homecare from a paid carer
- A short stay in a care home
- Getting friends and family to help
- Respite holidays
- Sitting services

Other help

- MindforYou offers supported holidays in the UK for people who are living with dementia and their carers to enjoy together
- Some charities, such as Revitalise, offer subsidised respite holidays for disabled people and their carers
- Family Fund helps with grants towards the cost of holidays for families on a low income who are caring for a child with a disability or serious illness
- Family Holiday Charity offers breaks at holiday sites, or grants to help with the cost of a holiday, for low-income families. You need to be referred by your social worker, GP or health visitor, or by a charity or other welfare agent
- Some charities and carers' organisations offer sitting services, where a trained volunteer keeps the person you care for company for a while, usually a few hours at a time. This type of sitting service is often free, or there may be a small charge.

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Caring for adults with MCAS

Caring for adults with MCAS

Support for Older People

Caring for 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 strain on personal relationships, as roles and dynamics shift to accommodate the increasing dependency of the person with MCAS.

For the individual living with the condition, needing a carer may lead to feelings of guilt, frustration, or a loss of independence, as they adjust to relying on someone else for tasks they may have once managed alone. These changes can affect their self-esteem and sense of identity, potentially leading to feelings of isolation or depression.

For the carer, the emotional toll of watching a loved one struggle, combined with the practical challenges of managing their care, 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.

Caring for someone with a chronic illness can take a toll on your physical and emotional health. Make sure to take time for yourself, rest when needed, and seek support from others who understand the challenges you face. By taking care of your own well-being, you will be better equipped to provide the care and support your loved one needs.

Other help

Age Concern and Help the Aged joined forces in 2010 to form Age UK, including Age Scotland, Age Cymru and Age NI. England tel: 0800 169 6565 Northern Ireland tel: 0808 808 7575 Scotland tel: 0845 125 9732 Wales tel: 0800 169 6565 www.ageuk.org.uk

Independent Age is a national charity focused on improving the lives of older people facing financial hardships. For general enquiries tel: 08003 196789, email: charity@independentage.org, Address: Independent Age, 18 Avonmore Road, London, W14 8RR

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Caring for children with MCAS

Caring for 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 the child's emotional needs can feel overwhelming.

MCAS often requires strict control over environment, diet, and activities, often limiting 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 the 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, 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.

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.

Caring for children with MCAS

Emotional support for Children

Caring for a child with MCAS comes with unique emotional challenges, as your child may feel frustrated, anxious, or isolated due to their condition. 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. You could help support your child emotionally as you:

- 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.
- 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 helps your child feel supported.
- 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.
- 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.

8

Young Carers

Young Carers

Young carers are children or teenagers who take on significant caregiving responsibilities for a family member, often a parent or sibling, who is living with a chronic illness, disability, mental health condition, or addiction.

Despite their age, young carers often perform tasks well beyond what is typically expected of someone their age, such as providing physical care, managing household duties, or offering emotional support.

While caring for a loved one can be rewarding, it can also be challenging, as young carers may face emotional strain, social isolation, and disruptions to their education and personal development.

Young carers often demonstrate immense strength, compassion, and resilience in their daily lives. Taking on the responsibility of caring for a loved one at such a young age is both challenging and admirable.

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.

If you are a young carer, remember are never alone; there are people, resources, and communities ready to offer guidance, encouragement, and help when you need it most.

Young Carers

Young Carers and School

- Teachers are there to help pupils get the most out of school. They can be a good person for you to speak to about any problems you have. 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 about what you do at home so that they can understand what is happening and give you more help.
- As a young carer, you might find school a place where you can forget about your caring responsibilities and feel "normal" for a while. But it can also be a place where you're under extra pressure or where people do not understand what your life is like outside school. It can sometimes be hard to juggle all your responsibilities as a young carer with the demands of teachers, friends and homework.
- You might not want your school to know you're caring for someone. But if they do not know about your situation, it will be difficult for teachers to understand if you struggle to keep up in class or do not do your homework. It's a good idea to let at least one teacher you feel able to trust know you're a carer.
- You might find it difficult to talk about your home life with a teacher, so you could ask someone in your family to write to the school, perhaps to the head of year.
- Some young carers find it easier to talk about the situation if they keep a diary or a list of all the jobs and tasks they have to do.

Young Carers

Young Carers and School

- There are lots of ways your school can help, 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.
- If you're given detention, you could ask to have it during lunchtime rather than after school because of your caring responsibilities.
- You may feel you have to miss school to care for someone. But missing school can affect your whole future. Try to get help as quickly as possible so the situation does not go on for a long time.
- A GP, nurse, social worker or another person whose job is to help the person you look after can organise more support at home to help you concentrate on school or college.

Young Carers

If you're having trouble with school or homework, your teachers may offer:

- extra time for school work when you have to give more help to the person you care for
- to talk to you privately about your home life
- homework clubs

As a young carer, you may miss out on opportunities to play and spend time with your friends and classmates. You may feel isolated from your friends because:

- you do not have as much free time as them
- you're often thinking about the person you look after
- you may be worried they will bully you

Being a young carer can make you stand out from other people, or you may find that you do not get included in certain activities.

It's important to get the help you need so that you have time to do the things you want to do and be with your friends.
If possible, put aside some time each day to do something you enjoy. Your local young carers.

Young Carers

Meet other young carers

Meeting up with other young carers is a great way to make new friends, have some fun and share some of your worries with people in similar situations to your own.

Young carers projects can help you have a break from home, plus meeting other young carers can help you to relax. 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.

Young Carers

Help from social workers

Help from 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.

Help from doctors, nurses and other health workers

If you're worried about your health, or the health of the person you care for, speak to a doctor or GP.
School nurses visit schools and are usually happy to speak with you about any of your health concerns.
Counsellors work in a variety of places, including schools, hospitals and youth centres.
Their job is to listen carefully and give advice – in a private setting.
Local mental health nurses can offer emotional support and advice about mental health conditions. If the person you care for has a "community psychiatric nurse", you can talk to the nurse about their condition and how you can help them cope.

Other organisations that can help young carers

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.

Young Carers

Your choices about caring

Some people start giving care at a very young age and don't really realise they're carers. Other young people become carers overnight.

If someone in your family needs to be looked after, you may really want to help them. But as a young carer, you shouldn't be doing the same things as adult carers.

Nor should you be spending a lot of your time caring for someone, as this can get in the way of you doing well at school and doing the same kinds of things as other children or young people.

It's important you decide how much and what type of care you're willing or able to give, or whether you should be a carer at all.

Decide whether you're the right person to offer the care needed by the person you look after.

All disabled adults are entitled to support from their local council, depending on their needs, so they shouldn't have to rely on their children to care for them.

Young carers' rights

If you or your parents request it, a social worker from your local council must visit to carry out a young carer's assessment.

This assessment is different from the one adult carers have. It'll decide what kind of help you and your family might need.

Even if the council has already carried out one of these assessments, they must do another if you or your parents feel that your needs or circumstances have changed.

A young carer's assessment can determine whether it's appropriate for you to care for someone else, and takes into account whether you want to be a carer.

The social worker must also look at your education, training, leisure opportunities and views about your future.

As part of the assessment, the social worker must ask about your wishes and involve you, your parents and anyone else you or your parents want to be involved.

All these people should receive a written record of the assessment. This will include whether the council thinks you need support, whether their services could provide you with it, and whether they'll give you it.

It should also explain what you can do if you or your parents disagree with the assessment.

If you and the person you care for both agree, the local council can assess your needs as a young carer and the needs of the person you care for at the same time.

If you're 16 or over and not in full-time education, you may be eligible for help finding work, as well as with your family's finances (for instance, through benefits such as Carer's Allowance).

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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.

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.

Don't Ignore Your 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.

Taking time for you

Self-Care

When we are caring for someone with MCAS, it is easy to feel that spending time on our own self-care is somehow self-indulgent, and those who are caring for others often fall into the trap of feeling guilty or ashamed if they spend a few moments on themselves. However, it's worth remembering the old saying that you can't pour from an empty cup, because it is absolutely true. Sometimes, the best things we can do for our loved-one is to look after ourselves, to ensure we are able to give them the care they need. It is actually essential, not self-indulgent.

There is also 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 be guilty of feeling 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 that 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.

Taking time for you

Self-Care

Professor Marie Asberg, an expert on burnout, talks about the funnel of exhaustion. Her research shows that, when we feel under pressure, we tend to drop the ‘play’ and the ‘rest’ elements of our day, leaving only ‘chores’ and ‘work’. As soon as we perceive that we don't have enough time or energy, it is the nourishing things that we drop first, such as eating wel, exercise, hobbies, and socialising with friends, etc. But it's ironic that these are also 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 that often begins with low mood and irritability, and ends with burnout and physical illness. 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. Spending some time thinking about how can you build a little bit of self-nourishment back into your day can prevent yourself from continuing in this downward spiral. http://www.mindfulnext.org/burnout-the-exhaustion-funnel/

Mindfulness is one of the best tools we have at our disposal to protect us from this negative downward spiral.

Mindfulness is, in a nutshell, ‘Becoming aware of our present moment experience, and welcoming what we find with a kind and open heart.’It uses tools like focussing on the breath, focussing on bodily sensations and sensory input, or focussing on movement, to ground us in the present moment, and then bringing a sense of self-compassion and non-judgment to whatever we find. We engage with and focus our attention on what we are physically experiencing in this moment, and allow whatever that is to be as it is, without needing to judge it or change it.

Taking time for you

Self-Care

Research shows that this has many benefits for us for our mental health, but also surprisingly, for our physical health too.

Present-Moment Happiness. A study by Harvard University in (2010?) showed that the more present we are, the happier we are. Present-moment experience is closely correlated to happiness levels, and people who spend their time focussed on the ‘here and now’ and not lost in rumination about the past or the future were more happy. Cultivating the art of present-moment awareness by using our senses as the point of focus helps us with this, and stops us from getting sucked into the rabbit hole of fear for the future or regrets about the past. The ancient Roman philosopher Seneca is quoted as saying ‘we suffer more often in imagination than in reality.’ There is a lot of truth in this, and worrying about the past or the future adds a greater burden of additional suffering than just dealing with what is actually happening in the present moment.

‘Put the Stress Down’. Using regular short Mindfulness practices allows us to ‘put the stress down’. If you take just 2 or 3 minutes a day to practice a very short mindfulness 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 and allows us to pick them up again and carry on for longer, ‘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.

Taking time for you

Self-Care

Increase Resilience. Another benefit of practicing Mindfulness regularly is that it helps to desensitize our amygdala, which is responsible for making us feel difficult emotions like anger, sadness, frustration, criticism etc. If we regularly take a moment to 'switch off' the amygdala, over time it becomes less sensitive to stress, and this helps us to become more resilient. Brain scans of Buddhist monks, who practice mindfulness regularly, show that their amygdala physically shrinks in size. But we don't have to become Zen Masters in order to benefit from this effect. Just a few minutes practice a day has measurable impacts on how reactive we are, and those who practice regularly find that when difficult things happen, they don't feel so upsetting, and we can cope with them better. This help us to manage the ups and downs of caring, and particularly the uncertainty of MCAS flares, with more resilience, and they become easier to navigate.

Connect to inner wisdom. When we use Mindfulness, an added benefit is that we become more aware of our bodies, and our own inner wisdom. The time we take during mindfulness practice to 'tune in' to our own inner world and hear our inner voice allows us to reconnect with our inner intuition. This often gives us moments of insight into what is needed in this moment, for both our own wellbeing, and for those around us. We become much more in tune with what we need, and what others around us need. By becoming more aware of our own inner wisdom, we can often make better decisions and care for our loved-ones in new, improved ways. This can be especially helpful when we are dealing with MCAS, because often those moments of insight can give us a clue as to what is causing a flare, what triggers may be involved, and how best to support our loved-one.

Taking time for you

Suggestions for 5 Short Daily Mindfulness Practices. Choose one or two of these Mini Mindfulness exercises and build them regularly into your routine for 1 or 2 minutes a day.

Breathing exercise. Spend a few seconds or 1 minute breathing deeply into your belly and focusing on making your exhale longer than your inhale. Focusing your whole mind on your breath, wherever you feel the breath most strongly in your body, and try and keep your mind there for a few seconds or 1 minute. This helps oxygenate our body tissue, and also regulate the nervous system.

Chair Breathing. Sit comfortably on a chair with your feet on the floor. Close your eyes if it feels ok, and focus on your breath. Imagine with each inhale that you are drawing the air all the way up from your feet into the top of your head, and with exhale, sending the air all the way down your body and out into the floor beneath your feet. You can imagine you are drawing up goodness and nourishment from the earth with each breath in, and sending any negativity, worry or tension out into the floor with each breath out.

Brow, Jaw, Shoulders. Notice if you are holding stress in your body and take a moment to let it go. Stop what you are doing for a few moments, close your eyes, take a few deep breaths, and then take your awareness to your brow, allow your mind to travel across your brow, and into your temples, and notice any tension there, and release it. Then take your awareness to your jaw, and notice if you are holding tension – similarly, release it. Finally, take your awareness to your shoulders, notice if you are holding tension there, and let it go.

Lotus Flower breathing. Hold your hand with the fingers closed together, as though they are a closed flower bud, and then as you breathe in, you slowly open your fingers, like a flower opening. As you breathe out, close your fingers back together. The aim is to really focus on synchronising your breath with the movement of your hand, so they are perfectly in sync, and holding your focus on hand movement and breath together.

Present Not Perfect. Stop what you are doing for a few moments, close your eyes, place a hand on your heart and take a few deep breaths, and say silently to yourself 'I choose to be present, not perfect.' Allow those words to sink in and notice how they make you feel. Repeat the words to yourself with each breath out.

For more tips on Mindfulness practices, and a some free Mindfulness downloads, visit the Download Page on my Website. https://livewellwithchronicillness.co.uk/downloads
You can also sign up to my Newsletter here.
https://livewellwithchronicillness.co.uk/subscribe

Taking time for you

Recommended Reads:

·Mindfulness: Finding Peace in a Frantic World by Williams and Penman
·Altered Traits: Science Reveals How Meditation Changes Your Mind, Brain and Body. By Daniel Goleman & Richard Davidson
Recommended Podcasts:
·Brene Brownhttps://brenebrown.com/podcasts/
·Kristin Neff https://self-compassion.org/with-kristin-neff/
·Sean Fargo - Mindfulness Exercises https://mindfulnessexercises.com/podcast/
Recommended Websites/Apps:
·Mindful.org https://www.mindful.org/
·Insight Timer.https://insighttimer.com/en-gb
Remember, you are not alone – there is a whole community of people who understand and recognise the difficulties we face when caring for someone with MCAS. Reach out for support.

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Legal rights for carers

Legal rights for carers

Your legal rights and Work

Managing work whilst caring for someone can be difficult, you have certain legal rights and entitlements.

Your rights under the 2014 Care Act

The Care Act of 2014 set 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.

The Children Act 1989 and the Children and Families Act 2014

Under these Acts, young carers (under 18) have the right to an assessment, which will look at the impact of caring, and whether the young person wishes to continue caring – and if it's appropriate for them.

When an adult is being cared for, the Council must consider any children potentially providing care. And they must actively seek to locate young carers in their area.

The Children and Families Act 2014 amended the Children Act 1989, and required councils to assess parent carers of disabled children under 18, on the basis of 'need'.

Your employment rights

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 could also be worth checking your employment contract as increasingly employers are recognising the value of supporting carers in their workforce and you might find that you are offered more generous terms.

Legal rights for carers

The Carers Leave Act 2024

The Carers Leave Act 2024 makes provisions for employees who balance work with caring responsibilities and allows employees to take up to one week of unpaid leave per year to provide or arrange care for a dependant with a long-term care need. The dependant does not have to be a family member, and could be anyone who relies on them for care.

The dependant is defined as anyone with an illness or injury whom requires or is likely to require care for more than three months, a disability under the Equality Act 2010, or issues related to old age.

Employees are entitled to carer's leave from their first day of work with their employer, and their employment rights, such as holidays and returning to their job, are protected during carer's leave.

As an employee you're allowed a reasonable amount of unpaid time off to deal with an emergency involving a dependant this includes spouse, partner, child, grandchild, parent or someone you care for. There is no limit on how much time off you can have in a 12month period however your employer may want to talk to you about it if it is affecting your work. Hospital appointments are not covererd under this as these are planned, your employer may make you use annual leave or parental leave to cover time off for these appointments.

Emergency time off can include the following:

- Illness, injury or assault – mental or physical illnesses; these do not need to be life threatening; it can include an existing condition that has worsened.
- Having a baby- if a dependant goes into labour unexpectedly and rely on you to take them to the hospital. You cannot take time off after the birth to care for the child unless you are the child's parent then you could be entitled to paternity leave.
- Disruption to care arrangements- if a childminder or carer does not turn up to look after the dependent or nursing home or nursery closes unexpectedly.
- If your child is involved in an incident in school time – fights, injured on school trip or suspended from school
- Info about planning for additional support for the person they care for so they can take a break/holiday etc if needed – perhaps a template plan they can complete that a friend or family member could use to support them in caring for the person living with MCAS
- Legal rights for carers – eg accommodations at work- carers coming into the home and having somewhere to stay etc

Legal rights for carers

The Equality Act 2010
In the UK, people have protection from discrimination in employment, in education and when receiving services.
They are protected from being discriminated against on the grounds of:

- disabililty
- age
- race
- sex
- religion/belief
- sexual orientation
- marital status
- gender reassignment

A carer must not be discriminated against on the basis of their association with a disabled person.[JM1] Your employer must not treat you unfairly for taking time off. Your employer cannot dismiss you or choose you for redundancy because you asked for time off to care for a dependant or refuse your reasonable time. They cannot refuse training or promotion due to time off.

Here is a case example: Jane works as a marketing manager at a large company. Her son, Mark, has a severe disability that requires frequent medical appointments and specialised care. Jane has requested a flexible working schedule to accommodate her son's needs, allowing her to work from home occasionally and adjust her hours to attend medical appointments.

Initially, Jane's supervisor, Tom, agreed to the flexible arrangement. However, over time, Tom began to show frustration about Jane's modified schedule. He would often make negative comments, such as, "I need someone more committed to this job," or "We can't have employees coming and going as they please."

One day, during a team meeting, Tom announced a new project that required a lead manager. Despite Jane's excellent performance record and experience, he gave the role to a less qualified colleague, stating that "we need someone who can fully dedicate their time and focus to this." When Jane asked why she was overlooked for the promotion, Tom hinted that her "other commitments" made her less suitable for the role.

This is an example of discrimination by association. Jane is being treated unfairly and denied opportunities at work not because of her own abilities or performance, but because of her association with her disabled son and the caregiving responsibilities that come with it. This kind of discrimination is illegal.

[JM1]Give an example here

Legal rights for carers

Top tips from the community
·In the beginning, when we weren't sure what exactly was causing symptoms, we kept a symptom/food/drink/meds/environment/activity diary going, to look back on in the event of a flare up, to try to identify any triggers and also to ensure all meds were taken (until we got into good habits, it was so easy to forget or miss a dose).
I put it all on a single page spreadsheet, printed it out every day and hung it on a clipboard in the kitchen. Was really helpful to the consultant, especially the details about food reactions."
·"PATIENCE is needed"

From a parent with a child with MCAS: "Photo and record EVERYTHING especially if you haven't been diagnosed.
Keep a diary of symptoms and food/triggers
Keep reading and researching
Follow a prescription information service so you know when shortages or discontinued medication happens
Order medication as far in advance as possible as often errors
Confirm any conversations in writing. Get any misinformation changed on hospital letters.
Build a team around the child and get as many people on board and supportive of your child's care so they can document also.
Don't stop fighting
Make sure the child has an ISAC test and a histamine urine test"

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Useful contacts

Useful contacts

Carer's Organisations
Carer's UK: Information and support on any issue for people caring for friends and relatives. Extensive details of the benefits available to carers and the people they are caring for. CarersLine: 0808 808 7777 (Wed & Thurs 10am-12pm, 2-4pm) England tel: 020 7378 4999 N. Ireland tel: 028 9043 9843 Scotland tel: 0141 445 3070 Wales tel: 029 2081 1370 Email: info@carersuk.org www.carersuk.org
Carer's Trust: Network of Carer organisations all across the U.K. Address: Carers Trust, 10 Regent Place, Rugby, CV21 2PNtel: 0300 772 9600, Email info@carers.org.
The Princess Royal Trust for Carers: Offers useful information and support for all unpaid carers throughout the UK. Unit 14 Bourne Court, Southend Road, Woodford Green, Essex IB8 8HD England tel: 0844 800 4361 Scotland tel: 0141 221 5066 Wales tel: 02920 221788 Fax: 0844 800 4362 Email: help@carers.org www.carers.org
Crossroads Association: Provides practical support in the home. 10 Regent Place, Rugby CV21 2PN Tel: 0845 4500350 Fax: 01788 565498 Email: communications@crossroads.org.uk www.crossroads.org.uk 19
Community Service Volunteers: Recruits and trains volunteers to help individuals in need of support. 237 Pentonville Road, London N1 9NJ Tel: 020 72786601 Email: information@csv.org.uk www.csv.org.uk
The Margaret Champney Rest and Holiday Fund: Organisation that gives small grants to carers. The Gate House, 9 Burkitt Road, Woodbridge, Suffolk IP12 4JJ Tel: 01394 388746 Email: ogilviecharities@btinternet.com www.theogilvietrust.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.

This includes:

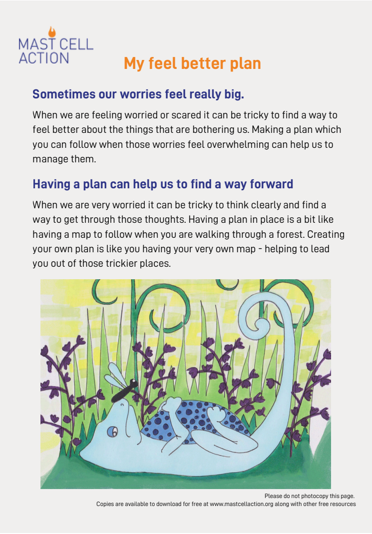
- Emergency medical information sheet (to give to emergency medical staff)
- Medicines log: mastcellaction.org/managing-triggers
- Trigger trackers: mastcellaction.org/managing-triggers
- The histamine bucket theory: mastcellaction.org/managing-triggers
- The spoon theory: mastcellaction.org/resources
- Feel better plan: mastcellaction.org/resources
- Wellbeing resources: https://www.mastcellaction.org/resources

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

Other tools and resources

We have developed multiple tools and resources that may be useful for people living with a mast cell disorder.

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



MAST CELL ACTION

My feel better plan

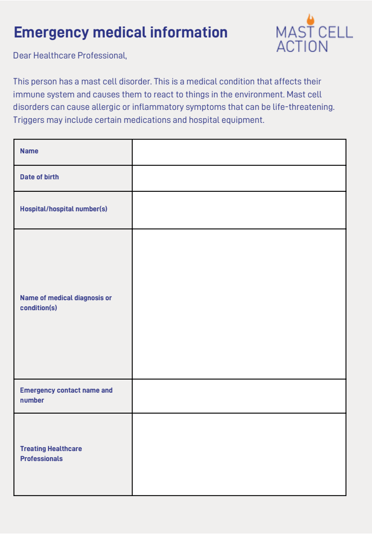
Sometimes our worries feel really big.

When we are feeling worried or scared it can be tricky to find a way to feel better about the things that are bothering us. Making a plan which you can follow when those worries feel overwhelming can help us to manage them.

Having a plan can help us to find a way forward

When we are very worried it can be tricky to think clearly and find a way to get through those thoughts. Having a plan in place is a bit like having a map to follow when you are walking through a forest. Creating your own plan is like you having your very own map - helping to lead you out of those trickier places.

Please do not photocopy this page.
Copies are available to download for free at www.mastcellaction.org along with other free resources



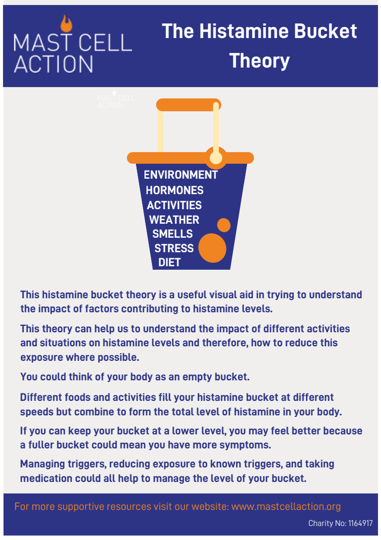
Emergency medical information

MAST CELL ACTION

Dear Healthcare Professional,

This person has a mast cell disorder. This is a medical condition that affects their immune system and causes them to react to things in the environment. Mast cell disorders can cause allergic or inflammatory symptoms that can be life-threatening. Triggers may include certain medications and hospital equipment.

Name	
Date of birth	
Hospital/hospital number(s)	
Name of medical diagnosis or condition(s)	
Emergency contact name and number	
Treating Healthcare Professionals	



MAST CELL ACTION

The Histamine Bucket Theory

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.

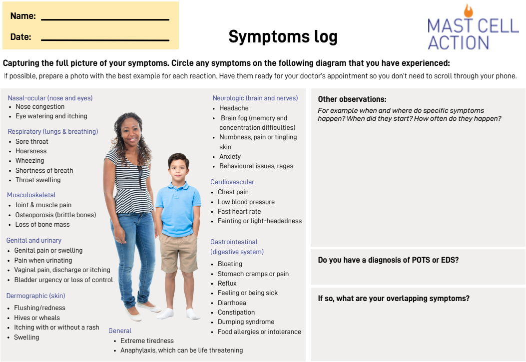
Different foods and activities fill your histamine bucket at different speeds but combine to form the total level of histamine in your body.

If you can keep your bucket at a lower level, you may feel better because a fuller bucket could mean 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: 1164917



Name: ____________________

Date: ____________________

Symptoms log

MAST CELL ACTION

Capturing the full picture of your symptoms. Circle any symptoms on the following diagram that you have experienced:

If possible, prepare a photo with the best example for each reaction. Have them ready for your doctor's appointment so you don't need to scroll through your phone.

Nasal-ocular (nose and eyes)
- Nose congestion
- Eye watering and itching

Respiratory (lungs & breathing)
- Sore throat
- Hoarsness
- 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

Other observations:

For example when and where do specific symptoms happen? When did they start? How often do they happen?

Do you have a diagnosis of POTS or EDS?

If so, what are your overlapping symptoms?

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

This work has been made possible by an award from The National Lottery Reaching Communities Fund. We extend our heartfelt thanks to The National Lottery Reaching Communities Fund for their generous support, which has enabled us to deliver this vital work.

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