



A guide to:

More effective conversations with your care team

**"It's a joint effort. My physicians listen to what I say,
and we come up with a plan that works for me."**

Barbara, living with polymyositis



Make the most of conversations with your care team

Whether you're newly diagnosed or have been living with a subtype of myositis for a while, this guide can help you prepare for conversations with your doctor and feel more supported during them.

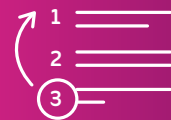
What will this guide teach me?



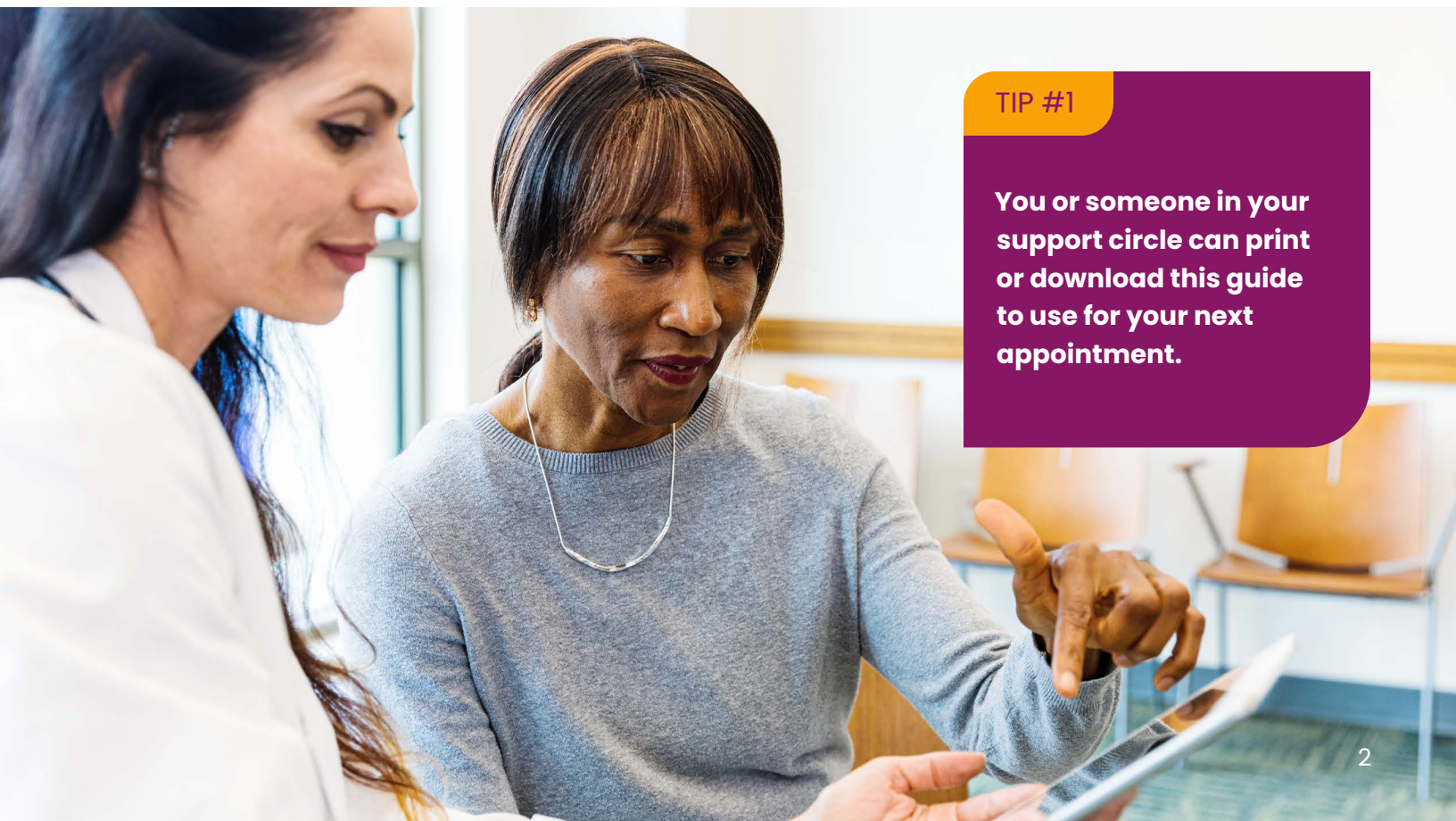
The key words and phrases your care team uses and what they mean



How to name and describe your symptoms



How to identify your priorities and talk to your care team about them



TIP #1

You or someone in your support circle can print or download this guide to use for your next appointment.

Think about your upcoming appointment(s)



What are the most important things you want to communicate to your doctor?

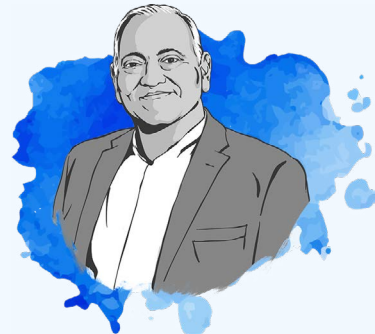


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“You know your body and can advocate for yourself to your doctors. It’s important the medical community has this information from all of us.”

Larisa

Living with immune-mediated necrotizing myopathy (IMNM)



“

“Keep fighting to find the care team you need and deserve.”

Sanjay

Living with antisynthetase syndrome (ASyS)

Common terms to describe myositis

Here you'll find explanations of several important terms related to myositis. Knowing them may help you feel more confident in conversations about your health.

Myositis

A medical term for muscle inflammation, myositis refers to **a group of several rare, progressive, autoimmune diseases that can affect the muscles, skin, and vital organs in the body**, causing muscle weakness, pain, and fatigue

Autoimmune disease

Relating to diseases like myositis where the body's **immune system**, which helps your body resist infection, mistakenly attacks its own healthy cells and tissues

Autoantibodies

Proteins produced by the immune system that can mistakenly attack the body's own healthy cells and tissues. They can lead to many autoimmune diseases, including myositis. Your doctor might also refer to these as **myositis-specific autoantibodies**



Subtypes of myositis

Although there are some common symptoms across different subtypes of myositis, each subtype is associated with unique autoantibodies and symptoms.

ASys

Antisynthetase syndrome

AN-tee-sin-THEH-tays SIN-droh-m

Can affect muscles, lungs, and other parts of the body, sometimes leading to conditions like interstitial lung disease (ILD) or Raynaud's phenomenon

DM

Dermatomyositis

DUR-ma-toh-my-uh-SY-tis or
DUR-muh-toh-my-uh-SY-tis

The most common subtype of myositis that can affect both the muscles and the skin

IBM

Inclusion body myositis

in-KLOO-zhun BAH-dee my-uh-SY-tis

Can involve muscle weakness that progresses slowly and difficulty swallowing

IMNM

Immune-mediated necrotizing myopathy

ih-MYOON mee-DEE-ay-tid NEK-ruh-tye-zing my-AH-puh-thee

Also called necrotizing autoimmune myositis (NAM), this subtype primarily affects the muscles and can cause upper arm and leg weakness

PM

Polymyositis

PAH-lee-my-uh-SY-tis

Can affect muscles, causing upper arm and leg weakness. With recent scientific advancements, diagnosis of polymyositis has evolved, and most patients are now being classified as having DM, IBM, IMNM, or ASys

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Here's an example of how you might talk to your doctor about your subtype:

“I'd like to talk to you about how my dermatomyositis symptoms are impacting me at work.”

Symptoms, conditions, and tests

Myositis symptoms

Your doctor may also use or listen for key terms to better understand your symptoms and how they're affecting your daily life. This information can help them support you with symptom management.

Muscle weakness: The result of **muscle atrophy, degradation, and/or necrosis**, muscle weakness is a reduction in physical strength of one or more muscles that can cause an inability to perform daily tasks like lifting or walking

Fatigue: A lack of energy or feeling of tiredness

Pain: A common and persistent symptom that may be present with the symptoms listed below

Functional limitations: Difficulty getting up from a seated position, lifting, and walking. Your doctor may use this information to understand the severity of your condition

Joint involvement: Painful, bothersome, and/or swollen joints

Dysphagia: Difficulty swallowing

Shortness of breath: Doctors often look for this in people with antisynthetase syndrome (ASyS) and may refer you to another specialist to help you with more targeted symptom management

Skin rash: Any area of irritated, inflamed, or swollen skin. It could appear red, bumpy, itchy, or as a scaly patch

Conditions that can accompany myositis

Certain subtypes of myositis may overlap with other associated conditions. Here are a few of those conditions.

ILD: Interstitial lung disease (ILD) refers to chronic lung conditions that cause inflammation and scarring of the lung tissue, making it difficult to breathe

Malignancy: A cancerous growth or tumor that has the potential to spread to other parts of the body

Arthritis: Inflammation of the joints that can cause pain, stiffness, and swelling

Myocarditis: Inflammation of the heart muscle that can lead to chest pain, fatigue, shortness of breath, and a rapid or abnormal heart rhythm

Raynaud's phenomenon: A condition in which the toes and fingers don't get enough blood flow. They may turn white or blue and feel cold or numb

Myositis-related blood tests: aldolase, CK, and ESR

Commonly used to help your care team get a clearer picture about how myositis is impacting your body. Your care team might run tests, such as **creatinine kinase (CK) and aldolase levels**, to monitor damage to muscles. **Testing sedimentation rate** (also called erythrocyte sedimentation rate [ESR] or sed rate) is used to gauge levels of inflammation in the body.

Your care team

There are a few types of doctors who specialize in treating myositis. You might have one or all of them as a part of your care team.

Rheumatologist

A doctor who specializes in diagnosing and treating autoimmune and musculoskeletal diseases that affect the joints, muscles, and bones

Contact info:



Neurologist

A doctor who specializes in diagnosing and treating disorders that affect the brain, spinal cord, and nerves

Contact info:



Dermatologist

A doctor who specializes in diagnosing and treating diseases that affect the skin, hair, and nails

Contact info:



Additional contact info

Examples: primary care physician, therapist, psychiatrist, general pharmacy information, or emergency contact

Contact info:



Effectively communicating symptoms and goals to your care team

Use the areas below to express what you **can't do**, **can do**, and what you **want to do** using the key terms and phrases on the previous pages. Talking to your doctors this way may help them understand all the ways myositis affects your life and what your goals are.

I CAN'T



Example: "I can't eat some of my favorite foods without having trouble swallowing."

I CAN



Example: "I can stand in the shower on my own."

I WANT



Example: "I want to be able to drive my daughter to dance class."

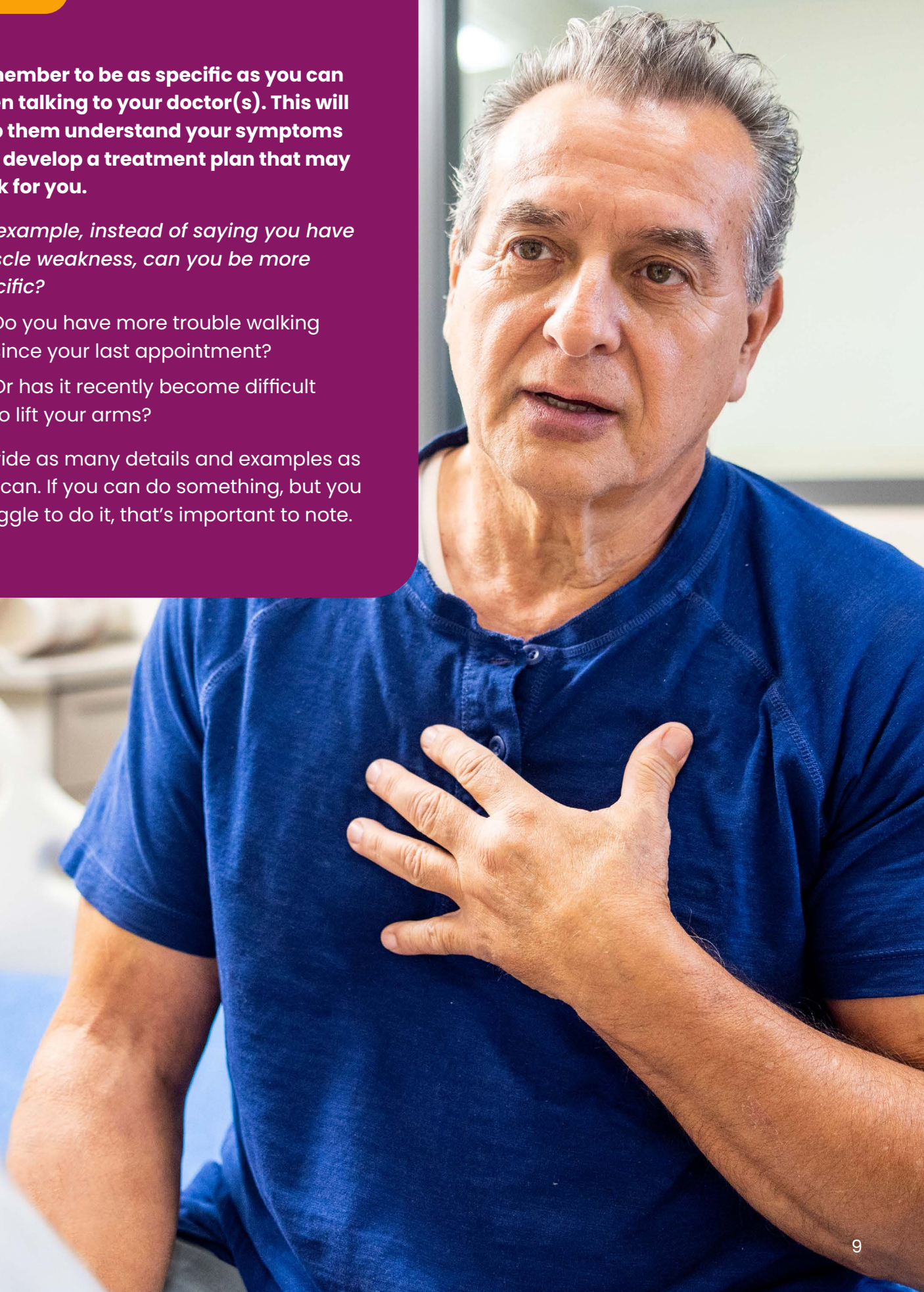
TIP #2

Remember to be as specific as you can when talking to your doctor(s). This will help them understand your symptoms and develop a treatment plan that may work for you.

For example, instead of saying you have muscle weakness, can you be more specific?

- Do you have more trouble walking since your last appointment?
- Or has it recently become difficult to lift your arms?

Provide as many details and examples as you can. If you can do something, but you struggle to do it, that's important to note.



Doctor's appointment priority list

Doctors' appointments go quickly, and you don't want to leave with unanswered questions. This worksheet can help you plan and organize everything you want to discuss with your care team. Use it to reflect on your symptoms and goals using the key terms and phrases on the previous pages.

What are your main symptoms?



Example: "Muscle weakness, skin rash, and chest pain."

How severe or concerning are your symptoms?



Example: "Can't sit up without help; have to use medical aids to shower."

How often are your symptoms happening?



Example: "I've had this skin rash for 2 months."

How are your symptoms affecting your life?



Example: "My partner has to help me go to the bathroom every day."

What do you wish you could do?



Example: "I wish I could cook on my own."

TIP #3

It may help to rate your symptom **severity** and **impact** from 1 to 10, or your symptom **frequency** as daily, weekly, or monthly.

It may also help to rate your **goals** in order of importance, from somewhat important to extremely important.



More from The Myositis Collab

Individual voices. Collective wisdom.



We believe no one living with myositis should have to navigate it alone. That's why we created a place where voices from across the myositis community can come together to find and share practical tips, honest stories, encouragement, and hope. Because we are stronger together.

Visit MyositisCollab.com to read, watch, and learn more.



All myositis community members featured in this guide are paid contributors to The Myositis Collab.

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