

Anaesthetic and Surgical Guide

Planning for surgery for people
with Mast Cell Activation Syndrome



WELCOME

Hello and welcome to this guide on surgery and anaesthetic for people living with Mast Cell Activation Syndrome (MCAS).

We understand that planning for surgery or any procedure requiring anaesthesia can feel daunting when you have MCAS. These situations can bring uncertainty - but with the right preparation and support, they can be managed safely.

Surgery and procedures are sometimes necessary, and careful planning makes all the difference. This guide, developed by members of our Medical Advisory Board, aims to help you feel more confident and informed about what to expect.

Inside, you'll find practical information to help you prepare for your procedure, along with guidance you can share with your medical team - including your surgeon and anaesthetist - so they can support you more effectively.

We hope this guide helps to reassure you and gives you the confidence to approach your procedure knowing that you are not alone.

Together, we can make sure every step of your care is as safe and supported as possible.



CONTENTS

1	What is MCAS?	4
2	General Considerations	5
3	Planning and Preparing for Surgery	6
4	FAQs Before Surgery	7
5	During Surgery	9
6	After Surgery	10
7	Discharge and Recovery	11
8	Further Information	12

What is MCAS?

Mast Cell Activation Syndrome (MCAS) is a condition which can develop in children or adults. MCAS forms part of a spectrum of mast cell disorders. Mast Cells are a type of blood cell found in all parts of the body. They are a key part of the immune system. Mast cells detect different types of triggers and tell other immune cells how to respond. Usual mast cell triggers include infections, parasites, viruses, stings and wounds.

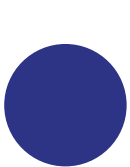
In people affected by MCAS, chemicals called mast cell mediators are released too frequently or abundantly, and/or in response to triggers that are not typically considered to be harmful, for example; foods or chemicals in the environment. This can lead to a wide range of symptoms that affect multiple parts of the body.

Common symptoms by organ system include:

- Skin: flushing, urticaria (hives), itching, angioedema,
- Digestive tract: abdominal pain, diarrhoea, food intolerances, reflux
- Musculoskeletal: joint hypermobility, osteoporosis, fibromyalgia-type pain
- Cardiovascular: hypotension, tachycardia (palpitations)
- Respiratory: wheezing, nasal congestion, sore throat
- Nervous system: headaches and autonomic dysfunction, brain fog, anxiety and depression, poor concentration/memory, sleep disorders
- Genitourinary: interstitial cystitis, dysfunctional uterine bleeding (painful periods)
- Systemic: fatigue, weight loss

Diagnosis is complex, and therefore it's unclear how common it is. However, the most recent consensus criteria publication suggests that up to 17% of people may have it. For more information on diagnosis, see our Primary Care Guide, [here](#).

The management goals when providing anaesthesia for procedures and surgery is to prevent worsening of mast cell symptoms and possible anaphylaxis (life threatening allergic reactions).



General considerations

“Will anaesthesia worsen my MCAS if I decide to have surgery?”

It's natural to feel worried about how anaesthetic might affect your MCAS. Everyone's experience with MCAS is unique, and that means each person's response to anaesthetic can vary too.

Many different factors can influence how your body reacts to anaesthesia - things like your overall health, body composition, smoking status, other medical conditions, the type of surgery you're having, and the specific anaesthetic drugs or techniques used. Your reactions may also depend on how active your symptoms are at the time and what your individual triggers are.

Some common triggers of mast cell activation around surgery and anaesthesia include temperature changes, friction or pressure on the skin, certain medications, contrast media, non-steroidal anti-inflammatory drugs (NSAIDs), stress, anxiety, and tiredness.

Although there isn't yet any published research on how often people with MCAS experience mast cell-related symptoms or reactions during anaesthesia, there is useful information from studies in mastocytosis - a different but related condition involving higher numbers of mast cells. In those studies, reactions were still uncommon, and with good planning, most people had straightforward, uneventful procedures.

The key message is that anaesthesia isn't a contraindication for people with MCAS. With the right preparation, careful communication, and a team who understand your needs, surgery can usually be carried out safely.

“What if the healthcare team is not familiar with MCAS?”

If your doctors or surgical team don't have much experience with MCAS, there are a few simple steps that can help:

- Provide letters from your GP or specialist explaining your diagnosis and any precautions that have worked well for you in the past.
- Share this leaflet with your medical team so they can understand MCAS and how it may affect your care.
- Point them to trusted resources, such as:
 - [Mast Cell Action Primary Care Guide](#)
 - [The Mast Cell Disease Society – Patient Resources](#)
 - [UK Mastocytosis Patient Group – Anaesthesia Information](#) (note that mastocytosis is similar but distinct from MCAS)

Planning and preparing for surgery

“How will I be assessed for surgery?”

Letting your healthcare team know about your MCAS as early as possible is an important first step. When you first meet with your surgeon to discuss a possible procedure, make sure they're aware of your condition before your pre-operative assessment is booked. This helps ensure everyone involved in your care has the right information from the start.

Before your surgery, you'll have a detailed assessment with a pre-operative nurse - often via a remote consultation. They will usually refer you to a Consultant Anaesthetist Pre-operative Clinic if additional considerations, including MCAS, are identified. This is a good opportunity to talk through your individual needs so you can make a plan together. Here are some ways to make that meeting as helpful as possible:

- Tell the Preoperative Assessment Clinic (POAC) team about your MCAS in case it hasn't been passed on by the surgical team.
- Share a full medical history, including any other conditions or medications.
- Prepare a list of any previous reactions to medications, substances, or situations - and describe what those reactions looked like.
- Identify your potential triggers that might arise during anaesthesia or surgery (for example, certain drugs, temperature changes, or friction).
- Understand that any extra investigations will depend on the type of surgery and your personal risk factors, not just your MCAS.
- Work with your team to agree an individualised plan, discussing the possible risks and benefits of surgery. This is called shared decision-making - a process that helps you and your healthcare team make informed choices together.
- You can learn more about shared decision-making here:
 - [NHS England: Shared Decision-Making](#)
 - [Centre for Perioperative Care video on shared decision-making](#)

It can also be very helpful to ask your GP or specialist to write a short letter for your surgical or anaesthetic team. This can outline your diagnosis, current treatments, and known triggers - helping your team plan ahead to minimise risks and keep you as safe and comfortable as possible.



Patient Medical History

DATE OF BIRTH

THE AREA IN AND AROUND YOUR MOUTH, YOUR...
MEDICATION THAT YOU MAY BE...
OR ANSWERING THE...

FAQs Before Surgery

“Will my history of sensitivity to general medications, chemicals, and anaesthetic drugs be considered?”

Your full history of any previous reactions and the nature of the reaction should be recorded during your preoperative assessment, so that it can be considered when planning your anaesthetic. Therefore, it is important that you explain in detail any sensitivities to drugs that are specific to you.

It is also important to let the preoperative assessment clinic know about any complementary medicines or supplements that you take.

“What is the risk of me suffering anaphylaxis during anaesthesia?”

The occurrence of anaphylaxis in people with MCAS undergoing anaesthesia is unknown. A large Spanish study of Mastocytosis (a related but different and more severe condition), reported a rate of 0.4% in adults (10 times higher than the general population), and it can reach 2% in children. Although this is ten times higher than the general population it is still very low, and the risk is further reduced by using pre-emptive medications (see below) and selecting anaesthetic drugs with the safest profile.

“Will MCAS be considered when deciding the time of my operation?”

Your healthcare team should take your individual needs into consideration when planning your surgery. For major operations, it's common for patients to be scheduled as the only case for a full morning, afternoon, or even the whole day - so in those situations, the timing may be fixed.

If you are having day-case surgery and you are concerned about delayed reactions to the anaesthetic and surgery, you could ask if it might be possible to book your surgery in the morning. This can give you more time in recovery afterwards, allowing your medical team to monitor you and make sure you're feeling stable and comfortable before you go home.

“I feel nervous about having surgery. Is there anything I can do?”

It's completely normal to feel nervous before surgery - and if you have MCAS, it's understandable to have extra worries about how anaesthetic or the procedure might affect your condition. The good news is that, with the right preparation and support, most people with MCAS have smooth and uneventful experiences. Talking openly about your concerns can also make a big difference. Share how you're feeling with people you trust - your partner, friends, or family. Taking time to prepare both physically and mentally before your procedure can also help you approach surgery with greater confidence and calm.

There are many ways to help your body and mind prepare for surgery, such as; gentle movement, relaxation techniques including breathing exercises, mindfulness, or guided imagery, which can help you imagine yourself recovering calmly and doing well. The Royal College of Anaesthetists (RCoA), in partnership with the British Society of Clinical and Academic Hypnosis (BSCAH), has produced a series of recordings that you might find useful to help you relax before surgery and to develop a positive mindset about your procedure and recovery.

<https://www.rcoa.ac.uk/patients/patient-information-resources/preparing-your-mind-surgery>

Many hospitals hold 'information sessions' for patients scheduled to have certain types of surgery, where you can learn about the procedure that you are having and how to prepare for it. Understanding what to expect can help you feel more confident, reduce anxiety, and give you a greater sense of control as you get ready for surgery.

Specific concerns regarding surgery and MCAS

“Should I take my usual medication on the day of surgery?”

Before your operation, your preop assessment team will record all the medications you take and let you know if any need to be paused or adjusted before surgery. It's important to follow their instructions carefully, as some medicines can affect anaesthetic drugs or recovery.

Your anaesthetist will also review your medications and make any adjustments needed to keep you safe and comfortable during your procedure. In general, most people with MCAS are advised to continue taking their MCAS-specific medications, such as antihistamines and H2 blockers (like Famotidine), on the day of surgery - but always confirm this with your healthcare team. Patients on Low Dose Naltrexone (LDN) should pause it 48 hours before surgery so that morphine related painkillers will work. Hospital staff may not be familiar with this medication.

“Will my specific triggers be considered?”

Your surgical plan should be individualised to your needs, including any known triggers. The team can take practical steps to help reduce risks, such as:

- Managing temperature changes in the operating room
- Minimising friction or pressure
- Monitoring closely for any early signs of mast cell activation or flare-up

Because pain and anxiety can sometimes trigger mast cell activation, your anaesthetist may recommend medication to help you relax before surgery and will ensure your pain relief is well managed afterwards.

During Surgery

Medication given before surgery to prevent mast cell mediator release symptoms

Prophylactic anti-mediator therapy (PAT) may be considered before surgery to reduce the risk of symptoms exacerbation and anaphylaxis. PAT means drugs that will help prevent a flare, and includes antihistamines, either oral (loratadine, cetirizine, fexofenadine) or intravenous (chlorphenamine or cetirizine) and famotidine; a benzodiazepine may be considered to prevent/reduce anxiety.

Anaesthetic drug management in MCAS

Your medical team will take great care in choosing the safest possible medications for your anaesthetic. Any drugs known to cause histamine release or that have previously caused you a reaction will usually be avoided.

There are safe and effective alternatives available in every category of anaesthetic drug - including those used to:

- induce anaesthesia (help you go to sleep),
- manage pain,
- relax muscles if needed, and
- prevent sickness (anti-emetics).

Your team will also select the lowest-risk options for skin antiseptics and antibiotics, helping to reduce the chance of triggering mast cell activation during your procedure.

The use of local anaesthetics should be preferred wherever suitable, as this simplifies things and reduces the need for other medications. The local anaesthetic drugs commonly used in the UK are considered low risk as MCAS triggers. However, those with a comorbid diagnosis of Ehlers-Danlos Syndrome (EDS) can experience local anaesthetic resistance. This may make things more challenging and require additional planning. If you have EDS, talk to your anaesthetist about this possibility prior to your procedure.



After Surgery

“Will the recovery staff be aware of my specific needs?”

Yes. The operating theatre team will make sure the recovery staff are fully informed about your MCAS and any special considerations for your care before you leave the operating room.

Most hospitals also hold daily team briefings, where the needs of each patient are discussed and recorded. This helps make sure that everyone involved in your care understands your condition and how best to support you as you recover.

“Will I have special monitoring after surgery?”

People with MCAS may recover a little more slowly after surgery. You might need closer or extended monitoring, careful pain management, and avoidance of known environmental triggers such as temperature changes or strong smells.

Everyone is monitored continuously in the recovery area after surgery, and then less often once they move to the ward. The level of monitoring you need will depend on the type of surgery you've had and how active your MCAS is.

In some cases, your team might decide that you would benefit from spending time in a high-dependency unit (HDU) after surgery, where you can be observed more closely and any issues can be addressed quickly.

Pain relief after surgery for people with MCAS

Paracetamol and synthetic versions of morphine type pain killers are usually well tolerated. Morphine, codeine and pethidine are best avoided. Appropriate local anaesthetic techniques using the safe local anaesthetics options are ideal forms of pain relief where feasible.



Discharge and Recovery

“Will I be more at risk of MCAS flare ups after surgery?”

Some people with MCAS may find that flare-ups are more likely after surgery, as the body goes through stress and may experience pain during recovery. This doesn't happen to everyone, but it's helpful to be prepared.

Working with your GP and healthcare team to create a plan in advance can make recovery smoother and reduce the risk of flare-ups. Your plan might include:

- Engaging community services early, so that support is already in place to monitor your recovery at home
- Keeping appropriate pain medication at home to manage discomfort safely
- Having an emergency medicine pack ready to help manage flare-up symptoms if they occur

“Will my GP be aware of my pending operation and the support I may need afterwards?”

You can ask your surgical team to keep your GP updated regarding the date of surgery. If you are admitted to the hospital following surgery, your GP will receive a copy of the discharge letter with the plan.



Further Information

“Where can I find further information about anaesthesia and preparing for surgery?”

- Information about different types of anaesthetics can be found at: <https://www.rcoa.ac.uk/patients/patient-information-resources/patient-information-leaflets-video-resources>
- Information about the risks associated with anaesthetics can be found at: <https://www.rcoa.ac.uk/patients/patient-information-resources/anaesthesia-risk>
- Information on preparing for surgery can be found at: <https://www.rcoa.ac.uk/news/fitter-better-sooner-preparing-surgery-information-toolkit-launches>
- Information about the surgical journey can be found on the Centre for Perioperative Care's website at: <https://cpoc.org.uk/patients>
- Information about pain medicine and pain conditions can be found on the Faculty of Pain Medicine's website at: <https://fpm.ac.uk/patients>



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

With special thanks

We would like to express our sincere thanks to Dr Anton Krige MBChB FRCA FFICM and Dr Tania Liva MD, DRCOG, DFRS, Dip BSLM/ISLM, LMCC, CCFP for so generously giving their time and expertise to create this resource.

Their insight, care, and commitment have been invaluable in helping us provide accurate, practical information to support people with MCAS as they prepare for surgery and anaesthesia.

We are deeply grateful for their contribution and for their shared dedication to improving understanding and care for those living with mast cell conditions.

Also our sincere thanks to graphic design volunteer Anna Sutherland for her invaluable work on this resource.