

Supporting Safe Learning for Students with MCAS

The resource pack to help
you to share vital
information about mast
cell disorder with schools



WELCOME

This kit has been specially designed for parents and primary caregivers of secondary school students who have a mast cell disorder, such as Mast Cell Activation Syndrome (MCAS).

We hope that this pack will empower you to share information about MCAS and to express your child's needs effectively.

Mast cell disorders are complex, and managing them can be a unique journey for each person. Diverse triggers and symptoms can make it challenging for young people to communicate their needs.

As a parent or carer, it can be challenging to advocate for your child and share the extensive information needed to fully explain their 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. These pages can be adapted to meet your child's specific needs.

We hope this kit will empower you to ensure the right support is in place for your child when they are outside the home.



CONTENTS

This Supporting Safe Learning for Students with MCAS 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. You might consider it a central database for all information relating to your child's mcas from which you can extract relevant information to be shared.

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

Student'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 example

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?
Mar 2016	Hospital admission for suspected allergic reaction to fish. Symptoms - swollen throat, hives and flushing. Difficulty breathing. Treated with antihistamines and steroid injection.
June 2016	Negative blood test results for fish allergy.
October 2016	Skin reaction to eating pineapple. Swollen lips, itching, hives and flushing. Followed by diarrhoea
January 2017	Severe gastrointestinal issues, cause unknown
March 2017	Facial flushing, lip swelling and itchy tongue caused by eating tomatoes
July 2017	Severe reaction to suntan lotion. Swelling, hives, flushing, itching.
November 2017	Hospital admission - blood in faeces, severe stomach pain
December 2017	Skin prick test positive for alcohol, latex, mold, pollen. Reacted badly to adhesive
March 2018	Feeling faint, dizzy, nearly passed out
July 2018	First appointment with new allergist. Tryptase negative. 24hr urine sample positive for prostaglandin D2. MCAS diagnosed. Started higher dose of antihistamines, and mast cell stabilisers.
October 2018	Saw dietitian, commenced low histamine diet

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	Known reactions to individual triggers	How to avoid or minimise exposure to the trigger

MY MAST CELL PROFILE - Mast cell triggers: Medications

Medicines including ingredients to avoid:	Known reactions to individual triggers	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	Known reactions to individual 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	Known reactions to individual 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, allowing breaks from lessons, 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 students 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.

Agree with the school which medications your child will carry with them and self-administer, and which should be stored by the school.



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 different teachers in the new school year.

You could ask to meet with your child's Tutor, SENCO and Head of Year before the start of each new school year. This will give you the opportunity to talk through your plan together and ensure there is a plan in place to share information with teachers so they are aware of your child's specific needs.

Young people with MCAS will often be learning how to advocate for their needs and starting to do this in the school environment with your support can be a good opportunity for them to practice in a familiar environment.



School catering

If your child will be eating food provided by their school, you could arrange a meeting with the head of catering to go through the menu and make a plan for the term or year ahead with safe foods or adaptations to existing menu items. It can be helpful to ask if you can swap email addresses so that you can contact the catering team at short notice.

Some members of our community have been able to agree some 'safe swaps' in school canteens, with a parent or carer sending an email to let the catering team know when their child will be having a meal at school so they can prepare the safe alternative.

Try to involve your child in these discussions where possible so that they know what has been agreed and can start to use their own voice to advocate for their own needs.



Food technology

Keeping students with MCAS safe during food technology lessons at secondary school requires careful planning and adaptations. It is essential to collaborate with school staff to develop a plan that addresses the student's specific triggers and needs.

Adaptations might include allowing the student to adapt recipes to use their own safe ingredients, ensuring that the cooking environment is free from cross-contamination with allergens, and providing alternative assignments when necessary. Sometimes it may be possible to provide an alternative space where your child can complete their lesson, or perhaps the recipe could be prepared at home.

Clear communication with the student about their comfort level and any symptoms they experience can help in making real-time adjustments. These measures can create a safer and more inclusive learning environment, enabling the student to participate in food technology lessons with confidence and less risk.



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.

Quick view care plans

In addition to a more complex care plan, some families have found it helpful to create a 'Quick View Care Plan' with their child's school.

This is a one-page document outlining key information about your child and their condition, detailing appropriate actions to take in various scenarios and sharing essential information they should be aware of - such as reasonable adjustments that should be put into place.

The use of a traffic light system to identify when a reaction is more serious, or when more urgent action should be taken can help; busy teachers to know how to respond if your child becomes unwell at school.

You could use the following template to build a quick view care plan with your child's school.

GREEN ZONE - Mild reaction

Details of mild reactions

Detail action to be taken

AMBER ZONE - Moderate reaction

Details of moderate reactions

Detail action to be taken

RED ZONE - Severe reaction

Details of severe reactions

Detail action to be taken



Sharing information with school

- a young persons guide

MCAS is complicated and it can be tough to explain your condition to others, but with the right tools and support, you can do it!

Below are some tips and techniques to help you share information about your MCAS with your teachers and classmates:

Be Confident and Clear

Start by explaining what MCAS is. You can say something like, "MCAS is a condition where my body reacts strongly to certain triggers, causing various symptoms." Keep it simple and to the point.

Speak Up

Don't be afraid to ask for what you need. Whether it's extra time on assignments, permission to carry your emergency medications, or a quiet place to go if you're feeling unwell, your school is there to support you, but you need to communicate your needs so they know how they can help. You might find the templates on the next pages helpful to enable you to share the right amount of information.

Practice Your Pitch

Practice what you want to say with a friend or family member. This can help you feel more comfortable and confident when you talk to your teachers.

Build a Support Network

Find a teacher you trust and talk to them about your MCAS as well as sharing with your friends. Having people at school who understand your condition can make a big difference when you're having a tough day.

Stay Positive

Remember, you are not alone. Many students have health conditions and need a bit of extra support. It's okay to ask for help and to take care of yourself.

What is MCAS?

Mast Cell Activation Syndrome (MCAS) is a condition that can affect both kids and adults and is part of a group of mast cell disorders. People with MCAS might also have other related conditions like mastocytosis or hereditary alpha tryptasemia syndrome (HATS).

In MCAS, chemicals called mast cell mediators are released too often, sometimes in response to triggers that aren't usually harmful, like certain foods or chemicals in the environment. This can cause a lot of different symptoms that affect many parts of the body.

Triggers and symptoms of MCAS vary a lot from person to person. Triggers could be things like strong smells, exercise, stress, or temperature changes. Symptoms can come and go, and they might change over time in the same person. This makes it hard to pinpoint specific triggers. As MCAS progresses, the number of triggers and how bad the symptoms are might get worse.

MCAS Symptoms

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



MCAS and me

My common triggers

Symptoms to watch out for

What to do if I have a reaction

Other important information

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)

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.

Involve your child in the planning as much as possible so they can share their thoughts and help explain their needs. This will also enable them to be fully aware of what is being put into place and who they should go to if they need help.

It may be helpful to raise your concerns with teachers about the behaviour of other students and how this might impact your child's MCAS. You could work with the teacher to consider specific rules which could be put into place for the whole cohort - such as banning aerosols, which could help to keep your child safer on the trip.

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.

TOP TIP: 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.

There may be food-sharing on the trip, so making sure your child is aware of what they shouldn't eat and that they have safe options to share can help them to feel included whilst staying safe.

TOP TIP: Providing food in a 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.

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.

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.

Be aware of the person responsible for managing your child's medication and speak to them directly to ensure you are comfortable that they understand your child's needs.



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 if needed
- 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 school who has a mast cell condition, it is possible 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, or activity leaders.

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. After-school clubs and activities may be able to make changes which make activities more inclusive so that your child can safely join in.



Sharing with others: Key information card

[Insert 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
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

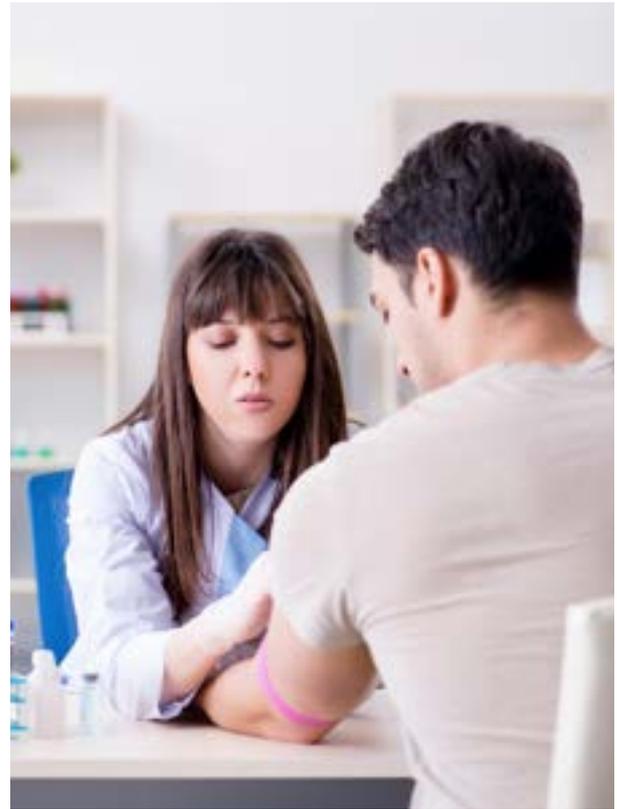
About mast cell disorders

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.

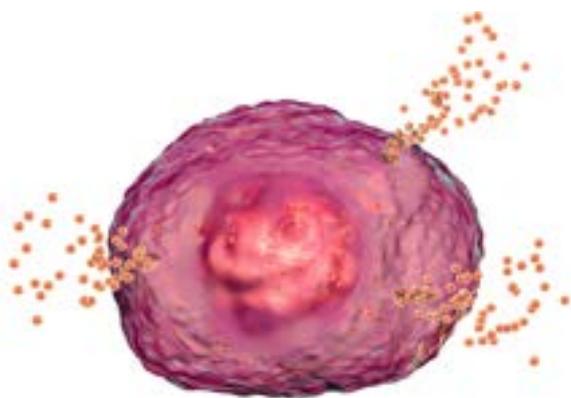
To do this, mast cells detect different triggers. Normally the triggers will be genuine threats to your health, like a virus or a cut, but in people with mast cell activation disorders, the mast cells can also respond to triggers that are usually harmless, like foods or chemicals in the environment.

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.



Find out more at
www.mastcellaction.org

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

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:

- 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.

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.



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

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: _____

MAST CELL ACTION **Symptoms log**

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
- Hoarseness
- Wheezing
- Shortness of breath
- Throat swelling

Musculoskeletal

- Joint & muscle pain
- Osteoporosis (brittle bones)
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Dental and urinary

- Dental pain or swelling
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Dermatologic (skin)

- Flushing/redness
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- Behavioral 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?




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	

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

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.

