MAST CELL
ACTION

Supporting Safe Learning for Students with MCAS

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

Registered Charity Number 1164917

WELCOME

MAST CELL ACTION

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.

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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.

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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.

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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 diahrroea
January 2017	Severe gastrointestinal issues, cause unknown
March 2017	Facial flashing, 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, latest, mold, pollen. Reactied 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

Child's name:_____________________________________ History: page _____ of ______

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?

Child's name:_______________________________________ History: page _____ of ______

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

Child's name:____________________________________ History: page _____ of ______

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

Child's name:____ History: page ______ of _______

MY MAST CELL PROFILE - Mast cell triggers: Medications

Medicines including ingredients to avoid:	Known reactions to individual triggers	Alternative medicines or how to avoid:

Child's name:__________________________________ History: page _____ of ______

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

Child's name:____ **History: page** _____ **of** ______

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:

Child's name:______________________________ History: page _____ of ______

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?

Child's name:____________________________________ **History: page** _____ **of** ______

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	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. These are given to stop a reaction from worsening and to relieve symptoms which may already be present - such as hives or a headache.
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** *Include what dose and how to take it.*	**How to store it**	**Notes**

Child's name:_____________________________________ History: page _____ of ______

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** *Include what dose and how to take it.*	**How to store it**	**Notes**

Child's name:____ History: page _____ of ______

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** *Include what dose and how to take it.*	**How to store it**	**Notes**

Child's name:____________________________________ History: page _____ of ______

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

Child's name:_________________________________ **History: page** _____ **of** ______

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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 adaptions 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.

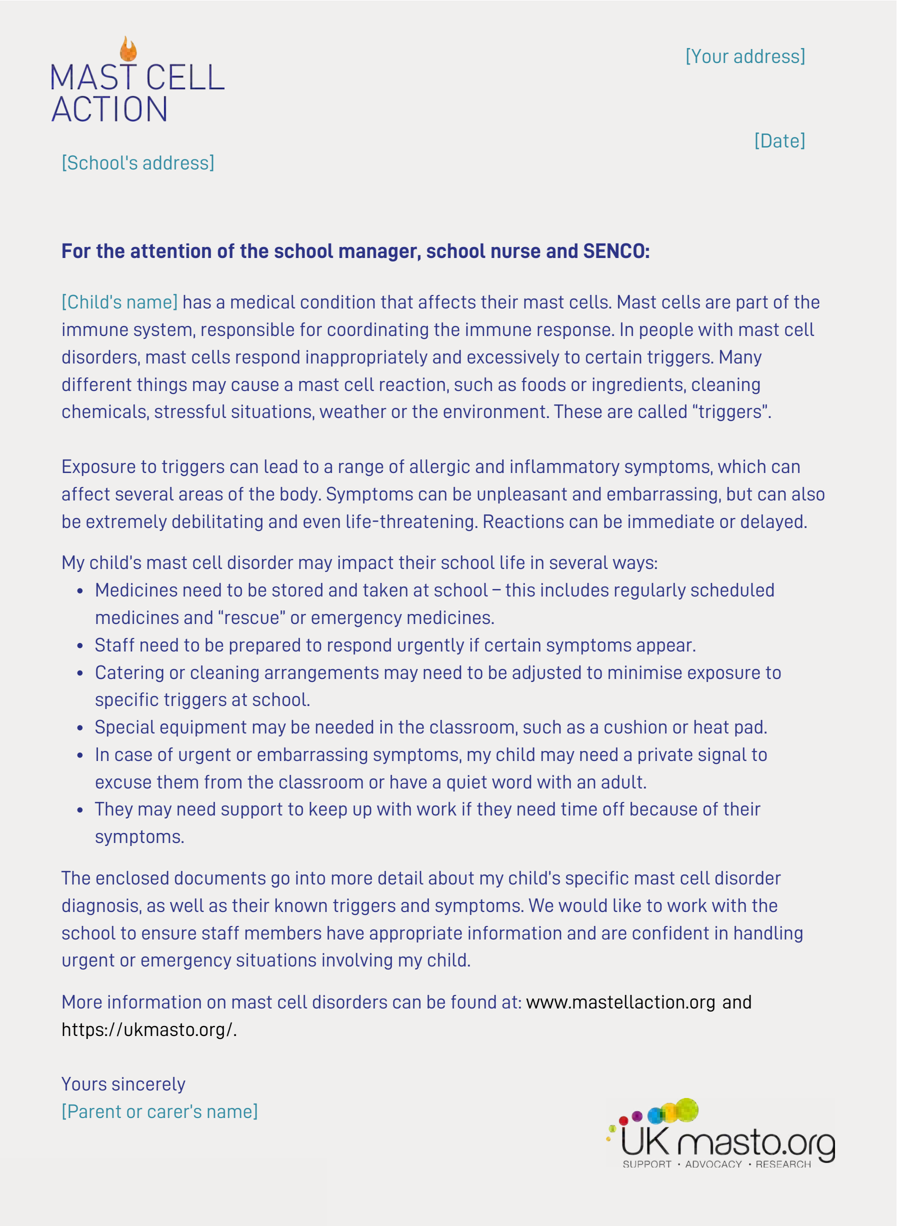
Clear communication with the student about their comfort level and any symptoms they experience can help in making real-time adjustments. These measures can create a safer and more inclusive learning environment, enabling the student to participate in food technology lessons with confidence and less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



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[Your address]

[Date]

[School's address]

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.mastellaction.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
- Hoarsness
- Wheezing
- Shortness of breath
- Throat swelling

Musculoskeletal

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

Genital and urinary

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

Dermographic (skin)

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

General

- Extreme tiredness
- Anaphylaxis, which can be life threatening

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

My symptoms

Use the space below to think about your child's symptoms and record the different symptoms in different parts of their body.

It might be helpful to look through the symptom graphic above with your child to help them recognise potential MCAS symptoms.

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

Child's name:______________________________________ History: page ______ of ______

INFORMATION FOR SCHOOLS

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

Child's name:____ **History: page** ______ **of** _______

INFORMATION FOR SCHOOLS

Dietary requirements to be communicated to catering staff

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

Child's name:____________________________________ History: page _____ of ______

INFORMATION FOR SCHOOLS

What is an emergency?

What to do in an emergency?

MEDICINES TO AVOID Please avoid administering the following medications.

Child's name:____ **History: page** _____ **of** ______

INFORMATION FOR SCHOOLS - Preventative medications

Page ______ of ______

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

Page ______ of ______

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 you 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 TOP: 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 you 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 accomodation 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 accomodation.

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

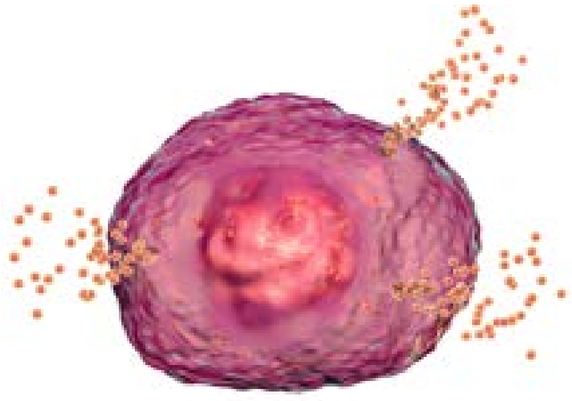
About mast cell disorders

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.

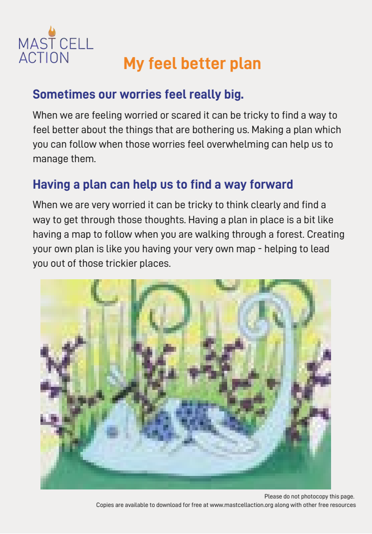
This includes:

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

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.



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My feel better plan

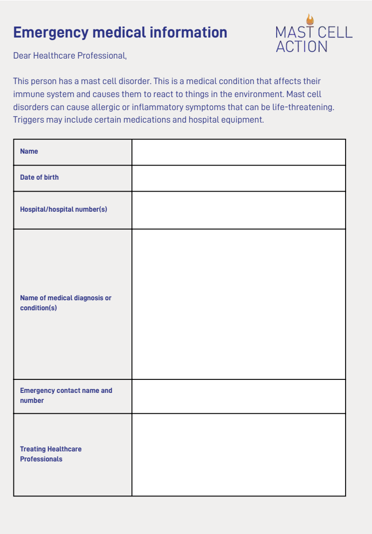
Sometimes our worries feel really big.

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

Having a plan can help us to find a way forward

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

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



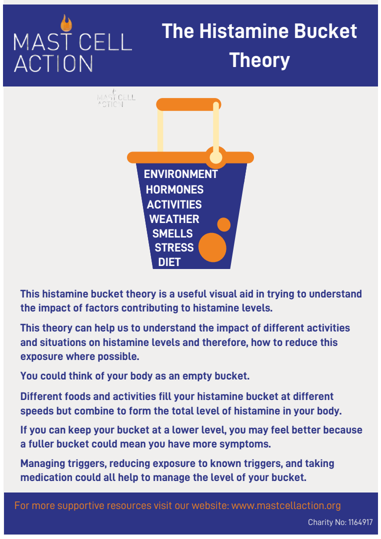
Emergency medical information

MAST CELL ACTION

Dear Healthcare Professional,

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

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



MAST CELL ACTION

The Histamine Bucket Theory

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

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

You could think of your body as an empty bucket.

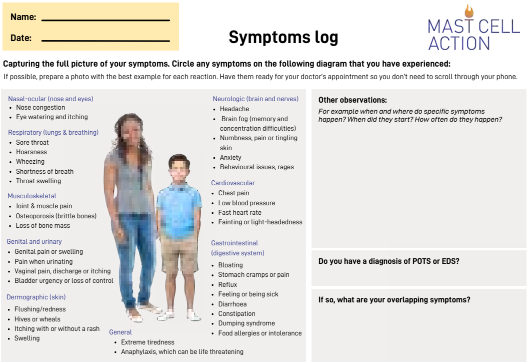
Different foods and activities fill your histamine bucket at different speeds but combine to form the total level of histamine in your body.

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

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

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

Charity No: 1164917



Name: ________________

Date: ________________

Symptoms log

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

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

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

Respiratory (lungs & breathing)
- Sore throat
- Hoarsness
- Wheezing
- Shortness of breath
- Throat swelling

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

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

Dermographic (skin)
- Flushing/redness
- Hives or wheals
- Itching with or without a rash
- Swelling

General
- Extreme tiredness
- Anaphylaxis, which can be life threatening

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

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

Gastrointestinal (digestive system)
- Bloating
- Stomach cramps or pain
- Reflux
- Feeling or being sick
- Diarrhoea
- Constipation
- Dumping syndrome
- Food allergies or intolerance

Other observations:

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

Do you have a diagnosis of POTS or EDS?

If so, what are your overlapping symptoms?

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	

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.

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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.

COMMUNITY FUND

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Mast Cell Activation Syndrome (MCAS) for teachers

What is Mast Cell Activation Syndrome?

Mast Cell Activation Syndrome (MCAS) is a condition which can develop in children or adults. Mast cells are part of the immune system and play a crucial role in defending the body against infections and other harmful substances. In people affected by MCAS, chemicals called mediators are released by their mast cells too frequently or abundantly, and/or in response to triggers that are not typically considered to be harmful, for example; foods or chemicals in the environment. This can lead to a wide range of symptoms that affect multiple parts of the body.

In MCAS, mast cells can be triggered by a wide range of stimuli, such as stress, food, medications, environmental factors, and even changes in temperature or humidity. This can cause a variety of symptoms, such as flushing, hives, swelling, abdominal pain, diarrhoea, headaches, and difficulty breathing. Symptoms can be mild or severe and vary from person to person.

You can find out more and download our free resources at www.mastcellaction.org

Registered Charity Number 1164917

MCAS Symptoms

MCAS symptoms are often unpleasant, debilitating and wide-ranging - affecting different parts of the body at the same time.

MCAS symptoms often come and go and their severity can fluctuate over time. In some cases, people may experience mild symptoms for a long time before seeing a sudden increase in the frequency or severity of their symptoms.

Sometimes there is an incident which triggers this sudden increase in symptoms - such as a severe infection or a medical procedure or operation.

The extent of symptoms for people living with MCAS can be substantial. The potential severity of symptoms along with the unpredictability of triggers can mean that the everyday lives of people with MCAS, their families and carers are considerably impacted.

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
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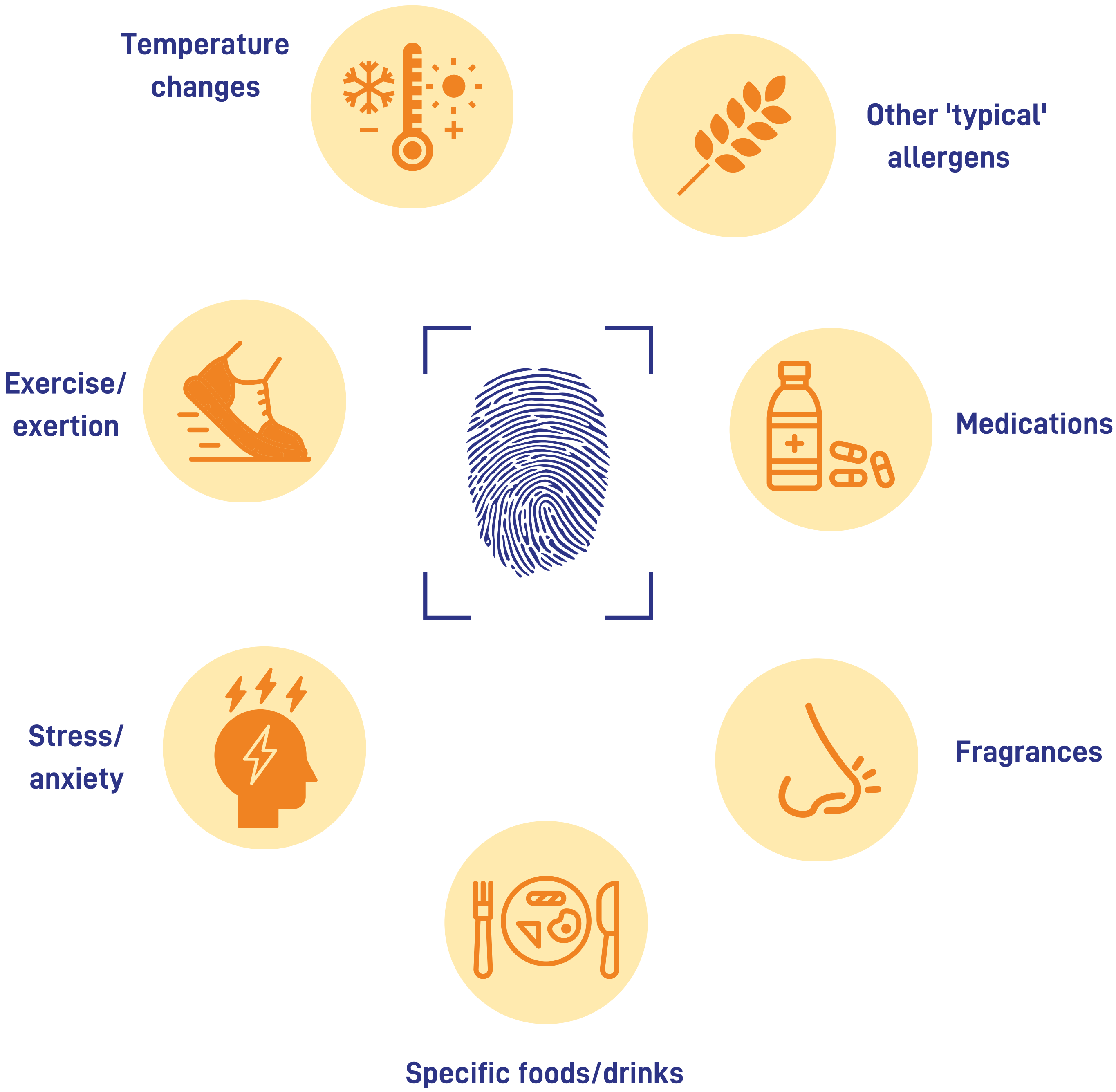
Gastrointestinal (digestive system)

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

MCAS Triggers

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

Common triggers include:



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

Young people with MCAS

Young people with MCAS may experience symptoms that interfere with their ability to focus, participate in class activities, or attend school regularly. Some young people may have mild symptoms, while others may experience severe symptoms that can impact their daily activities. Symptoms often fluctuate and flares of specific symptoms can continue for extended periods.

Young people with MCAS may be taking multiple medications to support the medical management of their condition, these medicines may need to be taken during school time either regularly or as part of their rescue plan.

Young people with MCAS may have to attend regular medical appointments and may need to rest at home when they are too unwell to attend school. This can lead to further disruption to their learning and supporting the child to catch up with any missed work can help to avoid any gaps in learning.

MCAS can also affect a young person's quality of life by limiting their ability to participate in physical activities, attend school regularly, and socialise with friends. It can also lead to anxiety and depression, as young people may feel isolated or misunderstood due to their symptoms.

How can teachers help?

Teachers and school support staff can work with parents and healthcare providers to develop a plan for managing symptoms and accommodations that may be needed in the classroom, such as providing extra breaks, allowing for a special diet, or using environmental controls to reduce exposure to triggers.

It is important for those caring for a young person with MCAS to be aware of the specific needs of young people with MCAS and to work closely with the student and their parents to ensure that appropriate accommodations and support are in place to help manage symptoms and minimise disruptions to their learning.

It is essential that everyone caring for a young person with MCAS has a good understanding of their condition and how to support their unique needs. Creating a plan to inform all staff including supply teachers and regularly keeping them up to date with any changes is vital to creating a supportive and inclusive learning environment for young people affected by MCAS.

Creating a safe environment

Creating a safe school environment for students with MCAS involves proactive adjustments to minimise exposure to potential triggers.

Learn about your student with MCAS, their symptoms, and triggers. This knowledge is crucial for recognising and responding to potential issues and helping to keep the young person safe..

Understanding that triggers can vary from person to person, it's crucial to identify and avoid specific triggers that cause symptoms for each student.

Tips for the classroom:

- Remove or avoid common triggers such as scented products, certain foods, and harsh chemicals. Ensure the classroom is free from perfumes, air fresheners, and scented cleaning products.
- Keep the classroom clean and free from dust and allergens.
- Ensure good ventilation by opening windows or using air purifiers with HEPA filters to reduce airborne allergens and irritants.

MCAS and stress

Creating a stress-free environment is also vital for students with MCAS as stress can be a trigger for many people.

Promote a calm and organised classroom, implement stress-reduction techniques, and be particularly vigilant during high-stress periods like exams.

Encourage open communication with students and their parents to ensure a thorough understanding of each student's specific needs and triggers.

Care plans

Many young people with MCAS will have a care plan designed to help keep them safe in a school environment. Familiarise yourself with the needs of the student with MCAS you are caring for to help you better accommodate their needs at school.

Rest breaks or ‘escape / time-out’ cards

Students with MCAS may need to take time out during the school day to rest, manage symptoms or avoid triggers that could exacerbate their condition.

Having a flexible approach and understanding from teachers ensures that students with MCAS can attend to their health needs promptly and return to class ready to learn. This strategy not only supports their physical well-being but also promotes a sense of security and inclusion within the school environment.

Exam concessions

Exam concessions can help students with MCAS to ensure they have an equal opportunity to demonstrate their knowledge and skills. Concessions might include extended time, additional breaks, or a separate, quiet room to reduce exposure to potential triggers.

Extended time allows students to manage their symptoms without the added pressure of strict time limits, while additional breaks provide opportunities to rest, or take medication as needed. A separate room can help minimise exposure to environmental triggers such as allergens, temperature fluctuations, or stress.

Seating plans

Allowing students to help determine their place in seating plans can support them in avoiding triggers and managing their symptoms effectively. Strategic seating arrangements might include placing students near windows for better ventilation, away from known allergens, or close to exits for easy access during emergencies or breaks.

Ensuring they are seated in a comfortable, quiet area can also help reduce stress and minimise exposure to irritants such as strong odours or temperature changes.

Uniform adaptions

Some people with MCAS react to different fabrics, while others may react to pressure. Reactions to temperature change will also impact the clothing that many young people with MCAS can wear.

Students with MCAS who are triggered by wearing their school uniform may need adaptions to reduce the risk of skin reactions or overheating.

Common adaptions for students with MCAS include allowing them to wear their PE kit at all times, allowing them to remove their blazer (if worn) whenever needed, and allowing adaptions to uniform, such as permitting shorts or clothes made from materials which are safe for individual students or authorising them not to wear a school tie.

Top tip for supporting a student with MCAS

Be understanding and empathetic: Understand that a young person with MCAS may have good days and bad days, and their symptoms may vary. Be empathetic to their situation, and provide support as needed.

Provide a safe environment: Ensure that the classroom and school environment is safe for a young person with MCAS. This can include avoiding the use of scented products or cleaning agents that can trigger symptoms.

Be aware of triggers: Be aware of the triggers that can cause symptoms in a young person with MCAS, such as certain foods, chemicals, or environmental factors. If you notice that a student is experiencing symptoms, check if they have been exposed to any of their triggers.

Be flexible: Be flexible with work including homework and provide extra breaks if needed. This can help reduce stress and allow the student to manage their symptoms better.

Communicate with parents/carers and healthcare providers: Communicate with the young person's parents and healthcare providers to get a better understanding of their condition and learn how you can support them in the classroom.

Prepare for school trips and residentials: School trips can be a particularly worrying time for families. Creating specific risk assessments for individual trips with parents or carers can help to ensure the safest experience possible for the young person with MCAS.

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ACTION

[Your address]
[Your address]
[Your address]
[Your address]
[Date]

[School's address]
[School's address]
[School's address]
[School's address]

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

My child, [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.
- My child may need a quiet space to rest when experiencing symptoms.
- 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’s health and wellbeing.

More information on mast cell disorders can be found at: www.mastellaction.org.

Yours sincerely

[Parent or carer’s name]