

Stronger Together: Shared Decision-Making in Systemic Mastocytosis

Living with systemic mastocytosis can bring many questions.¹

Shared decision-making is about having open, respectful conversations with your healthcare team – so your voice and values are part of the plan.²



Before the doctor’s appointment

You are not alone:

Your care is a team effort. With a rare and complex condition like systemic mastocytosis (SM), your experiences and preferences are just as important as medical facts.¹⁻⁴

Prepare for your visit:

Write down your questions, goals, and concerns, especially about symptom triggers, treatment effects, or recent flare-ups. Every detail helps your care team tailor their care approach to your specific needs.¹⁻³

It is YOUR story:

Because SM presents differently for each person, your symptom patterns and daily challenges provide vital information that medical tests alone cannot show. Your lived experience fills important gaps.¹⁻⁵

Bring support:

Having a friend or family member with you can help if you feel anxious or forgetful. Your story and your voice help guide care decisions that fit your life with SM.^{4,6}



During the doctor’s appointment

Share openly and specifically:

Be open and specific about your symptoms. Describe even small or unusual experiences, flushing, fatigue, pain or allergic-type reactions. People living with SM often adapt to their symptoms, so every detail matters.^{1,5,7}

Ask about all your care options:

Treatments can differ depending on the form of SM you have. It is okay to ask, ‘What are my options?’ or ‘Can you explain this another way?’^{1,2,6,7}

Include what matters to YOU:

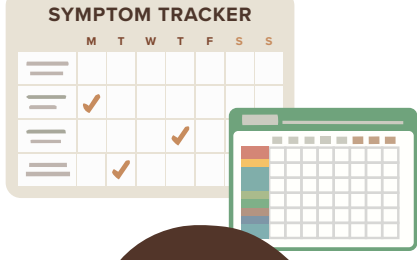
Talk about how SM affects your daily life: your work, sleep, emotional well-being or energy levels, not just your test results.^{1,2,5-7}

Take your time to understand:

SM care often involves several specialists. Ask for clear, simple explanations about medications, triggers or procedures, and do not hesitate to ask for things to be repeated. Ask for written or visual materials to help you remember and understand the information.¹⁻⁷



After the doctor’s appointment



Write things down:

Summarise the main points, such as changes in medication, next tests, or instructions about managing allergic or emergency reactions related to SM.⁷

Stay connected with your care team:

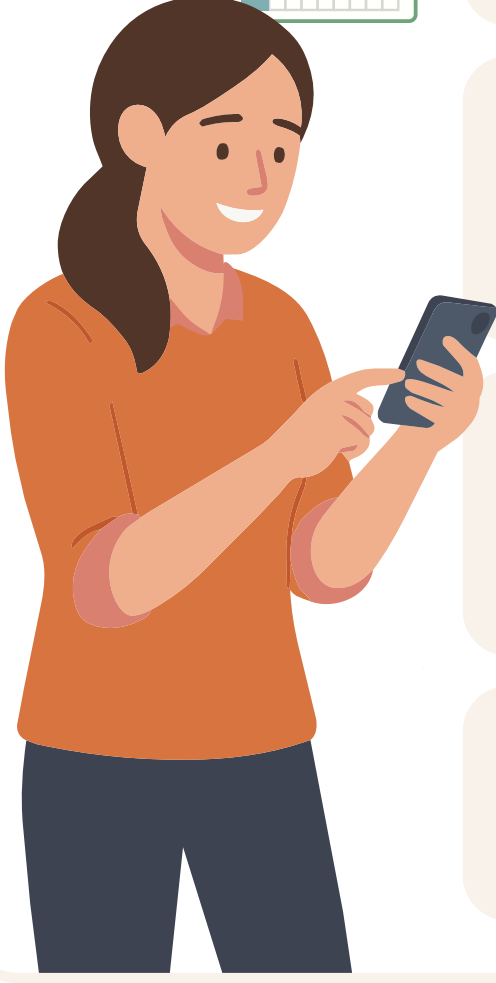
Follow up if new symptoms appear or if you think of more questions later. Specialist nurses or advanced practitioners can help explain medications, side effects and emergency plans.^{7,8}

Track your symptoms and emotional well-being:

Use a diary or app to record triggers, flare-ups, fatigue, and other symptoms. These patterns can guide better treatment and more effective shared decision-making at your next visit.¹⁻¹⁰

Update your plan as your condition changes:

Revisiting decisions helps ensure your care continues to match your current health and life goals.^{1,2,5,7-9}



You are the expert in your life. Asking questions, sharing your experiences and feeling heard are all part of good care. **Your voice matters!**

To gain a better understanding of SM, visit: www.navigatingSM.com

References:

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