MAST CELL ACTION

Getting the Right Support at School for a Child with MCAS

Practical guidance for schools, teachers and families





Registered Charity Number 1164917

1 Helping children with MCAS feel safe, supported and included

Every child deserves to feel safe, understood and able to participate fully in school life.

For children living with Mast Cell Activation Syndrome (MCAS), everyday school activities can sometimes present unexpected challenges. If those who support them understand their condition and make appropriate adjustments, this can make a real difference to their safety, wellbeing and learning.

Understanding MCAS is the first step towards making school more accessible.

This guide has been developed to help schools and families work together to understand a child's individual needs, put practical support in place and create a positive learning environment.

Understanding MCAS

MCAS is a condition involving mast cells, which are an important part of the immune system. In MCAS, mast cells become activated inappropriately or excessively and release chemical substances called mediators. This can lead to a range of symptoms affecting different parts of the body.

Children with MCAS may experience a wide array of symptoms including abdominal pain, nausea, flushing, itching, hives, headaches, dizziness, breathing difficulties and fatigue. Some children may also experience severe reactions, including anaphylaxis.

Symptoms and triggers vary considerably between individuals and may change over time. A child may feel relatively well one day but be unable to manage their usual activities the next.

TOP TIP

There is no single approach that works for every child with MCAS. Understanding the individual child's needs is essential.



2 Working together to support a child

Good communication between the school, family and child is an important step in putting effective support in place. A meeting with the child's teacher, Special Educational Needs Coordinator (SENCO) and/or relevant pastoral staff can provide an opportunity to discuss how MCAS affects their school day and agree what support is needed.

Where appropriate, the child's healthcare professionals can provide information about their medical needs and management arrangements.

It can be helpful to agree:

- Who will be the main point of contact at school.
- Which staff need information about the child's condition.
- How symptoms will be managed during the school day.
- How and when the arrangements will be reviewed.

The child's own views should be included wherever possible. They may be able to explain what helps them, what they find difficult and how they would prefer to ask for support.

Families, schools and healthcare professionals each bring valuable knowledge to help children thrive.

What does the school need to know?

School staff do not need to understand every aspect of MCAS. They do, however, need the right information to support the individual child.

This may include:

- Any known or suspected triggers relevant to school, such as particular foods, fragrances, cleaning products, temperature changes or physical exertion.
- How the child may present when unwell, including symptoms that are not immediately visible to others.
- Whether the child needs rest breaks, access to medication, alternative foods, changes to activities or adjustments to their learning environment.
- What medication is required at school, who is responsible for administering it and where it will be stored, in accordance with the child's agreed healthcare arrangements.
- How to recognise and respond to serious symptoms, including any prescribed emergency medication and the child's individual emergency action plan.

This information should be recorded clearly and shared securely with staff who need it, including relevant supply teachers and staff supervising school activities.

3 Making the school day more manageable

Relatively straightforward adjustments can make a significant difference to a child's ability to participate in school.

Depending on their individual needs, schools could consider:

- Allowing access to a quiet space or additional breaks when symptoms occur.
- Reducing exposure in the classroom and other school environments to identified triggers, such as particular fragrances or cleaning products.
- Considering the child's seating proximity to doors, toilets, ventilation or other facilities that could be troublesome or helpful.
- Working with families and catering teams to accommodate dietary requirements.
- Allowing adjustments to uniform where this contributes to symptoms.
- Agreeing a discreet way for the child to share that they feel unwell or need support.
- Adapting lessons, PE or practical activities where required, without unnecessarily excluding the child.

Preparing for symptoms and emergencies

Some children with MCAS experience symptoms that require prompt support, while others may be at risk of more serious reactions. Schools should work with families and relevant healthcare professionals to agree appropriate medical arrangements, including an Individual Healthcare Plan where needed.

Arrangements should identify who is responsible for providing assistance, where prescribed medication is kept, which staff require training and what should happen during an emergency.

A short school support summary can help staff access essential information quickly, but it must not replace an individualised medical emergency action plan.

Staff must follow the child's prescribed emergency instructions and the school's emergency procedures.

Adjustments should be based on the child's needs and reviewed as those needs change.

4 Keeping support up to date

A child's needs may change as their symptoms, treatment or school environment changes.

Reviewing agreed arrangements at least annually, and sooner when circumstances change, can help ensure that support remains appropriate.

Useful review points include the beginning of a new school year, a change of teacher, a move to a different school or a significant change in the child's health.

The aim is to create an environment where the child can learn, build friendships and participate in school life with the support they need.

MCAS symptoms and triggers often change over time.

For more information, support and resources, visit mastcellaction.org



5 Practical tool: My MCAS School Support Summary

The child, family and school could complete this summary together. Use this tool alongside, not instead of, the school's individual healthcare and emergency plans.

Child's name and class	
Main school contact	
Parent/carer contact details	
My main symptoms at school	
My known triggers and how staff can help me avoid them	
What helps when I am feeling unwell	
The adjustments we have agreed	
Who I should speak to when I need help	
Where to find my medication and emergency plan	
Date reviewed / next review	

6 About us

Mast Cell Action is the UK charity dedicated to improving the lives of people affected by Mast Cell Activation Syndrome (MCAS).

We provide trusted information, practical resources and opportunities for connection, while working with healthcare professionals, researchers and decision-makers to improve understanding, diagnosis and care.

We've created a wide range of free resources to help people affected by MCAS, their families and the professionals supporting them. From everyday living to education and healthcare, our guides offer trusted information and practical advice.

Find more information, resources and support at

www.mastcellaction.org

Our vision is a world where everyone with MCAS gets the diagnosis, treatment and care they need.

7 Thank you

We are grateful to E H Smith Charitable Trust and Baron Davenport's Charity for their generous support of our work with children and young people affected by MCAS.

This resource would not have been possible without their generosity and commitment to helping children with MCAS feel safer, better understood and supported in education.

If you can, please consider making a donation.

Your support helps us develop more resources, support families and work towards a future where no one has to face MCAS alone.

mastcellaction.org/donate