Please refer to the final page of this material for adverse event reporting.

PATIENT



Preparing for your myasthenia gravis (MG) appointment

Questions to ask yourself

If you have myasthenia gravis, or "MG", you are likely to have regular appointments with your doctor or nurse.

These visits are where you make decisions about your care and treatment together. This guide is to help you prepare for these appointments, so that you will be able to:

- Explain how MG is affecting your daily life
- Share what matters most to you about your treatment
- Work as a partner with your healthcare team to make joint decisions

Research shows that when patients and doctors make decisions together, patients get better care and have better health outcomes.

Take some time to think through these questions. You can work through Part 1 at any time, even if it is weeks or months until your visit. Then look at Part 2 closer to your visit (a few days or even the evening before).

Part 1: To complete at any time

Your MG symptoms

Space for your notes:

What symptoms of your MG bother you most?

These might be the symptoms that most impact your daily life.

Have you noticed anything (any triggers) that makes your MG symptoms worse?

Your goals

Space for your notes:

What do you most want from your treatment for MG?

It might help to think about the aspects of your life that are most affected by your MG symptoms or current treatment.

What does an acceptable quality of life look like to you?

This might include being able to do certain activities that are important to you.

Your treatment

Space for your notes:

Are you aware of the different options for managing MG and their pros and cons?

Treatment can include different types of medication as well as surgery and physiotherapy. Ask your doctor or nurse about these during your visit.

What aspects of treatment are most important to you?

For example, your thoughts and preferences around:

- How you take (or receive) a medication – e.g. by mouth, an infusion in hospital or an injection at home
- How often you take (or receive) the treatment
- How well it works
- How well you tolerate it
- Whether a treatment might affect your appearance or weight
- How much it costs (if you pay for or towards your treatment)

Space for your notes:

Do you know if your vaccinations (immunisations) are up to date?

You can ask about this during your visit. Some treatments need you to have additional vaccinations or antibiotics. You might also need **blood tests** to check for infections.

Do you have any questions for your doctor on lifestyle changes that might help your MG?

For example, questions on diet or what level of exercise is "safe"?

Pregnancy and family planning
(if you are a woman of childbearing age)

Space for your notes:

If you are planning a family or could become pregnant, it is important to know how MG (and certain treatments) can affect pregnancy and how pregnancy can affect MG symptoms.

Ask your doctor or nurse to explain.

Other points

Space for your notes:

Do you know when and how to seek urgent help if your MG symptoms get worse?

Ask your doctor or nurse to explain. Worsening symptoms can put you at risk of a medical emergency called myasthenic crisis.

Do you have any other questions or concerns about your MG or treatment?

Make a note to ask these during your visit.

Do you have any other health issues or conditions?

Your doctor or nurse will ask you about this. If you take any prescription or over-the-counter medications or dietary supplements (e.g. vitamins or herbal products), it may be helpful to bring an up-to-date list of these to your next visit.

Part 2: To complete shortly before your visit

How your MG is affecting your life

Space for your notes:

Have your MG symptoms got any better or worse in recent weeks?

It can be helpful to complete a symptom diary in the month before your visit, especially if it is several months or more since your previous visit.

Are your symptoms, and how severe they are, changing day to day and during the day?

How?

Again a symptom diary is helpful to track any peaks and dips.

Do you feel generally tired and fatigued (beyond any symptoms of muscle weakness)?

Does anything make this fatigue better or worse?

Have you been sleeping well over the past few weeks?

Do you think you have been getting enough sleep?

Is your MG affecting your quality of life?

How?

Think about whether you can do the things you want to.

Is your MG affecting your mental well-being?

How?

If your doctor or nurse has asked you to fill out a questionnaire about your symptoms and disease burden, did the questions cover everything that's bothering you?

Or is the disease affecting you in other ways that you would like to tell your doctor about?

Your current treatment

Space for your notes:

If you are already on treatment for your MG, is it working well enough for you?

Why or why not?

Have you noticed any side effects from your current treatment?

If you are already on treatment for your MG, are you hoping to change treatment?

Pregnancy
(if you are a woman of childbearing age)

Space for your notes:

Are you or could you be pregnant now?

If so, be sure to mention this during your MG appointment.

You will also need to discuss your MG with the doctors or nurses who are managing your pregnancy. You may need specialist pregnancy care.





Adverse event reporting

Please report suspected side effects. If you have an adverse event to report for a UCB product, please follow the current regulatory procedure in your country or visit https://www.ucb.com/contact to access the contact page of the UCB corporate website where you can report adverse events to UCB local affiliate contacts or UCBCares®.

UK patients: Please report suspected side effects to the MHRA through the Yellow Card scheme, via the Yellow Card website www.mhra.gov.uk/yellowcard, the free Yellow Card app available in Apple App Store or Google Play Store. Alternatively, you can call 0800 731 6789 for free, Monday to Friday between 9 am and 5 pm.

By reporting side effects, you can help provide more information on the safety of the medicine.

Adverse events should also be reported to UCB Pharma Ltd via UCBCares® on 0800 279 3177 (freephone) or by email UCBCares.UK@ucb.com.

MG, myasthenia gravis.

This resource was developed by UCB Biopharma SRL in collaboration with neurologist and comprehensive care goals consensus author, Dr Carolina Barnett-Tapia, University of Toronto, and patient organisation representatives, Charlotte Carpenter of myaware, Allison Foss of the Myasthenia Gravis Association, Sylwia Łukomska of Stowarzyszenie Miastenia Gravis – Face to Face, and Maya Uccheddu of the Italian Myasthenia Gravis Association and the European Myasthenia Gravis Association, who all received financial remuneration. Development of the clinical activation toolkit was funded by UCB Biopharma SRL. Terms and conditions apply.

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