

For the Community, By the Community: Tips for Meaningful Conversations about Mast Cell Diseases

Because their impact can be invisible, mast cell diseases (MCD) like systemic mastocytosis (SM) can be hard to fully explain and challenging for others to comprehend. This can lead to feeling misunderstood—and sometimes even dismissed.

To help you feel empowered to share your story and build a support network, people living with MCD shared practical tips.

Starting Small

“You don’t have to share everything all at once. As you build confidence, you will feel more comfortable sharing more. The first time is the hardest, but the more you do it, the easier it becomes.”

Rachell
living with SM

“One of the most important things I’ve learned is not everyone needs to hear your whole story. I start with small, digestible aspects of my disease and then gauge someone’s reaction to decide if I feel comfortable being vulnerable and explaining more.”

Dani
living with mast cell
activation syndrome (MCAS)

“If you’re not sure how to speak with your loved ones about your MCD, try inviting them to your doctor’s appointments as a first step. This gives them the opportunity to hear what you’re going through firsthand and ask the doctor any questions directly.”

Kelly
living with SM

Choosing the Right Words for You

“I try to find a ‘common language’—whether it’s with friends, family, people online or my doctor. For instance, instead of sharing the most precise medical description of what I’m going through, I’ll try to find more relatable words for someone.”

Jenna
living with MCAS

“In conversations with my family, I speak openly and honestly, whether it’s something good or bad. I do this through phone calls, group texts, or even during casual dinner table chats. For my healthcare team, I come with clear, organized notes on what has changed since my last appointment.”

Kelly
living with SM

“When it comes to conversations with loved ones, you know these people well, so lean into that. If they’re someone who is more in touch with their feelings, focus more on the emotional impact. If it’s someone who is more logical, focus more on the facts of your experience with MCD.”

Joanna
living with MCAS

Building Your Support Network



"If you find a social media post resonates with you, do not hesitate to reach out privately via direct message. Consider a simple note, like 'I saw your post about [topic] and I am working through something similar. Would you be open to talking more?' This can open the door to a meaningful connection."

Rachell
living with SM

"Find an online space where you can meet friends with a similar mast cell disease or another chronic illness. Having people to talk to who 'get it' can be incredibly helpful and validating."

Jenna
living with MCAS

"I've met some of my favorite people by connecting with them online and I consider them part of my support network. I can go to them and discuss any of my symptoms, knowing that they'll understand because they've had similar experiences, which I find very valuable."

Joanna
living with MCAS



Speaking with Your Healthcare Team



"When going to appointments, I always bring notes to share with my healthcare team so I can let them know as accurately as possible how I've been feeling since my last appointment."

Kelly
living with SM

"My best tip for connecting with healthcare professionals is to focus on one to three goals per appointment so you can stay focused and on track."

Joanna
living with MCAS

"When approaching conversations with your doctors about MCD, I always recommend people speak calmly, openly and honestly. Your medical team cannot support you if you are not transparent with them."

Rachell
living with SM



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