

PATIENT RIGHTS & SELF-ADVOCACY GUIDE

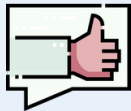
This guide provides a practical overview of how individuals living with MPS can understand and assert their rights within the healthcare system. It also offers tools to help you communicate clearly, make informed decisions, and navigate challenges such as denied care or coverage.



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Understanding Your Rights

Small, consistent adjustments can make a meaningful difference in managing pain and fatigue. The strategies below are simple, low-risk tools that can be incorporated into your daily routine. Try one or two at a time, notice how your body responds, and adjust as needed.



Informed Consent

You have the right to understand and agree to treatments before they happen.



Refusal of Treatment

You have the right to decline or stop treatment at any time.



Clear Communication

You have the right to receive information in a way you understand.



Access to Records

You can request and review your medical records.



Second Opinions

You may seek another medical opinion.



Privacy

Your personal health information must be protected.

Interacting with Insurers & Authorities

You may need to communicate with insurance providers or healthcare systems to access care. This can include submitting documentation, responding to requests, or appealing denied services.

Self-Advocacy: Communicating Your Needs

Self-advocacy means expressing your needs clearly, asking questions, and taking an active role in your care decisions.

Quick Tips



Be clear about your symptoms and concerns



Ask questions if something is unclear



Take notes or request written instructions



Bring someone you trust if needed

Helpful Phrases

"Could you explain that in simpler terms?"

"What are my options?"

"Can I have that in writing?"

Self-Advocacy Checklist: How to Speak Up for Yourself

Before Your Appointment

- ☐ Prepare written questions
- ☐ Review your recent symptoms
- ☐ Bring relevant documents
- ☐ Decide your main goals for the visit

During the Appointment

- ☐ Take notes
- ☐ Ask for clarification if something is unclear
- ☐ Request a second opinion if needed
- ☐ Bring a support person (optional)

After the Appointment

- ☐ Review your notes
- ☐ Follow up on referrals or tests
- ☐ Confirm next steps in writing if necessary