



## Questions to ask your doctor

If your General Practitioner suspects that your symptoms may be caused by a mast cell disease, they should refer you to the appropriate specialist for further investigation.

Generally, any **Immunologist** or **Haematologist** can help diagnose a mast cell disease, such as Mastocytosis and mast cell activation syndrome (MCAS). If you have skin-based symptoms you may also be referred to a **Dermatologist**.

MCAS diagnosis can be challenging in that it does not yet have a clearly defined diagnostic metric, and is often associated with other underlying conditions, this means it can take more time to diagnose and find an appropriate treatment plan.

If you do not achieve an immediate diagnosis this does not mean your symptoms are not legitimate. If you need support finding a specialist in your area, please reach out to us at [info@mastocytosis.org.au](mailto:info@mastocytosis.org.au).

## I have an appointment, now what?

In the lead up to your appointment, please make some brief notes for your specialist on:

- your symptoms
- rating of symptom variations, for example, how bad they can be when you experience a flare/or experience symptoms (-/10)
- your knowledge/thoughts on possible triggers
- any strategies you have implemented for managing/ treating symptoms and how effective they are (-/10)

Keep this info brief and in bullet point form.

## Questions to ask your specialist

Your new specialist will work through a range of questions with you in your first appointment. Having a conversation with any doctor is easier when you are prepared. To help you with this we have created a list of questions that can help start a conversation with your new doctor about investigation, pre-diagnosis, mast cell disease diagnosis treatment and ongoing support.

To help ensure you do not forget any questions you can [download and print this list](#). Please note, not all questions will apply to you.

We recommend you take two copies of your history and symptoms, and your questions list to the appointment so you can go through the information with the specialist in real time and leave a copy with them for your file.

## Pre-diagnosis

- These are my current symptoms. What do you think could be causing these symptoms?
- What is the process for reaching a diagnosis?
- Do you require any additional information from me and my other doctor/s to help with diagnosis?
- What tests might I require?
- Can you please explain what you are testing me for and why?
- How frequently should I see you to reach a diagnosis and develop a treatment plan?
- Can we trial treatments before a diagnosis is reached? OR if you are already on medications that are helping some but not all symptoms: I am taking X, Y and Z which are helping minimise my symptoms. Is there anything else I can take to address X, Y, Z symptoms?
- Are you able to update my GP and [insert names of other relevant specialists] of our progress?

**Note:** TAMS supports self-advocacy and recognises independent research can strengthen your ability to advocate for yourself and ask informed questions. We encourage you to ask your specialist questions, however, we **do not** support self-diagnosis.

If your GP/other specialist have suggested you could have a mast cell disease, or you have concerns about having a mast cell disease please ask the specialist:

- Do you think a mast cell disease could be causing my symptoms, X, Y, X?
- Why/why not?

## When testing for a mast cell disease

- Can you tell me more about mast cell diseases?
- What leads you to believe mast cell disease is my primary diagnosis?
- Which specific mast cell disease do I have?
- Can you explain how the pathology results I have point to a mast cell disease?
- Are there any additional tests I should have to confirm the diagnosis?
- If the specialist is leaning towards a diagnosis of mastocytosis: Should I be tested for the c-KIT D816V mutation? (To rule in/out systemic mastocytosis)
- What symptoms (if any) cannot be explained by this diagnosis? And can you help me manage these also, or refer me to a specialist who can?

## Post diagnosis

- What type of mast cell disease do I have? And how was this confirmed?
- Will I always have my mast cell disease diagnosis?
- Can we discuss ways to manage each of my symptoms?
- Can we discuss ways to help me set reasonable expectations of the level of improvement for each of my symptoms?
- Will I need tests before treatments can be decided on?
- What are my treatment options and what treatment plan do you recommend? Why?
- What are the possible short- and long-term side effects of the treatments you are recommending?
- Do any of the treatments recommended have a risk of negative interactions/additional side effects?
- What is the goal of this treatment plan?
- What type of follow-up will I need after I start treatment? (Review dates)
- Are these treatments permanent, or is it possible I will have to change treatments in the future? If so, what would necessitate this?
- Are there any clinical trials open to me?
- Do you have any educational materials about my mast cell disease you can provide me?

## Ongoing support and disease management

- How will my diagnosis and treatment impact my daily life? Will I be able to continue to work and support my family financially? If not, is financial support available to me, and how do I apply for this?
- If my daily life (work/study) is likely to be impacted/continue to be impacted, can you write a letter to my workplace/place of study to help them understand my condition and note possible adjustments they could make to lessen risks of external aggressors to condition? (e.g., no spraying perfume in the office, moving workstation away from the kitchen/break room)
- Is my ongoing treatment expensive? Who can help me manage concerns about affording medical care and treatment?
- Are there any other lifestyle changes I should make?
- Is there a health care team involved in my case? If yes, what does each member do?
- Which members of my team should I contact first if I have questions or issues (GP, Dietician, Specialist's office, etc)?
- Who will mainly be coordinating my ongoing treatment and follow-up care?
- If I do not have a team, will you write to my other physicians (Obstetrician, Gynaecologist, Urologist, Cardiologist, Physiotherapist, Physiologist, etc), so they understand my diagnosis and treatment plan under your care and any implications my diagnosis or treatment will have on my broader health issues?
- What other support services are available to me and to my family?