

MAST CELL

FREEDOM KIT

The resource pack to help
you to share vital
information about your
child's mast cell disorder



WELCOME

Welcome to your mast cell freedom kit. It has been developed for parents and main carers of school-aged children who have a mast cell disorder, such as mastocytosis or mast cell activation syndrome (MCAS).

We hope that this pack will give you the freedom to share information about MCAS and to express your children's needs.

Mast cell disorders are complex, and each person's experience of managing their condition is unique. Diverse triggers and symptoms can make it daunting for children to talk about their needs.

It can also be challenging for you as a parent or carer to advocate for your child and to be able to share the volume of information required to fully explain your child's needs.

The tools and templates in this pack are designed to help you identify, organise and share the right level of information about your child's mast cell disorder with others. The pages can be adapted to meet your child's specific needs. We hope this kit will help empower you to ensure the right support is put in place for your child when they are outside the home.



Other resources

This pack is part of a group of materials that we have developed for children and families. We hope that these resources will support you in being able to talk about MCAS and share your experiences and needs.

Our [Casper the Chameleon storybook](#) is about a chameleon who has MCAS. This resource was created to help give children the words to describe the way they are feeling and to talk about the experiences and emotions they may have because of living with MCAS. You can order your copy on our website.

You can also download other resources from our website such as medication timetables, a parent support leaflet and a variety of wellbeing resources.

Visit www.mastcellaction.org/resources for further information.



CONTENTS

This mast cell freedom kit has been designed to help you capture and share information about your child. It includes:

1

MY MAST CELL PROFILE (YOUR RECORD)

This section is for you to create, review and update. You may wish to gain input or support from your healthcare professional(s) to fill in certain sections. It is designed to be the single source of current information about your child's mast cell disorder.

2

SHARING WITH OTHERS

This section contains tools and resources to use when sharing information about your child's mast cell disorder. They can be completed, as needed for each situation, using the information you have compiled in Section 1.

3

MAST CELL INFORMATION

This section is a source of information about mast cell disorders and associated conditions. Not all of it will apply to your child. You may wish to share some of this information with others or copy relevant wording into the "My mast cell profile" section of this folder.

4

OTHER TOOLS AND RESOURCES

This section includes other tools and resources and links that may be useful for you or your child in managing their mast cell disorder.



1

MY MAST CELL PROFILE (YOUR RECORD)



MY MAST CELL PROFILE

This section is for you to create, review and update. It is designed to be the single source of current information about your child's mast cell disorder that can then be summarised to share with others. Think of it a bit like the "red book" that you were given when your child was born to record their weight and vaccinations.

You may wish to gain input or support from your healthcare professional(s) to fill in certain sections. It includes:

Page name	Purpose
My mast cell information	Use this section to record your child's medical contacts, diagnoses and important medical history.
My mast cell triggers	Use this section to record your child's known triggers, sensitivities and intolerances. There is also space to include notes on how to avoid or minimise exposure to that trigger. We suggest including only known intolerances or triggers, or suspected triggers that you would like to discuss with your school (or other care environments). Visit mastcellaction.org/mcas-triggers for resources that explain how to manage triggers in more detail, including tools to help identify or confirm suspected triggers.
My mast cell symptom management	Use this section to record information about your child's symptoms and how to treat or manage them. Note that there is space to list medicines on the next page.
My mast cell medicines	Use this section to record details of all the medicines your child takes or may need to take. Consider storing the patient information leaflets (found inside the medicine box) or any other instructions from your doctor in this folder. To help you track medicine doses, a medicines log can be downloaded from mastcellaction.org/managing-triggers .
My urgent/emergency situations action plan	A step by step plan of what to do in urgent and/or emergency situations.

MY MAST CELL PROFILE - Me and my mast cell disorder

Child's name	
Date of birth	
NHS number	
Hospital name(s) and number(s)	

Medical contact details

Name	Telephone/email	Hospital/clinic	Specialism

MY MAST CELL PROFILE - Brief medical history

As your child's medical history may be complex, we suggest including key events, hospital admissions, severe reactions and positive test results in the space below. Print additional copies of this page if you need more space.

Date	What happened?

MY MAST CELL PROFILE - Diagnoses

Note whether these are suspected or confirmed.

Sensitivities & intolerances should be recorded on the next page.

Date	Diagnosis	Test used	Responsible specialist

Date	Confirmed allergy	Test used	Responsible specialist

MY MAST CELL PROFILE - Mast cell triggers: Foods

Known intolerance or trigger	How to avoid or minimise exposure to the trigger

MY MAST CELL PROFILE - Mast cell triggers: Medications

Medicines including ingredients to avoid:	Alternative medicines or how to avoid:

MY MAST CELL PROFILE - Mast cell triggers: Environment

These could include mould, pesticides, fragrances, chemicals, weather, temperature, barometric pressure, pollen index.

Environmental triggers	How to avoid or identify high-trigger environments

MY MAST CELL PROFILE - Mast cell triggers: Other

These could include exercise or exertion, emotions, anxiety.

Other triggers	How to avoid or minimise exposure to these triggers:

MY MAST CELL PROFILE - Symptom management

Consider what to do in different environments, e.g. at home, at school, at an out-of-school activity, at a friend's house.

Print additional copies of this page if you need more space.

Symptom	What to do if this happens?

Mast Cell Medications

Multiple types of medication are often used to treat people affected by Mast Cell Activation Syndrome. The table below clarifies what the different types of medication are and when they are likely to be used.

Type of medication	Purpose
Preventative	Preventative medications are used to try and prevent reactions from happening. These medications will be taken regularly even if your child doesn't have symptoms. They can help to stabilise your child's mast cells so they experience less symptoms.
Rescue	<p>Rescue medications are used to manage the symptoms which occur as a result of having a reaction. Because symptoms can vary so much, there are a large variety of rescue medications which can be used to support the management of symptoms.</p> <p>These are given to stop a reaction from worsening and to relieve symptoms which may already be present - such as hives or a headache.</p>
Emergency	Emergency medications are only used in emergency situations. These are used to treat life-threatening or severe symptoms such as anaphylaxis.

If your child has epi-pens, you should have an anaphylaxis plan provided by the prescriber. Links to some of the main allergy action plan resources are:

- anaphylaxis.org.uk/wp-content/uploads/2021/10/Model-Policy-for-allergy-management-at-school.pdf
- anaphylaxis.org.uk/anaphylaxis-risk-assessment-v7
- bsaci.org/professional-resources/resources/paediatric-allergy-action-plans

MY MAST CELL PROFILE - Preventative medicines

These are medicines that your child will take regularly, even when they don't have symptoms. They are given to reduce or stop symptoms before they happen.

Medicine name	When to take it <i>Include what dose and how to take it.</i>	How to store it	Notes

MY MAST CELL PROFILE - Rescue medicines

These are medicines that your child will take if they have certain symptoms. They are given to stop a worsening reaction.

Medicine name	When to take it <i>Include what dose and how to take it.</i>	How to store it	Notes

MY MAST CELL PROFILE - Emergency medicines

These are medicines that your child will take in an emergency situation. Describe what an emergency looks like in the space below. If your child has Epi-pens and has been given an allergy action plan, you should also share this.

Medicine name	When to take it <i>Include what dose and how to take it.</i>	How to store it	Notes

MY MAST CELL PROFILE

My urgent/emergency situations action plan

Describe step-by-step what to do in case of a certain symptom or event that needs urgent action. You may wish to discuss this plan with your doctor. Depending on your child's particular needs, "what to do" may include taking rescue medication and calling a parent or carer, or taking emergency medication and calling 999.

Situation	What to do

2

SHARING INFORMATION WITH OTHERS



Sharing information with school

Trusting a new school or education setting to look after your child who has complex needs can be a worrying time.

Sharing information with them can help to aid the transition, reducing the stress and anxiety.

It can also help to give you the confidence that those who are caring for your child have the information they need to support your child.

Remember that your child has a right to expect reasonable adjustments to be made to help them feel safe and minimise exposure to triggers when they are at school. Your child may also have other needs which need to be catered for.

The school cover letter template in this pack will help to introduce mast cell disorders to key contacts, such as the school manager, school nurse or special educational needs coordinator (SENCO).

Page name	Purpose
Where to begin?	Things to think about when sharing information about your child's mast cell disorder – both at school and in other types of care environment.
Letter for schools	A letter template that can be sent to your child's school to introduce mast cell disorders and explain why reasonable adjustments are needed for your child. This letter is intended to accompany more detailed information about your child's specific diagnoses and management plan, which can be supplied using the school's own templates or the templates below.
Information for schools	A set of templates with spaces for important information about your child's mast cell disorder to share with school. These may be used to supplement school's own templates if they are not adequate for your child's needs.
Key information card	One page with essential information about your child's mast cell disorder. It is designed to be shared with adults who have a temporary caring role, such as an activity leader.

School information templates:

Notes for completion

The following pages include templates for compiling information for schools about your child's mast cell disorder. These may be used to supplement your school's existing templates to ensure they adequately cover your child's needs.

School will need to know:

- Basic details about your child's diagnosis & emergency contact details.
- Triggers and symptoms that may need to be managed at school.
- Any specific actions that school staff need to take in the event of certain symptoms occurring. For example, administering medicine, taking child to a quiet space, or using a heat pad.
- How to store & administer preventive, rescue and emergency medicines.

TOP TIP: Consider including photographs of your child's reactions if you think this would be useful for school staff.



What does school need to know?

Current information about emergency medical contacts, symptom management and medicine schedules should be held on file by the school, alongside an allergy action plan (if you have one). The school may have existing templates for children with medical needs. These can be a useful starting point, but they may need adapting or supplementing with templates from this pack to ensure they meet your child's needs.

In addition, your child's school should have processes in place to notify and inform staff who will be responsible for your child for shorter periods of time, perhaps a supply teacher or volunteer, and with catering or cleaning contractors.

You can ask school to share this process with you and agree any additional steps that are appropriate to ensure your child's comfort and safety.

How often should I review this information?

The information held by school can be updated regularly, as your child's needs change, or at specific points in the school year. It is often useful to revisit your plan towards the end of the summer term, especially if your child will be having a different teacher in the new school year.

You can ask to meet with your child's new teacher before the start of each new school year. This will give you the opportunity to talk through your plan together and ensure the new teacher is aware of your specific concerns in relation to your child's wellbeing.

Although this pack is mainly aimed at supporting younger children, there are elements which are still relevant for older school settings and can be used in combination with other methods such as young people communicating their own needs.



Sharing information with school

This template has been designed to allow you to share information about mast cell conditions and the additional needs your child may have as a result of having a mast cell condition.

This word template is available to download from mastcellaction.org/children-with-mcas

The templates that follow will allow you to provide more detailed information about your child's specific needs.



MAST CELL ACTION [Your address]

[School's address] [Date]

For the attention of the school manager, school nurse and SENCO:

[Child's name] has a medical condition that affects their mast cells. Mast cells are part of the immune system, responsible for coordinating the immune response. In people with mast cell disorders, mast cells respond inappropriately and excessively to certain triggers. Many different things may cause a mast cell reaction, such as foods or ingredients, cleaning chemicals, stressful situations, weather or the environment. These are called "triggers".

Exposure to triggers can lead to a range of allergic and inflammatory symptoms, which can affect several areas of the body. Symptoms can be unpleasant and embarrassing, but can also be extremely debilitating and even life-threatening. Reactions can be immediate or delayed.


My child's mast cell disorder may impact their school life in several ways:

- Medicines need to be stored and taken at school – this includes regularly scheduled medicines and "rescue" or emergency medicines.
- Staff need to be prepared to respond urgently if certain symptoms appear.
- Catering or cleaning arrangements may need to be adjusted to minimise exposure to specific triggers at school.
- Special equipment may be needed in the classroom, such as a cushion or heat pad.
- In case of urgent or embarrassing symptoms, my child may need a private signal to excuse them from the classroom or have a quiet word with an adult.
- They may need support to keep up with work if they need time off because of their symptoms.

The enclosed documents go into more detail about my child's specific mast cell disorder diagnosis, as well as their known triggers and symptoms. We would like to work with the school to ensure staff members have appropriate information and are confident in handling urgent or emergency situations involving my child.

More information on mast cell disorders can be found at: www.mastcellaction.org and <https://ukmasto.org/>.

Yours sincerely
[Parent or carer's name]


UK masto.org
SUPPORT • ADVOCACY • RESEARCH

TOP TIP

Arranging a meeting with your child's school to discuss their needs in person can be a great opportunity for you to work with them to clearly identify all of your child's needs. This can also give teachers the opportunity to ask any specific questions they may have.

MY MCAS PLAN

I have Mast Cell Activation Syndrome (MCAS).
Sometimes this can make me feel really poorly.
These are some things you should know so that
you can help me to stay well.

Name: _____

Class: _____

Date: _____

Things that make me feel unwell:

Things that help me to feel better:

Things that make me feel worried:

How my teachers can help:

INFORMATION FOR SCHOOLS

Personal information	
Name	
Class	
Date of birth	
Name of medical diagnosis or condition(s)	

Key contacts			
Name	Relationship	Contact number	Contact if...

INFORMATION FOR SCHOOLS

Known or suspected triggers	
Name of trigger	How to minimise trigger exposure at school

INFORMATION FOR SCHOOLS

Managing symptoms at school	
Description of symptom	Action(s) to be taken if symptom occurs at school

INFORMATION FOR SCHOOLS

Dietary requirements to be communicated to catering staff

Other reasonable adjustments (e.g. facilities, equipment, and devices)

INFORMATION FOR SCHOOLS

What is an emergency?

What to do in an emergency?

MEDICINES TO AVOID

Please avoid administering the following medications.

Name		Class	
Parent's signature		Date	

These medicines need to be taken according to a certain schedule, as described below

Medicine name	How to give it (what dose and how to administer)	Time of dose	Who administers (child/adult)	Storage instructions (e.g. fridge, room temperature)	Notes (What to do if dose is missed/child is sick)

INFORMATION FOR SCHOOLS - Preventative medications

Name		Class	
Parent's signature		Date	

These medicines are needed at certain times to control or prevent worsening symptoms

Medicine name	When to give it (what dose and how to administer)	How to give it (what dose and how to administer)	Who administers (child/adult)	Storage instructions (e.g. fridge, room temperature)	Notes (What to do if dose is missed/child is sick)

Planning for school trips

School trips can be worrying as you may not know what new triggers your child might encounter on their trip and there may be less adults than there would be in a school setting to help take care of your child if they are unwell.

Sometimes key carers who would support your child in a school setting might not be going on a trip with your child which can also be worrying - or there may be an overnight stay.

Planning for your child's expected needs on the trip along with the teacher who will be responsible for your child can help to ensure your child has the support they need.

Creating a specific risk assessment with the school which includes any additional needs your child may have, such as avoid certain things, taking extra breaks or bringing safe food can help the school to be prepared to meet their needs.

Often, it can help to have a meeting with the teacher(s) who will be caring for your child during the trip. They can outline the activities that are planned and where the children will be staying. You could use this opportunity to discuss any specific concerns you have and how any challenges may be managed.

TOP TIP: Some schools may find it useful to have a school trip bag with all essentials which is separate from those which are kept in school



Food on school trips

If it is a day trip, you will likely be able to use your usual food preparation arrangements such as sending a safe packed lunch.

If your child is staying away overnight consider all of the meals they will need during this time.

Often the menu is planned ahead of trips, so the school may be able to let you know which meals are planned for other children so that you can provide something similar for your child.

Creating a list of exactly what your child should eat at which times to share with your child's teacher may help as they can then refer to this during the trip.

Extra food could be sent in an additional suitcase to make it easier for the teachers to manage on the coach.

To avoid your child taking lots of additional items with them, it may be possible to arrange to pass extra belongings directly to your child's teacher.

TOP TIP: Providing food in a pyrex (or similar) glass dish with a lid which can then be put straight in the oven can reduce the potential for cross contamination while preparing your child's food.



Medication on school trips

If it is a day trip, the school is likely to be aware of your child's usual daily needs and rescue medications.

If your child is going on a residential trip, there may be additional medications which your child doesn't usually take at school but has in the mornings or evening.

It is likely that permission will need to be given for the school to administer additional medications.

Creating a chart to detail exactly which medications should be taken at which times and how these should be taken can help to ensure these are administered correctly.

If your child usually takes responsibility for measuring a liquid medicine or counting out their own pills, communicating this to the school can help to ensure there is consistency for your child while they are away from home.

Top Tip: Asking the school to prepare an emergency pack with medications, your child's care plan and your contact details can help to ensure your child's needs are met during emergency evacuations such as fire drills.



School residential tick list

Things to do before the trip

- Speak to the school to create a specific risk assessment for your child.
- Remember to include additional triggers they may not usually encounter in the school environment.
- Agree what will happen in an emergency - if the trip is far away, how will you be contacted and who will be responsible for your child until you arrive?
- If your child reacts to air fresheners and cleaning products, liaise with the school to ensure the coach company and accommodation are able to support your child's needs
- If your child needs to be able to access toilets frequently or urgently, plan how these needs will be met with the school. They may be able to allocate your child a room near to a toilet in the accommodation.

Things to pack

- Safe food for all meals and snacks
- Bedding washed in safe washing powder and softener
- Additional personal care products your child may require - such as hand soap, toilet paper and towels
- Medications - both preventative and rescue medications with clear instructions for administering
- Medical information in case of an emergency visit to hospital
- A printed copy of your child's care plan and the specific care plan you have developed for the trip

MCAS in the curriculum

Allergies are often covered in the school curriculum and information about MCAS can also be included in these sessions.

If you have a child or children attending your school who has a mast cell condition, it is likely that there will be triggers at school which could make them unwell. Giving other children an understanding of typical MCAS triggers and symptoms can help children affected by MCAS to feel less isolated and more supported.

It can also help to educate children about the potential triggers of MCAS and specific triggers that a child has if they are happy for this to be shared. In this way, a child's peers can help to support their avoidance of these.

Mast Cell Action is happy to support the development of educational materials to be shared in schools. Please contact us by email at info@mastcellaction.org for more information and advice.



Sharing information with adults outside school

Other adults may be involved in the temporary care of your child, for example friends' parents, activity leaders or babysitters.

They are not likely to need the same level of detail as the school, but they still need to know what to do in urgent or emergency situations.

The **Key information card** in this pack is designed to help you tailor information for different care environments, based on the triggers your child is likely to encounter in that setting.

You can also use the letter template to share information about your child's Mast Cell Condition with your childcare provider.

Remember that your child has a right to expect reasonable adjustments to be made in order to help them to be safe and to minimise exposure to triggers.



Sharing with others: Key information card

*[Insert Child's
Photo]*

_____ 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.

As a result, they may have allergic or inflammatory symptoms that are unpleasant and/or serious and may need urgent attention.

These things can make them unwell:	
They MUST avoid:	
Symptoms that need urgent action and what to do if these symptoms arise:	
Carries an epi-pen:	Yes / No
Child has been trained to use an epi-pen	Yes / No
Other key information	

Sharing with others: Information for clubs

What is an emergency?

What to do in an emergency?

MEDICINES TO AVOID

Please avoid administering the following medications.

**EMERGENCY
CONTACT:**

3

Mast cell
information





Mast cell information

This section includes information about common mast cell disorders and associated conditions. Share this information with others or copy relevant wording into the personal profile section of this folder, if you find it helpful.

It includes information about:

- **Mast cell disorders**
- **Mast cell activation syndrome**
- **Mastocytosis**
- **Other conditions associated with mast cell disorders**

If you are concerned that your child may have symptoms of one of the conditions detailed in this section, you may find it useful to speak to your child's Healthcare Professional to discuss this further

About mast cell disorders

What is a mast cell?

Mast cells are a type of blood cell found in all areas of your body such as under the skin, beside nerves, and inside organs. They are a key part of your immune system involved in fighting infections and healing wounds.

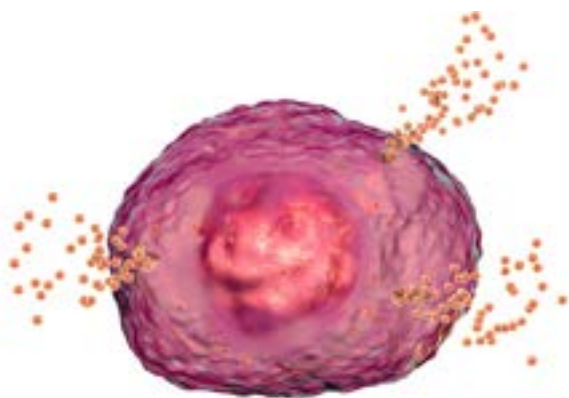
To do this, mast cells detect different triggers. Normally the triggers will be genuine threats to your health, like a virus or a cut, but in people with mast cell activation disorders, the mast cells can also respond to triggers that are usually harmless, like foods or chemicals in the environment.

Mast cells contain chemical mediators that are released in response to these triggers.



There are over 1000 mediators that can be released, including cytokines and chemokines, prostaglandins, leukotrienes, histamine and multiple different enzymes.

The most commonly known are Histamine and Tryptase. Under normal circumstances mediator release is beneficial in fighting infections and for wound healing.



In people with mast cell disorders, mediators are released too strongly, too frequently or in response to usually harmless triggers.

Types of mast cell disorders

A person with a mast cell disorder may have one or more of the following diagnoses:

Mastocytosis is a condition where a person has an increased number of Mast Cells releasing mediators at a higher level than normal.

There are two types: Cutaneous Mastocytosis and Systemic Mastocytosis. There is a known genetic mutation – the KIT mutation – that can be used to help diagnose mastocytosis.



HATS (Hereditary alpha tryptasaemia):

This is a newly recognised condition where mast cells produce too much of the chemical mast cell mediator Tryptase.

A genetic mutation has recently been found to be responsible for this condition (affecting a gene called TPSAB1), which means that a genetic test can be used to help with its diagnosis.

MCAS (Mast cell activation syndrome): A

group of mast cell disorders in which a person seems to have a normal number of mast cells, but these are over-active, release too many mediators, or are activated by harmless triggers.

The term Idiopathic MCAS is used where the triggers are felt to be unknown or inconsistent following allergy testing.

What are the symptoms of mast cell disorders?

Symptoms of mast cell disorders are caused by the excessive or inappropriate release of mast cell mediators. The effects of mast cell mediators are different in different parts of the body; this means that symptoms can range from itching to low blood pressure to joint pain, and from mild allergic reactions to life-threatening anaphylaxis.

Mast Cell Activation Syndrome (MCAS)

MCAS is an immune disorder in which mast cells are inappropriately activated by triggers such as food or chemicals in the environment.

Symptoms are wide-ranging and can affect multiple parts of the body. It can affect both adults and children, often starting suddenly and getting worse over time.

Symptoms may include:

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



Nasal-ocular (nose and eyes)

- Nose congestion
- Eye watering and itching

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

More information can be found at www.mastcellaction.org

Mastocytosis

Mastocytosis is a rare condition where mast cells accumulate under the skin, as well as in the bones and intestines or other organs.

Having too many mast cells can cause a range of symptoms including itchy bumps, digestive issues (e.g diarrhoea), and bone pain. There are two main types of mastocytosis:

- Cutaneous mastocytosis where mast cells gather in the skin
- Systemic mastocytosis where mast cells gather in other tissues such as the organs and bones.

Cutaneous mastocytosis

Cutaneous mastocytosis is when mast cells gather in the skin but are not found in large numbers elsewhere in the body. This condition mainly affects children.

The most common symptom of this condition is abnormal growths on the skin, such as bumps and spots. These can form anywhere on the body and sometimes blister.

Maculopapular Cutaneous Mastocytosis (MPCM), formerly known as Urticaria Pigmentosa (UP), is the most common form of cutaneous mastocytosis. It creates pink or brown marks on the skin.

Cutaneous Mastocytosis



Maculopapular Cutaneous Mastocytosis



Systemic mastocytosis

Systemic mastocytosis is when mast cells gather in the body's tissues, such as the skin, the internal organs and bones. This condition mainly affects adults.

Some people with systemic mastocytosis experience episodes of severe symptoms that last 15-30 minutes. These episodes are often triggered by something specific such as physical exertion or stress.

Symptoms might include skin reactions, vomiting or diarrhoea, muscle and joint pain, mood changes, headaches and extreme tiredness (fatigue).

There are three types of systemic mastocytosis that give rise to different symptoms:

Indolent mastocytosis leads to symptoms that are usually mild to moderate. It accounts for around 90% of all adult systemic cases.

Aggressive mastocytosis is when mast cells multiply in the organs, such as the spleen, liver and digestive system. This condition creates symptoms that are more wide-ranging and severe. Skin symptoms are less common.

Systemic mastocytosis with associated blood disease is a condition that affects the blood cells. It can lead to a type of blood cancer called chronic leukaemia.

Systemic mastocytosis



More information about mastocytosis can be found here:

NHS website: [nhs.uk/conditions/mastocytosis](https://www.nhs.uk/conditions/mastocytosis)

The UK Mastocytosis Support Group: [Ukmasto.org](https://www.ukmasto.org)

Common conditions in people with mast cell disorders

We know that mast cell disorders can overlap with and/or co-exist with a number of other conditions.

In particular, it has been increasingly reported that if you have MCAS you may also have a diagnosis of connective tissues disease such as Ehlers-Danlos Syndrome (EDS) and/or dysautonomia for instance postural orthostatic tachycardia syndrome (POTS).

Despite knowing this, the exact relationships between MCAS and these two medical 'co-morbidities' is not yet fully understood.



A diagnosis of MCAS can also overlap with other potentially related diagnoses, including Long Covid, multiple chemical sensitivity syndrome, migraine and chronic fatigue syndrome.

Similarly, the relationship with these conditions also requires further research and understanding, particularly in the case of Long Covid.



"A diagnosis of MCAS can also overlap with other potentially related diagnoses"

Asthma

Asthma is a condition that affects the airways in the lungs. It can make breathing difficult, causing symptoms like coughing, wheezing and breathlessness.

Asthma often starts in childhood and is commonly found in people with other allergies.



Certain things (triggers) can make asthma worse, but these are not the same for everyone. Common triggers include colds or viruses, pets, pollen, pollution, house dust mites and stress.

In many cases, asthma can be controlled with medicines, including inhalers.

For some people, symptoms are severe & affect many aspects of their day-to-day life.

Everyone with asthma is at risk of an asthma attack, which can be life-threatening. It is important to take action if you notice any signs that your asthma symptoms are getting worse.

More information about asthma can be found here:

NHS website: [nhs.uk/conditions/asthma/](https://www.nhs.uk/conditions/asthma/)

Asthma and lung UK: [asthma.org.uk](https://www.asthma.org.uk)

Allergic rhinitis (hayfever)

Allergic rhinitis (commonly known as hayfever) is where your nose gets irritated by something you are allergic to.

Pollen is the main trigger, but pets, house dust mites, mould and pollution can also cause symptoms like sneezing, runny nose, runny or watery eyes, cough and itching.

You are more likely to have allergic rhinitis if you have other allergies or conditions like eczema or asthma. Symptoms of allergic rhinitis can often be controlled using nasal sprays, eye drops and medicines called antihistamines.

More information about hayfever & allergic rhinitis can be found here:

NHS website: [nhs.uk/conditions/allergic-rhinitis/](https://www.nhs.uk/conditions/allergic-rhinitis/)

Allergy UK: [allergyuk.org/types-of-allergies/hayfever/](https://www.allergyuk.org/types-of-allergies/hayfever/)

Coeliac disease:

Coeliac disease is a condition where your immune system attacks your own tissues when you eat gluten – a protein found in wheat, barley and rye grains.

Coeliac disease is an auto-immune condition, which is different from an allergy or intolerance.



Continued exposure to gluten can lead to damage to the gut (small intestine), leading to symptoms such as diarrhoea, stomach (abdominal) pain and bloating.

It can also make it harder to absorb nutrients, leading to weight loss or vitamin deficiencies. Following a gluten-free diet should help control symptoms and prevent long-term complications.

More information about Coeliac disease can be found here:

NHS website: [nhs.uk/conditions/coeliac-disease/](https://www.nhs.uk/conditions/coeliac-disease/)

Coeliac UK: [coeliac.org.uk/home/](https://www.coeliac.org.uk/home/)

Crohn's disease

Crohn's disease is a type of inflammatory bowel disease (IBD). It causes swelling, inflammation or damage to parts of the digestive system (e.g. stomach or intestines).

This can lead to stomach aches and cramps, severe diarrhoea, extreme tiredness (fatigue) and weight loss.

Crohn's disease is a lifelong condition and symptoms flare ups can be hard to predict. People with Crohn's disease are likely to have periods of good health, known as remission, and times when the condition is more active.

More information about Crohn's disease can be found here:

NHS website: [nhs.uk/conditions/crohns-disease/](https://www.nhs.uk/conditions/crohns-disease/)

Crohn's and Colitis UK: [crohnsandcolitis.org.uk/](https://www.crohnsandcolitis.org.uk/)

Fibromyalgia

Fibromyalgia is a long-term condition that can cause pain all over the body. It can also cause increased sensitivity to pain, extreme tiredness (fatigue), stiff muscles, headaches, difficulty sleeping and “brain fog” or problems with memory and concentration.

The exact cause of fibromyalgia is unknown. It may be related to changes in the way the brain processes pain messages carried around the body.

Some people may be more likely to develop fibromyalgia because of genes inherited from their parents.

Fibromyalgia more often affects women than men. There is no cure for fibromyalgia, but a medications can help control symptoms.

Exercise, relaxation and stress-reduction measures also may help.



More information about Fibromyalgia can be found here:

NHS website: [nhs.uk/conditions/fibromyalgia/](https://www.nhs.uk/conditions/fibromyalgia/)

Crohn's and Colitis UK: [fmauk.org/](https://www.fmauk.org/)

Gastro-oesophageal reflux disease (GORD or GERD)

Sometimes known as acid reflux, this is a condition where acid from the stomach leaks up into the food pipe (oesophagus or gullet). It usually happens because the ring of muscle at the bottom of the food pipe becomes weakened. The most common symptom is heartburn, which feels like burning in the middle of the chest. It can also cause a sour taste in the mouth.

There is often no obvious reason why people get acid reflux. It can be made worse by certain foods or drink, being overweight, smoking, being pregnant, or being stressed or anxious. Simple lifestyle changes can help reduce heartburn, including eating smaller meals or losing weight. Medicines can also help relieve symptoms.

More information about GORD can be found here:

NHS website: [nhs.uk/conditions/heartburn-and-acid-reflux/](https://www.nhs.uk/conditions/heartburn-and-acid-reflux/)

Hypermobile Ehlers-Danlos Syndrome

The Ehlers-Danlos syndromes (EDS) are a group of connective tissue disorders. Connective tissue is the framework of the body: it provides support to the internal organs, blood vessels, bones, skin and muscles.



EDS causes the connective tissue to be fragile or stretchy. Typical symptoms of EDS include stretchy skin, increased range of movement in the joints (hypermobility), or skin that breaks or bruises easily. EDS is caused by a gene mutation, or a change in the DNA. This gene mutation can run in families, inherited from one or both parents. Sometimes, a new gene mutation can arise, meaning a person has no family history.

Hypermobile EDS (hEDS), which used to be known as hypermobility type or type 3 EDS, is thought to be the most common genetic connective tissue disorder. As well as hyperflexibility of the joints, hEDS can be associated with loose ligaments, dislocated joints, skins problems and digestive (gut) issues.

hEDS is often diagnosed in people who also have MCAS, although we do not yet know what the connection is between these two conditions.

More information about EDS can be found here:

NHS website: [nhs.uk/conditions/ehlers-danlos-syndromes/](https://www.nhs.uk/conditions/ehlers-danlos-syndromes/)

Ehlers-Danlos Support UK: ehlers-danlos.org/

Hypermobility Syndromes Association: hypermobility.org/ehlers-danlos

Postural orthostatic tachycardia syndrome

Postural orthostatic tachycardia syndrome (PoTS) is an abnormal increase in heart rate that occurs after sitting up or standing. PoTS is caused by a problem with the autonomic nervous system – the part of the nervous system that isn't controlled by thinking. Normally when you stand up, your blood vessels quickly narrow to increase your blood pressure and maintain blood flow to the heart and brain. In PoTS, this doesn't happen properly so your heart races to compensate.

Symptoms of PoTS include feeling dizzy, light-headed, fainting, blacking out, palpitations or headache. These symptoms can usually be relieved by lying down.

More information about PoTS can be found here:

NHS website: [nhs.uk/conditions/postural-tachycardia-syndrome](https://www.nhs.uk/conditions/postural-tachycardia-syndrome)

PoTS UK: potsuk.org

Myalgic encephalomyelitis (ME) or chronic fatigue syndrome (CFS)

A long-term (chronic) condition that affects many parts of the body, including the nerves and the immune system. It can cause pain, extreme tiredness (fatigue) and a range of other symptoms. It means the body and brain may take a time to recover after expending even a small amount of energy. While the exact cause of ME/CFS is not clear, in most people it seems to be triggered by an infection.

People with ME/CFS can vary a lot in how they are affected by the symptoms how long they last. Some people recover completely, while others remain ill for many years. Some people may be able to work full-time with accommodations, others may be bedbound and have trouble communicating.

Symptoms can also vary from day to day, week to week, and month to month.

More information about ME/CFS can be found here:

NHS website: [nhs.uk/conditions/chronic-fatigue-syndrome-cfs/](https://www.nhs.uk/conditions/chronic-fatigue-syndrome-cfs/)

Action for M.E: [actionforme.org.uk/](https://www.actionforme.org.uk/)

The Brain Charity UK: [thebraincharity.org.uk/condition/chronic-fatigue-syndrome](https://www.thebraincharity.org.uk/condition/chronic-fatigue-syndrome)

Irritable Bowel Syndrome

Irritable Bowel Syndrome (IBS) is a common condition affecting the digestive system or gut. It causes symptoms like stomach cramps, bloating, diarrhoea and constipation. These tend to come and go over time, and can last for days, weeks or months at a time.



IBS is usually a lifelong problem. It can be very frustrating to live with and can have a big impact on your everyday life. Since there is no cure, diet changes and medicines can often help control the symptoms. The exact cause is unknown – it's been linked to things like food passing through your gut too quickly or too slowly, oversensitive nerves in your gut, stress and a family history of IBS.

More information about IBS can be found here:

NHS website: [nhs.uk/conditions/irritable-bowel-syndrome-ibs/](https://www.nhs.uk/conditions/irritable-bowel-syndrome-ibs/)

The IBS network: [theibsnetwork.org/](https://www.theibsnetwork.org/)

4

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:

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

Visit our [mastcellaction.org](https://www.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.

Communication cards

It can be difficult for children to communicate their needs at times – especially when they are not with their everyday carer. These cards are designed to be used by children if they need help from an adult.

Top tip: print and laminate these cards so that your child always has one to hand

I need to talk to an adult immediately <input type="checkbox"/>	I need to talk to an adult immediately <input type="checkbox"/>
I need to talk to a grown up at the next break <input type="checkbox"/>	I need to talk to a grown up at the next break <input type="checkbox"/>
I need medication <input type="checkbox"/>	I need medication <input type="checkbox"/>
I need _____ <input type="text"/>	I need _____ <input type="text"/>

I need to talk to an adult immediately <input type="checkbox"/>	I need to talk to an adult immediately <input type="checkbox"/>
I need to talk to a grown up at the next break <input type="checkbox"/>	I need to talk to a grown up at the next break <input type="checkbox"/>
I need medication <input type="checkbox"/>	I need medication <input type="checkbox"/>
I need _____ <input type="text"/>	I need _____ <input type="text"/>

Emergency medical information

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	

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

Symptoms log

Name: _____
Date: _____

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.

Neuro-ocular (nose and eyes)

- Nose congestion
- Eye watering and itching

Respiratory (lungs & breathing)

- Sore throat
- Heariness
- Whooping
- Shortness of breath
- Throat swelling

Musculoskeletal

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

Dental and urinary

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

Dermatologic (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?

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



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I need medication	<input type="checkbox"/>
I need _____ _____	<input type="checkbox"/>

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

Emergency medical information

These are the medication that my child takes

Medicine name	Dose	Frequency

Emergency medical information

KNOWN TRIGGERS TO AVOID

Please help me to avoid these triggers where possible

MEDICINES TO AVOID

Please avoid administering the following medications.



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 and <https://ukmasto.org>

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