



MOGAD Doctor Discussion Guide

Questions to Ask Your Doctor About MOGAD

Living with Myelin Oligodendrocyte Glycoprotein Antibody Disease (MOGAD) can involve many medical decisions. Bringing questions to your appointments can help you better understand your condition, discuss treatment options, and participate actively in your care.

Use this guide to help structure conversations with your doctor and record notes during your visit. We recommend reviewing this guide before your appointment and highlighting or selecting the questions most relevant to you. Your provider may have limited time for your visit, so we recommend that you start with your most important questions first.

Understanding My Diagnosis

- What is MOGAD, explained in simple terms?
- What symptoms or clinical presentations are common in MOGAD?
- How is MOGAD different from other conditions such as MS or NMOSD?

Notes:

My Doctor's Experience and Care Team

- Do you frequently treat MOGAD patients?
- What hospital are you affiliated with for inpatient care or emergencies?
 - If you are not affiliated with a hospital, how would my care be coordinated during a hospitalization?
- Are you involved in MOGAD research or clinical trials that I can learn about?
 - Does your clinic participate in MOGAD clinical trials?
- Who should be part of my care team?

Possible specialists may include:

- Neurologist or neuroimmunologist
- Neuro-ophthalmologist
- Pharmacist (for medication management and drug interactions)
- Urologist
- Neuropsychologist
- Physical therapist
- Occupational therapist
- Low-vision specialist
- Mental health professional

If my doctor is not a MOGAD specialist:

- Can you refer me to a MOGAD specialist?
- Are you open to consulting with a MOGAD specialist?

Notes:

Treatment Options

- Can you outline the protocol for both acute treatments and long-term treatments (including order, timing, and method of delivery)?
- What medications may help prevent future attacks?
- What are the benefits and risks of these medications?
- How effective are these treatments for people with MOGAD?
- Are there any clinical trials that may be appropriate for me?
- Can I speak with a pharmacist about medication management or side effects?

Medication delivery options may include:

- Infusions at home
- Infusions in a hospital or clinic
- Self-injected medications

Notes:

Determining Whether to Start Treatment

- Do you recommend starting preventative treatment now?
- What factors would change the treatment plan?
- If I delay treatment, can I start later?
- Are there risks to waiting?
- What tests are required to monitor treatment safely?

Examples may include:

- Blood tests
- MRI scans
- Other safety monitoring

Notes:

Monitoring My Disease

- How will my disease be monitored?
- How often should I have follow-up appointments?
- What tests will I need regularly?

Monitoring tools may include:

- MRI scans
 - Blood monitoring
 - Optical Coherence Tomography (OCT)
 - Visual Field Testing (VFT)
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- I am claustrophobic — what options are available for MRI scans?
 - I am allergic to contrast dye — what alternatives exist?

Notes:

Relapse and Disease Management

- Based on my medical history, what are the chances I will experience another attack?
- What symptoms may indicate a relapse?
- How can I distinguish a relapse from a pseudo-relapse?
- What triggers might cause a pseudo-relapse?
- Who should I contact if symptoms occur?
- What should I do if symptoms occur on weekends, holidays, or after hours?

Notes:

Emergency Planning

- What symptoms require immediate emergency care?
- Where should I go in an emergency (nearest appropriate hospital)?
- Is there anything I should communicate to emergency providers about MOGAD treatment?
- Can we create a written relapse or emergency action plan?

Notes:

Lifestyle and Complementary Approaches

- Are there supplements that may help with symptoms or medication side effects?

Examples patients sometimes ask about:

- Vitamin B12
- Vitamin D3
- Alpha-lipoic acid

- Are there supplements I should avoid?
- Are there complementary or holistic approaches that may help?
- Do you recommend a specific diet?

Examples include:

- Anti-inflammatory diet
- Mediterranean diet

- Are there foods I should avoid?

Notes:

Long-Term Outlook

- What is the long-term prognosis for someone with MOGAD?
- With disability being a possibility, do you have any tips for preventing or delaying this?
- Are patient assistance programs available?

Notes:

Insurance and Treatment Access

- What is the insurance approval process for treatment?
- What happens if insurance denies coverage?
- Are any assistance programs available?

Notes:

Pediatric Questions (For Parents and Caregivers)

- How will my child's treatment change as they grow?
- Will their treatment plan change when transitioning to adult care?
- How can we manage frequent needle sticks?
- Does my child need a port for infusions?
- What side effects should we expect from treatment?

School Considerations:

- Should my child have an IEP or 504 plan?
- Can my child participate in sports or physical education?
- What should teachers or the nurse watch for?

Emergency Planning:

- What symptoms require a visit to the emergency department?
- Is it safe to travel?

Notes:

My Questions

Write down additional questions you would like to ask your doctor.

A Note on Your Care

MOGAD treatment approaches can vary. If you feel unsure about your diagnosis or treatment plan, seeking a second opinion from a MOGAD specialist is reasonable and common.

You are an important part of your care team, and asking questions is an important step in advocating for your health.