

Travelling with MCAS

Navigate the World Safely:
Tips and Resources for
Managing Mast Cell Activation
Disorders on the Go,
Wherever you Go

Registered Charity Number 1164917



WELCOME

OVERVIEW

Welcome to the Mast Cell Action Travel Resource Pack, your comprehensive guide to planning and enjoying safer travels with Mast Cell Activation Syndrome (MCAS).

This resource pack is designed to support individuals with MCAS and their families in navigating the complexities of travel, ensuring that you have the tools and information needed to manage your condition effectively while on the go.

Whether you are embarking on a short trip within the UK or an international adventure, this guide will provide you with practical advice, checklists, and tips to make your journey as smooth and enjoyable as possible.

This resource pack is organised into several sections, each focusing on a different aspect of travel with MCAS.



THINKING ABOUT TRAVELLING



PLANNING



Whatever stage of travelling you're at, whether you're dreaming, planning, on your way, or already at your destination, each phase of the journey comes with its own set of considerations and opportunities.

TRAVELLING



MANAGING EMERGENCIES



HOMETIME!!!



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THINKING ABOUT TRAVELLING



Reasons to travel

Traveling with MCAS requires extra planning and care, but having a clear understanding of your reasons for travel can help guide your decisions and provide motivation when challenges arise.

Whether you're travelling for leisure, business, personal goals, or other reasons, defining your purpose can help you make informed choices and stay focused on what matters most to you.

Leisure and relaxation

If your goal is to relax, explore new places, or enjoy time with loved ones, focus on destinations and activities that promote calm and rest. Select locations known for their tranquillity, accessibility, and MCAS-friendly amenities, such as allergy-friendly accommodations or outdoor spaces with fresh air.

Business or Professional Goals

When travelling for work or professional development, consider how to balance your commitments with your health needs. Look for ways to reduce stress, such as staying close to meeting venues or choosing travel times that align with your best energy levels. Communicating your needs with colleagues and setting realistic expectations can help you stay on track.

Personal Goals or Milestones

Whether it's achieving a personal goal, attending a significant event, or ticking off a bucket list item, your reason might be deeply personal. Reflect on what this trip means to you and how it aligns with your values. Documenting your goals can serve as a powerful reminder of why you're making the effort, especially if challenges arise during your travels.



IMPORTANCE OF PLANNING FOR TRAVEL WITH MCAS

Travelling with MCAS requires careful planning and consideration to avoid potential triggers. The unpredictability of MCAS might make travel feel daunting, but with the right preparation, you can minimise risks and focus on enjoying your trip.

It's important to approach travel with a mindset that prioritises your health and comfort. From selecting the right destination to packing essentials, every step of your journey can be tailored to suit your needs.

By anticipating potential challenges and planning for contingencies, you can reduce the impact of MCAS symptoms and handle unexpected situations with greater ease.

Remember, flexibility and self-advocacy are key; don't hesitate to adjust your plans if necessary and communicate your needs to those around you.

Be prepared for energy-intensive research while you plan; allow several days or even weeks to complete this process so that you can pace whilst you plan



PLANNING



Planning your trip

When planning a trip with MCAS, taking into account the timing, climate, and structure of your journey can significantly impact your experience and help you manage symptoms more effectively. Here are some key considerations to help you make your travel as comfortable and enjoyable as possible:

- If your flare-ups are worse during certain seasons (eg when the pollen is high or it's very warm), consider going away at a 'less reactive' time of the year for you as you may be able to enjoy the experience more.
- Consider the climate at your destination at the time of travelling, especially if changing temperature/climate can be a trigger for you
- Consider the best time of day to travel, e.g., if you have more energy at particular points of the day or if it's a flight, and consider times when people are less likely to be eating and drinking.
- Consider splitting up your travel, perhaps staying overnight and travelling over 2 days instead of taking one longer flight/drive.
- Speak to people about the destination you're considering – can they recommend any particular hotels, other accommodation or restaurants? This can provide extra reassurance or help to narrow down your focus.

Consider the benefits of self-catering vs all-inclusive – some people prefer the reassurance of all-inclusive/communicating their needs once and trusting in the hotel to support, others prefer the variety of finding good restaurants or shopping in a supermarket and having the option to eat in an apartment.



Selecting Your Destination

Choosing the right destination is a crucial part of planning a successful trip when living with MCAS. Your destination can significantly impact your experience, comfort, and overall well-being, so it's important to select a location that aligns with your health needs and travel goals.

By planning carefully, you can set yourself up for a smoother and more enjoyable experience. Here are some key considerations to keep in mind when selecting your travel destination:

Accessibility and Comfort

Choose destinations that accommodate your specific needs. Look for places with good healthcare facilities, easy access to rest areas, and MCAS-friendly food options.

Environmental Considerations

Consider climates and environments that suit your health. For example, you might prefer a destination with low humidity, minimal allergens, or good air quality.

Proximity

If long-distance travel feels overwhelming, explore closer-to-home destinations that still offer a sense of adventure and change of scenery.



ALTERNATIVES TO FLYING

If flying is not safe for you, there are lots of alternatives so that you can still enjoy your holiday!



Road trip and ferries (to get into France, Holland and Ireland)



Eurostar; London to Paris, Amsterdam, Rotterdam and Brussels



Travel within the UK without leaving the country - more info on this further on in the guide



TRAVELLING IN THE UK

TIPS FOR TRAVELLING IN THE UK

RESEARCH AND PLAN AHEAD

- Look for accommodations that can suit your requirements and cater to dietary needs if not self-catering
- Use the questions from the accommodation screening in this guide to email them directly and then create your shortlist

ACCESSIBLE TRANSPORT OPTIONS

- Consider taking the train, as many UK train services offer excellent assistance for disabled passengers.
- If you prefer driving, plan your route to include frequent stops for rest and ensure that your vehicle is stocked with necessary supplies

ADVOCATING WITH CARDS

- Wear a sunflower lanyard to discreetly indicate that you have a hidden disability. This can help staff and the public understand that you may need extra assistance or accommodations.
- Apply for the Access Scheme for attractions and accommodations. This scheme provides information on accessible destinations and helps ensure that venues can cater to your specific needs.
 - To apply you will need to submit medical documentation and outline which accommodations suit your requirements

OTHER IMPORTANT PREPARATION

- Always carry your emergency medications, personal care products, and safe snacks to avoid exposure to food allergens and triggers
- Before visiting attractions or dining out, contact the venues to confirm they can accommodate your dietary and environmental needs - advanced preparation is your best friend here!

TRAVELLING IN THE UK

UK DESTINATION IDEAS FOR STAYCATIONS

CORNWALL

- Known for its beautiful beaches and scenic coastal paths, Cornwall offers numerous accessible accommodations and attractions.
- Consider visiting the Eden Project, which provides comprehensive accessibility information and support for visitors with disabilities.



LAKE DISTRICT

- This stunning national park features accessible trails and accommodations, making it ideal for nature lovers.
- Some hotels and B&Bs are beginning to offer services tailored to guests with fragrance sensitivities and dietary restrictions.

EDINBURGH

- A city rich in history and culture, Edinburgh has many accessible attractions, including Edinburgh Castle and the Royal Mile.
- The city also boasts a variety of restaurants that cater to dietary needs, making it easier to find safe dining options.



BRIGHTON

- This vibrant seaside city is known for its inclusivity and accessibility.
- Brighton offers accessible beaches, a variety of dining options, and attractions like the Brighton Pavilion and the British Airways i360.

Preparing your mind and body

Travelling with MCAS involves more than just logistical planning; it's also about getting your body and mind ready for the adventure ahead. By taking proactive steps to prepare yourself physically and mentally, you can boost your confidence and set a solid foundation for a smoother travel experience. Take a look at these practical strategies for calming your body, managing stress, and fostering a positive mindset.

Preparing your body

- In the run-up to your trip and particularly in the days before, focus on safe foods, minimise stress, and take any medications you may require to prepare your body for travel
- Try to minimise your schedule and get plenty of rest
- Speak to your medical team about your plans and take their advice to help prepare physically for your trip.

Preparing your body

- Focus on the things you are looking forward to about your trip, reread your checklists and confirm that you have prepared everything possible
- You could talk things through with a friend and ask them to help you to double-check your lists.
- Pick 1 or 2 things you are excited about for your trip and focus on them if you feel wobbly!
- Speak to family and friends about how you feel, let them help to reassure you and keep you focused on the reasons you are doing this.
- Remind yourself that people travel successfully all the time and you can do it, too
- Remember that you are an MCAS Warrior!



PRE-TRAVEL CHECKLISTS

LOCATION

- Research and decide your travel destination

ACCOMMODATION

- To select your accommodation, begin with the screening process on the next page, creating a shortlist of suitable places and then select your preference
- Consider the safest option for you, with your MCAS triggers in mind. Is a hotel a better option? Or perhaps an AirBNB apartment where you have a more enclosed space and can prepare your own food.
- Ensure daily activities are within the accommodation vicinity

TRAVEL

- Evaluate the journey duration; include all modes of transport and any necessary stopovers - create a list of who to contact to make suitable adjustments at each stage of the journey.
- Think about how you might be able to break up the journey to reduce fatigue
- If you will need to hire a vehicle, contact the hire company to discuss them removing potential triggers from the vehicle prior to collecting it.

LOCAL CONDITIONS AND AMENITIES

- Locate nearby amenities, including the nearest medical facility or hospital; find out their procedures for anaphylaxis, asthma attacks and MCAS flare ups
- Identify nearby restaurant options that cater to your dietary requirements and consider room service availability for flare-ups. For self-catering apartments check distance of supermarkets and if they stock foods you tolerate

ITINERARY

- Plan rest days according to the schedule - remembering to add extra days for contingency and finding out cancellation policy for activities

ACCOMMODATION SCREENING PROCESS

Ask the questions which are relevant to you of the potential accommodations and create a table with a shortlist. Use each question as a column header and the accommodations that tick all boxes can be considered and compared for pricing and activity suitability

THE BUILDING AS A WHOLE

- Are pets allowed or is it a pet free resort (for allergies) - ask about strays
- Do you spray fragrance in communal areas of the accommodation?
- Is the pool chlorine or salt water?
- Does the on-site medical centre have equipment for anaphylaxis and asthma attacks, and where is the nearest hospital?

THE ROOM OR INDIVIDUAL SPACE

- Are rooms carpeted?
- Can the room be cleaned with a scent free cleaning product we provide?
- Can the sheets and towels be laundered with a scent free detergent we bring?
- Can the soft furnishings (e.g. rugs, throw cushions etc) be removed from the room and larger armchairs/sofas be covered with a sheet to limit dust?
- Is there a fridge for medication storage?
- Can dietary requirements be catered to by the chefs?
- Do you offer room service (for flare up days) and can options be customised to dietary restrictions?

ORGANISING TRAVEL INSURANCE

- Obtain travel insurance quotes **BEFORE** booking flights and accommodation
- You will need to ensure the travel insurance companies cover all pre-existing conditions including MCAS.
- Use comparison sites and specify 'pre-existing conditions' (e.g., Money Supermarket, Go Compare) and also specific insurers (e.g., Insure and Go, Avanti) to find suitable policies. It's often better to jump on a call rather than fill the online form so they can better tailor it to you
- Maintain an up to date list of all health conditions in an easily accessible format to disclose when purchasing insurance
- Give yourself ample time to carefully read through policy wording; check for COVID-19 coverage and ensure you understand excess requirements
- Ensure you are familiar with the next steps in case you need to claim whilst travelling. Print out all policy documents and keep them in your hand luggage throughout travel.
- Annual travel insurance can often be better value, so explore options.
- If you do not have an MCAS diagnosis, speak to your insurance provider about how to best share the symptoms you have.

“A recent learning curve has been that not only do you need to have all pre-existing conditions noted, if you have had ANY doctor appointments in the past 2 years that were not directly related to the pre-existing conditions, this will VOID your insurance if not declared !!!!”



VACCINATIONS

- Ideally you would have an appointment to discuss your requirements with a travel nurse 12 weeks (or more) before travelling to discuss which vaccinations are needed for your planned holiday

For long-haul destinations, a course of certain vaccinations is spread over a number of weeks. Clinics will often give 2 or more different vaccines at the same time,.

Speaking to your travel nurse prior to receiving vaccinations and making a plan to minimise the risks could help to keep you safe.

Adjustments that might help include:

- Having vaccines one at a time, rather than multiple on the same occasion.
- Liaising with your MCAS doctors to create a plan to minimise the risks.
- Pre-medicating where appropriate.





MOBILITY ASSISTANCE

- Review transfer options between the airport (or mode of transport) and accommodation, ensuring they offer assistance services
- Investigate whether the airport offers assistance services for mobility support (if required) and caters to dietary requirements
- Confirm the accommodation is step-free and fully accessible, with disabled access rooms available.
- For unpredictable and variable mobility, check if there is a buggy service or wheelchair hire at the hotel/resort.
- Confirm the availability of a beach/water wheelchair if visiting a beach destination. For activities (theme parks, shopping centres, zoos etc) enquire about mobility assistance services
- Wearing the Hidden Disabilities Sunflower discreetly indicates to people around you including staff, colleagues and health professionals that you have a hidden disability and you may need additional support, help or more time. Sunflower Lanyards are available free of charge to customers from businesses and organisations who are members of Hidden Disabilities Sunflower.

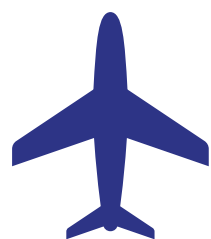
MEDICAL PAPERWORK

- Vaccinations may be required for some destinations so ensure you've booked this in 6-8+ weeks before travel. You may want to leave additional contingency to recover from any flare ups triggered by required vaccinations
- Give yourself ample time to order repeat prescriptions from your GP - if travel is longer than the allotted prescriptions typically last, tell them about travel and they should be able to dispense extras to account for the travel. You may ask them to dispense additional medications in case of emergencies where you are in the travel destination longer than expected.
- When you receive your prescriptions, keep the most recent prescription script next to the medications as important paperwork for when you travel.
- Always keep medications, supplements and any other essential strategies with you in your hand luggage (never in checked in hold baggage)
- Ask your doctor for a signed letter listing your medical conditions, or a print-out of all of your health conditions and prescribed medications on the NHS system, in case you're asked to present documentation during travel or in any medical circumstances
- Compile a list of emergency contacts, including healthcare providers and local emergency numbers at your destination. Include your GP & Consultant contact numbers in case of complications.
- Check with airlines their criteria for having a 'fit to fly' letter signed before you travel, and ask your GP to fill in the form well in advance of travel if you fit the criteria. If you don't require this you may still like to ask your GP to kindly write a line on the print out of your health conditions that you're 'fit to fly' in case airport security or the airline still demands some medical proof that you're okay to fly.



DIETARY NEEDS

- For each stage of the journey consider whether an alternative meal can be pre-ordered, or whether you'll need to bring your own food from home.



Bringing food in a clear bag so it can easily be seen by airline staff and security can help to avoid justifying it as an extra bag. Ice boxes are typically allowed through airport security if declared for medical needs. Speak to the airline ahead to confirm beforehand.



If a foot passenger on a UK Ferry, you may be able to arrange clearance with them to carry a cool box as hand luggage with essential perishable foods necessary for the journey. Speak to them prior to travel to ensure you have access to safe foods.

- Create allergy cards with foods that you can eat cards, print and laminate several copies to give to waiters or chefs throughout the trip
- Check that the accommodation restaurants (if included in your package) can cater for your dietary restrictions
- Research other restaurants in the vicinity of your accommodation, or nearby the itinerary for activity days out and look up their menus online (if possible) - email or call in advance if you can
- For impromptu restaurant visits check before you sit down whether they're happy to cater to your allergies. If in doubt or they don't seem to take the restrictions seriously, don't hesitate to leave and find somewhere else that feels safer. Always carry snacks with you in case mealtimes are delayed.
- For self-catering accommodation where you'll be cooking for yourself, research the nearest grocery stores before you leave. If they don't have many items you can tolerate, consider bringing non-perishable foods in your luggage with you.

PLANNING AHEAD: TRANSPORT

Being prepared with transportation is crucial when travelling with MCAS, as it allows you to maintain control over your environment and minimise exposure to potential triggers. Different modes of transportation come with varying levels of comfort and risk, so careful planning can help you choose the best option for your needs. Check out the top tips below while you plan.

- Choose the Mode of Transport that Best Fits Your Needs: Consider all available options—car, train, bus, ferry, or plane—and select the one that offers the most comfort, control, and flexibility for your MCAS needs.
- Before booking, research the specific transport providers. Check for any MCAS-friendly policies, such as availability of hypoallergenic seating, flexibility with bringing your own food, or accommodations for medical needs.
- Reach out to airlines, train companies, or bus services ahead of time to discuss your specific requirements. Inform them about your triggers, ask about meal accommodations, and inquire about procedures for managing exposure to potential triggers like pets, perfumes, or food allergens.
- Always have a flare-up kit or rescue bag with essential medications, safe snacks, water, and comfort items such as a personal air purifier or mask. Keep this kit easily accessible during your journey to manage symptoms quickly and effectively.
- For train, bus, or ferry travel, check accessibility features like elevators, ramps, and nearby seating options. This can help you avoid unnecessary exertion or stress, which can exacerbate symptoms.
- Travel during times of the day when your energy levels are higher or when public transport is less crowded. This can help you avoid peak times when allergens or triggers like food and perfume are more prevalent.
- Anticipate possible delays and prepare by packing extra snacks, medications, and comfort items. Having a buffer of supplies can keep you safe if travel times are extended unexpectedly.
- Be prepared for changes or cancellations. Knowing alternative routes, transport options, or nearby hotels can provide peace of mind and flexibility if your original plan needs to change.

PLANNING AHEAD: TRANSPORT - FLYING

Flying can present unique challenges for those with MCAS, from navigating crowded airports to managing the controlled environment of an aeroplane. However, with careful preparation and thoughtful planning, you can significantly reduce the risks and make your flight as comfortable as possible.

- When booking your flight, select seats that best suit your needs, such as aisle seats for easy access to the restroom or seats near the front of the plane where air circulation is typically better. Consider upgrading to seats with extra legroom or even first class if it provides a quieter and more controlled environment.
- Request pre-boarding to allow extra time to settle in, wipe down surfaces, and ensure your seating area is as trigger-free as possible. This can help you avoid the rush of boarding and reduce exposure to crowds.
- Since airline food may contain common allergens or unknown ingredients, bring your own safe meals and snacks. Ensure your food complies with airline security regulations by packing items in clear containers and carrying a doctor's note if needed.
- Wearing a mask can help filter airborne allergens and irritants. Consider a high-quality mask like an N95 or similar. Personal air purifiers can also help improve the air quality around your seat.
- Request to avoid duty-free areas or perfumed zones at the airport, as these can be high in triggers. If avoidance isn't possible, move through these areas quickly while wearing a mask.
- Cabin air can be dry and exacerbate symptoms. Drink plenty of water before and during the flight to stay hydrated. Bring your own water bottle and fill it after passing through security.
- Aeroplanes can be cold or warm, and sudden temperature changes can trigger symptoms. Dress in layers so you can easily adjust your clothing to stay comfortable.
- Inform the flight crew about your MCAS and any specific needs you may have. They can assist in managing your environment, such as turning off scented products or helping you move seats if needed.
- Security checks can be stressful, especially with medical equipment and medications. Keep all medical items, including your flare-up kit, in a clear, easy-to-access bag, and have documentation ready, like a doctor's note, to explain your needs.

PLANNING AHEAD: ACCOMODATION

Selecting the right accommodation is a critical part of planning your trip with MCAS, as where you stay can greatly affect your comfort and ability to manage symptoms. Consider the following tips for planning ahead when thinking about your accomodation.

- Contact accommodations directly to inquire about their ability to meet your requirements, such as fragrance-free environments, pet policies, and accessibility features.
- Consider the benefits of self-catering options, which offer greater control over your food and environment, versus hotels that can provide convenience and support with dietary needs if communicated clearly in advance
- Reading reviews from other travellers with similar health concerns can also provide valuable insights
- Request a room with hard flooring if possible or opt for accommodation options with no carpets if feasible
- Opt for fragrance-free environments or consider wearing a mask in communal spaces.
- Arrange to bring your own sheets and towels, or even a sleeping bag to avoid potential triggers in washing detergents.
- If dust is an issue., ask the hotel to remove soft furnishings like rugs and throw cushions and cover sofas and armchairs to minimise dust exposure.
- Consider the noise levels of the accommodation and its surroundings, as high noise can contribute to stress and discomfort.
- Know where the nearest medical facilities are located and have contact information for local healthcare providers in case of an emergency.



PLANNING AHEAD: DINING

Whether you're eating out at restaurants or preparing your own meals, careful planning can help you avoid potential triggers and maintain control over your diet. Use the top tips below to think ahead and plan the safest dining options for you.

- Prepare allergy cards to inform restaurants about food allergies, if you are travelling abroad, it may be useful to add pictures of foods to your cards to avoid any issues with translation.
- Research and contact restaurants in advance to confirm they can cater to your dietary needs.
- For self-catering apartments, research nearby supermarkets to ensure they stock foods you can tolerate. Bring non-perishable foods from home if necessary.
- Pack a supply of safe snacks and meals to ensure you always have options that meet your dietary requirements, especially for times when suitable food options are unavailable.
- Share your dietary needs and food preferences with travel companions so they can support you in finding suitable dining options and help manage your food-related needs.
- Be prepared to adapt your dining plans if necessary. Having backup options and being willing to make adjustments can help you manage any unexpected situations.
- If you find a good restaurant, consider going back. You could even have the same meal again (although, of course, make sure to carefully communicate your needs every time).



PLANNING AHEAD: STRESS MANAGEMENT

Traveling with MCAS can sometimes be a source of stress, from managing symptoms in unfamiliar environments to dealing with unexpected changes. Effective stress management is key to ensuring a positive travel experience and maintaining your well-being. This section focuses on strategies to help you reduce stress and stay calm during your trip.

- Save guided meditations on your phone to manage stress during potential flare-ups. These can be a quick and effective way to regain composure. Free apps such as Insight Timer might also help.
- Download calming music, binaural beats, or YouTube visualisation videos. These tools can help you relax and focus on something other than the stressor.
- Incorporate stress-relief practices such as deep breathing exercises, mindfulness, or meditation into your daily routine. These techniques can help calm your mind and manage anxiety during travel.
- Have backup plans in place for potential issues, such as alternative accommodations, transportation options, or dining choices. Knowing you have solutions ready can alleviate stress if things don't go as planned.



PACKING TIPS

SLOW AND STEADY

- Pack incrementally over several weeks or even months to manage energy levels and avoid last-minute stress.

COMFORT IS KEY

- Use packing cubes to organise your items and ensure easy access.
 - Pop these in the wash before you use them so they don't smell 'new'
- Use as many surfaces as you can that avoid you bending down.
 - E.g. put the suitcase on a bed sofa or table, so that it's not on the floor and avoids exerting extra energy
- Make it fun - perhaps play music or podcasts whilst you pack and change it from a boring stressful task to a fun one that gets you excited for the trip



PACKING LISTS

MEDICATIONS AND MEDICAL SUPPLIES

- Prescription medications
- Over-the-counter medications as needed/tolerated:
 - Pain relievers (e.g., paracetamol, ibuprofen)
 - Anti-diarrheal medications
 - Antacids or acid reducers
 - Anti-nausea medications
 - Digestive enzymes
 - Electrolyte tablets, sachets or concentrate
 - Binders
- Medical documentation:
 - Recent prescription script (within 3 months)
 - Doctor's letter explaining your condition(s) and necessary treatments
 - Fit-to-fly sign-off (if required)
 - Emergency contact information
 - Travel insurance policy printout with how to claim info
 - Personal Emergency Plan
 - Allergy cards and foods that you can eat cards
 - Medical alert ID (on your phone and/or a bracelet or lanyard)

"I always pack extra medication just in case I lose some or some get damaged. I'd rather be safe than sorry."



PACKING LISTS

HYGIENE AND PERSONAL CARE:

- Hygiene Products:
 - Fragrance-free hand soap, shower gel, shampoo, conditioner
 - Safe cleanser, toner, moisturiser and lip balm
 - Unscented deodorant
 - Toothpaste, toothbrush, mouthwash, floss and hairbrush
 - Fragrance-free cleaning product
 - Fragrance-free laundry detergent
 - Your own sheets and towels, or a sleeping bag
- Sanitation Supplies:
 - Hand sanitisers if tolerated (unscented)
 - Disinfecting wipes if tolerated (unscented)
 - Travel-sized tissue packs
 - Toilet seat covers
 - Female sanitary products
 - Razor, tweezers, nail clippers, mini scissors
- Other Items:
 - Masks with adequate filters
 - Portable air purifier (mini)
 - Travel air purifier (in hand luggage)
 - Scent-free sunscreen and after sun
 - Scent-free mosquito repellent
 - Travel first aid kit; plasters/bandages, bite or sting cream, antiseptic
 - Make up

SYMPTOM SPECIFIC MANAGEMENT

- Hot water bottle and ice packs
- Migraine relief over-the-counter medications and devices
- Light sensitivity glasses &/ sunglasses
- Supplements
- Rash management e.g. specific moisturiser, hydrocortisone etc

PACKING LISTS

DIETARY NEEDS

- Food and Snacks:
 - Non-perishable snacks that meet your dietary needs
 - Meal replacement shakes or bars
 - Powdered or concentrated milk alternatives
- Meal Preparation:
 - Portable cutlery set
 - Collapsible bowls and cups
 - Safe cooking utensils (e.g., mini frying pan)
 - Small cutting board
 - Portable water filter

COMFORT AND CONVENIENCE

- Comfort Items:
 - Neck pillow, other blow up pillows or beanie pillows
 - Eye mask
 - Earplugs or noise-canceling headphones
 - Lightweight blanket
 - Portable electric fan
- Clothing:
 - Layers for varying temperatures
 - Comfortable shoes
 - Socks and undergarments
 - Sun hat or cap
 - Scarf or shawl for additional warmth
- Travel Accessories:
 - Packing cubes
 - Luggage tags
 - Ziplock bags for organisation
 - Reusable shopping bags (always pack more than you think)
 - Post-it notes (to advocate to housekeeping about cleaning procedure)

PACKING LISTS

TECHNOLOGY AND ENTERTAINMENT

- Devices:
 - Mobile phone and charger
 - Tablet or e-reader
 - Laptop and charger
 - Portable charger or power bank
 - Noise-canceling headphones
 - Camera and charging equipment
 - Adapters suitable to the destination plus extension cable
- Entertainment:
 - Books or e-books
 - Downloaded movies or TV shows
 - Music playlists
 - Podcasts or audiobooks
 - Downloaded meditations
 - Games (travel console, cards etc)

MISCELLANEOUS

- Important Documents:
 - Passport
 - Visa (if needed)
 - Proof of vaccinations (if applicable)
 - Travel insurance details
 - Hotel and flight confirmations
 - Printed itinerary
 - Travel locks for luggage
- Advocacy
 - Medical information card
 - MCAS advocacy info card
 - Help request card (customise a card to your needs to ask nonverbally)
 - Sunflower Lanyard Scheme
 - Access Scheme card (for staycations)

TRAVELLING



POSITIVE MANTRAS

Travelling with MCAS can bring uncertainties and challenges, but maintaining a positive mindset can make a significant difference in your experience. Positive affirmations and mantras are powerful tools that can help you stay calm, focused, and resilient as you navigate your journey.

By repeating these affirmations, you can reinforce your inner strength, remind yourself of your preparedness, and stay connected to the joy and purpose of your travels. Use these mantras whenever you need a boost of confidence or a moment of peace, helping you to manage stress and embrace your adventure with optimism and grace.

"I am prepared and capable of managing whatever comes my way."

"I choose to focus on the joy of new experiences."

"I deserve to enjoy this journey, one moment at a time."

"I breathe deeply, stay calm, and remain present."

"I am not alone; I have the tools and support I need."



STRESS MANAGEMENT

Once your holiday begins, maintaining a sense of calm and managing stress becomes essential to fully enjoy your time away. Travelling with MCAS presents its own set of challenges, but by focusing on strategies to manage stress in the moment, you can enhance your experience and ensure a more enjoyable trip. This section provides practical tips to help you stay relaxed and adaptable during your holiday.

- Implement mindfulness techniques that you're used to confidently using at home before you travel
 - This could be focusing on the 5 senses to divert your attention from the flare up happening in your body, to what's in your environment
 - Imagining roots extending from your feet down deep into the earth
 - Breathing techniques such as diaphragmatic breathing or box breathing
 - Lightweight devices such as Sensate or other nervous system regulation devices to support the transition out of a fight or flight response
- You may use EFT tapping to rapidly calm your nervous system in a short 15 minute session, apps such as The Tapping Solution might be helpful.
- Schedule rest days between activities to recuperate and avoid overexertion during your trip.
- Consider the histamine bucket theory; and plan rest and isolation days after after travel days or activity days to reduce histamine load.
- Be prepared for changes and adapt your plans as needed. Flexibility can help you stay calm and focused, allowing you to handle unexpected situations with greater ease.



MANAGING FATIGUE

Many people with MCAS experience fatigue as a symptom, which could potentially be a barrier to travelling. Planning ahead can help to reduce the impact that fatigue could have on your travels. Remember to listen to your body, and incorporate self-care strategies that work for you. Planning your itinerary wisely can help you to be able to enjoy more of your time away whilst managing fatigue.

- **Pace yourself:** Schedule your activities with ample rest breaks in between. Avoid overloading your days to prevent exhaustion.
- **Choose rest-friendly accommodations:** Opt for a comfortable place to stay with amenities that support quality rest, such as quiet rooms, blackout curtains, and air conditioning. Consider locations with easy access to rest spots like parks.
- **Stay close to essentials:** Whether it's restaurants with safer options or a nearby pharmacy, being close to what you need can reduce stress and save energy.
- **Rest when needed:** Listen to your body, it's okay to skip an activity or take extra rest if you're feeling drained. Your health comes first.
- **Travel comfortably:** Whether it's a long flight or a car ride, pack items that help you rest comfortably, such as travel pillows, blankets, or an eye mask..
- **Inform your travel companions:** Let those you're travelling with know about your condition and your need for rest breaks or special accommodations.
- **Rest before you leave and when you get home:** Being well rested before your holiday and making sure you have a quiet day or two planned for your return can make a significant difference in managing fatigue. Allowing yourself time to recover and adjust before and after your trip can help you feel more refreshed, reduce the likelihood of a flare-up, and make the overall travel experience more enjoyable.

"Travelling with MCAS is all about balancing the excitement of new experiences with the need for careful planning and self-care. It's not always easy, but by listening to my body, planning ahead, and staying flexible, I've found ways to enjoy my adventures while keeping my health in check."



MANAGING EMERGENCIES



EMERGENCY PROTOCOLS

STEP-BY-STEP PLAN FOR DEALING WITH REACTIONS

Recognise Symptoms Early:

Be aware of the signs and symptoms of an allergic reaction or MCAS flare-up.

- Skin: Hives, swelling, rashes, flushing, itching.
- Muscles and Bones: Muscle pain, muscle fatigue, joint pain, brittle bones, numbness, tingling.
- Urinary and Genital Systems: Pain when urinating, bladder urgency, loss of bladder control, genital pain and swelling, discharge, itching.
- Neurological Symptoms: Headaches, brain fog, anxiety, anger, behavioral issues, numbness and tingling, acute back pain, seizures.
- Cardiovascular System: Chest pain, lightheadedness, low blood pressure, tachycardia.
- Respiratory System: Congestion, itchy and watery eyes, increased mucus production, coughing, airway constriction, increased susceptibility to infections, asthma-like symptoms, anaphylaxis.
- Gastrointestinal System: Diarrhoea, constipation, abdominal cramping, reflux, dumping syndrome, nausea, vomiting, persistent gastrointestinal pain.
- General Symptoms: Fatigue, feeling unwell, redness of the skin, swelling of the face.

IMMEDIATE ACTIONS

Administer emergency medications in line with your medical rescue plan.

Medication	Dosage	When to Use
Epinephrine		
H1 Antihistamines		
H2 Antihistamines		
Inhalers		
Other Medications		

EMERGENCY PROTOCOLS

CONTACT EMERGENCY SERVICES

Call emergency services immediately if symptoms worsen or do not improve after using rescue medications where symptoms are urgent.

Emergency Contact	Phone Number	Notes
Local Emergency		
Personal Doctor		
Hospital Name		

INFORM OTHERS

Notify those around you about your condition and let them know how they can assist.

Contact	Phone Number	Notes
Family Member		
Travel Companion		
Hotel Reception		

FOLLOW UP CARE

- Ensure you receive follow-up medical care after an emergency.
- Keep a detailed record of the incident for future reference.

PERSONAL EMERGENCY PLAN

NAME

DATE OF BIRTH

Emergency Contacts	Relationship	Phone Number	Notes

EXISTING MEDICAL CONDITIONS

KNOWN ALLERGIES AND TRIGGERS

Medication	Dosage	Frequency

STEPS FOR MANAGING REACTIONS

Medical Facility Name	Address	Phone Number

HOMETIME!!!



BACK TO DAILY LIFE

Returning to your daily routine after travelling can be both a relief and a challenge. It's important to transition back to your regular life in a way that prioritises your health and well-being.

Before you go on holiday, the following preparations might help when you return:

- Prepare and freeze some meals, so that you can have safe food easily when you get back
- If you will be coming back from a hot climate, put a jacket or blanket in your car boot for when you arrive to help you acclimatise to the colder weather
- Clean and prepare your house for your return, so that you can get straight into comfy clothes/bed (perhaps lay out your 'flare kit' just in case)
- Book extra time off work for recovery, so that you don't have to rush back to work or responsibilities and have time to recover and unpack etc

Once you're back home, it might be helpful to:

- Be gentle with yourself and be proud of what you achieved!
- Consider taking time to reflect on your trip if it takes time for you to recover, look at photos to remind yourself of the good times that you had and the experience
- Review and update your packing lists to see if you forgot anything this trip, or would amend anything for future trips
- Take the time to positively review any good providers, praise great customer service you had etc - this helps other people in the future as well as the providers to recognise they are making a difference.
- If you are able, do also recommend your trip on the MCAS Facebook group to inspire other people
- Consider booking your next trip!

INFORMATION TO SHARE WITH OTHERS



TOP TIPS FROM OUR COMMUNITY

Lots of members of our community reviewed this resource before we shared it with you. They shared some great tips which we want to pass along!

“

I always travel with my own sheets in my carry-on luggage along with towels and all products required for washing and being able to sleep in a hotel. In the event of a plane cancellation, I have needed to sleep in a hotel room whilst travelling.

“

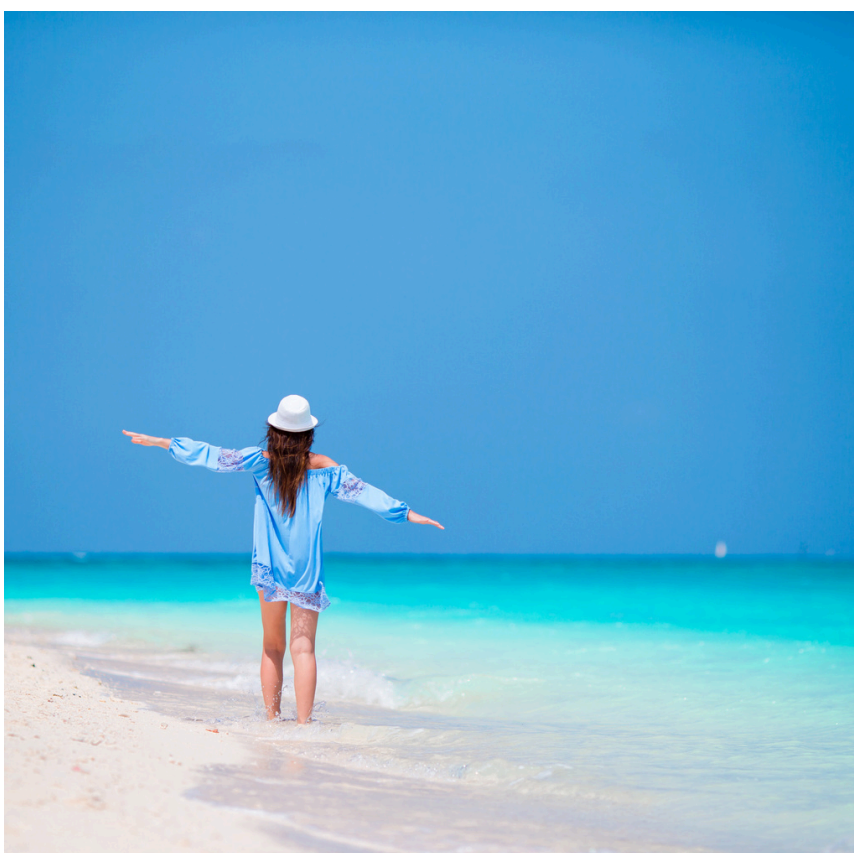
I always put a copy of my medication prescriptions in the same bag as the medication and carry a separate copy. This way you can inform security staff it is there and not be stopped. I have Xolair and this can only be out of the fridge for 4 hours maximum.

”

“

On route, I always book a lounge with a shower so that I can shower on route and minimise my fragrance load. I always wear long-sleeved trousers and tops to avoid needing to touch anything. I pre-board and wipe down my seat and those closest to me. Staff will assist with putting your bag in the overhead locker to ensure you maximise your energy.

”



“

Airline staff will provide ice but not let you put medication in their fridges. Take a waterproof bag with you, which will not leak and can be topped up with ice as required. I have a medical-grade ice bag for my medication.

”

TOP TIPS FROM OUR COMMUNITY

Lots of members of our community reviewed this resource before we shared it with you. They shared some great tips which we want to pass along!

“

Mobility assistance: Due to variable mobility and the significant difference in the plane's distance from the main check-in, I will always book wheelchair assistance. It is much easier to say on the day that you are happy to walk, if not too far, than not to book it. I will also book mobility assistance for my husband/companion, as if they do not have space on the assistance buggy; you will be parted. (We were advised of this recently by the mobility assistance team.) You can also notify the mobility team that you cannot go through duty-free areas (there is 98% always an alternative except for very small airports.

”

“

I was recently stuck in Australia for an emergency and needed to access health care. Ensuring that I had a copy of all my consultant letters was vital in being able to access my extensive medication. Also, knowing what medications you can buy in the country you are visiting and what you cannot will be helpful. Some medicines are unavailable in certain countries, so researching this before going to the country is important. I have been caught out a couple of times. For example, steroid cream is not available over the counter in Malta. Loratadine is not available in Australia, etc.

”



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

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