

The impact of **remaining** and **fluctuating** gMG symptoms

Following established Delphi panel methodology, this survey has been designed to elicit consensus regarding how remaining symptoms and changes in the intensity and unpredictability of symptoms, despite treatment, may affect a person's day to-day activities while living with generalised myasthenia gravis (gMG).

You may leave the survey and resume where you left off at any point, but you must use the same device to resume.

This survey is the first part of a two-phase study including two survey rounds (both are designed to take no more than 40 minutes to complete), which all participants will complete.

Please ensure you answer each question presented in this survey to the best of your ability.

Please contact the fieldwork agency SHG: gintare.civelyte@surveyhealthcareglobal.com if you would like to review or amend your consent that you have previously provided for this study.

- * 1. You were previously provided with a unique ID number via email from the third-party recruitment agency. Please enter the unique ID number you have been assigned for this survey below:

The impact of remaining and fluctuating gMG symptoms

This survey is designed to take no more than 40 minutes to complete. When prompted to enter a free-text response, please feel free to provide key words, where applicable, if this simplifies the task.

The free-text responses captured in this survey (the first round) will be consolidated within the second-round survey. The second-round survey will use more multiple choice and rating questions with the aim of seeing where certain statements or key points can reach a consensus amongst the group.

For further information, please refer to the study brief that has been shared with you by the fieldwork agency.

The impact of remaining and fluctuating gMG symptoms

While the burden of living with myasthenia gravis (MG) is relatively well-characterized, very little is known from the scientific literature on the specific burden of remaining symptoms and changes in the intensity and unpredictability of symptoms on the day-to-day lives of those living with generalised myasthenia gravis (gMG).

Therefore, the aim of this project is:

- To describe, from a qualitative perspective, how remaining symptoms and changes in the intensity and unpredictability of symptoms, despite treatment, may affect a person's day-to-day activities while living with gMG.

For the purpose of this survey, we have defined "remaining symptoms" as "Symptoms that occur despite treatment for gMG". You will be able to refer back to this definition throughout the survey by clicking on the (?) symbol in relevant questions.

Please note that questions regarding "remaining" symptoms of gMG have been colour coded in blue and questions regarding the "intensity/unpredictability" of symptoms of gMG have been colour coded in purple for clarity.

The impact of remaining and fluctuating gMG symptoms

Generalised myasthenia gravis (gMG) is commonly associated with remaining symptoms and changes in the intensity and unpredictability of symptoms that may affect a patient's ability to carry out their daily activities, their social life, mental wellbeing, work and education, and plans for the future.

This introduction section is designed to gain a broad insight into the most burdensome remaining symptoms of gMG and to understand how the intensity and unpredictability of these symptoms may impact areas of patients' lives.

- * 2. 1. Limb muscle weakness, diplopia (double vision), difficulties in chewing/swallowing, breathing difficulties and drooping eyelids have been described to be among the most burdensome remaining symptoms of gMG.
Please rank the following remaining symptoms from most burdensome to least burdensome (with 1 being least burdensome and 5 being most burdensome). [Please rank all option(s).]
Tip: Remaining symptoms refers to symptoms that occur despite treatment for gMG.

Limb muscle weakness (e.g., arms or legs)	:	_____
Diplopia (double vision)	:	_____
Difficulties in chewing/swallowing	:	_____
Breathing difficulties	:	_____
Drooping eyelid(s)	:	_____

Our initial research highlighted that **remaining** symptoms and changes in the **intensity and unpredictability** of symptoms of gMG have a substantial impact on patients' ability to carry out daily activities including housework, self-care and participating in hobbies. Patients frequently report requiring help from support networks (including family, friends and partners) to carry out these daily activities.

In this section, we would like to explore the impact that remaining symptoms and changes in the intensity and unpredictability of symptoms of gMG have on your ability to carry out daily activities.

- Tip: Remaining symptoms refers to symptoms that occur despite treatment for gMG.

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- Please rank on a scale of 1–9 (with 1 being completely disagree and 9 being complete agreement). (Select one option)

* 9. 3. d) Please provide rationale for your answer to the above question.

[illegible]

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* 10. 4. a) Please rank on a scale of 1-9 (with 1 being no impact and 9 being maximal impact) the impact that remaining symptoms of gMG have on your ability to cook. (Select one option)

Tip: Remaining symptoms refers to symptoms that occur despite treatment for gMG.

1	2	3	4	5	6	7	8	9
☐	☐	☐	☐	☐	☐	☐	☐	☐
No impact								Maximal impact

* 11. 4. b) How much do you agree with the following statement: There are days I am unable to cook due to unexpected changes in the intensity of my symptoms of gMG, therefore I need to order food or find other alternatives.

Please rank on a scale of 1-9 (with 1 being completely disagree and 9 being completely agree). (Select one option)

1	2	3	4	5	6	7	8	9
☐	☐	☐	☐	☐	☐	☐	☐	☐
Completely disagree								Completely agree

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In this section, we would like to explore the impact that remaining symptoms and changes in the intensity and unpredictability of symptoms of gMG have on your ability to carry out daily activities.

Tip: Remaining symptoms refers to symptoms that occur despite treatment for gMG.

[illegible]

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[illegible]

- * 16. 5. e) Based on your previous answers in this section, what strategies do you use to mitigate your remaining symptoms of gMG with regards to eating habits?

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18. 6. b) Please rank on a scale of 1-9 (with 1 being no impact and 9 being maximal impact) the impact that the changes in the **intensity and unpredictability** of your symptoms have on your ability to participate in hobbies that involve physical activities.

* 19. 6. c) Please provide your rationale for the rating you provided for the impact of **intensity** of your symptoms.

* 20. 6. d) Please provide your rationale for the rating you provided for the impact of **unpredictability** of your symptoms.

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- * 21. 6. e) Please describe any non-physical hobbies (e.g. playing video games, reading, painting) that may be impacted by your **remaining symptoms** and provide rationale.

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- * 22. 6. f) If you did not experience **remaining symptoms** of gMG, what hobbies would you consider taking up?

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In this section, we would like to explore the impact that remaining symptoms and changes in the intensity and unpredictability of symptoms of gMG have on your ability to carry out daily activities.

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In this section, we would like to explore the impact that remaining symptoms and changes in the intensity and unpredictability of symptoms of gMG have on your ability to carry out daily activities.

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Our initial research has identified that many patients find themselves unable to commit to social plans due to remaining symptoms and changes in the intensity and unpredictability of symptoms of gMG, and consequently, their social circles have been impacted.

In this section, we would like to explore the impact that **remaining** symptoms and changes in the **intensity and unpredictability** of symptoms of gMG have on your social life.

- Tip: Remaining symptoms refers to symptoms that occur despite treatment for gMG.

Please rank on a scale of 1–9 (with 1 being completely disagree and 9 being completely agree). (Select one option)

* 28. 9. c) Please provide your rationale for your above ranking.

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In this section, we would like to explore the impact that remaining symptoms and changes in the intensity and unpredictability of symptoms of gMG have on your social life.

Tip: Remaining symptoms refers to symptoms that occur despite treatment for gMG.

	No impact -	1	2	3	4	5	6	7	8	Maximal impact -	9
* (a) Intensity		○		○	○	○	○	○	○		○
* (b) Unpredictability		○		○	○	○	○	○	○		○

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[illegible]

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In this section, we would like to explore the impact that remaining symptoms and changes in the intensity and unpredictability of symptoms of gMG have on your social life.

1 2 3 4 5 6 7 8 9

○ ○ ○ ○ ○ ○ ○ ○ ○

No impact Maximal impact

[illegible]

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In this section, we would like to explore the impact that remaining symptoms and changes in the intensity and unpredictability of symptoms of gMG have on your social life.

* 37.12. Based on your previous answers in this section, what strategies do you use to mitigate your **remaining symptoms** of gMG with regards to fulfilling your social life and relationships?

[illegible]

Our initial research has identified that remaining symptoms and changes in the intensity and unpredictability of symptoms of gMG can lead to feelings of anxiety and frustration in patients as many perceive gMG to be limiting their independence. In addition, symptoms of gMG reportedly impacted the way patients perceive themselves.

In this section we would like to explore the impact that remaining symptoms and changes in the intensity and unpredictability of symptoms of gMG have on your mental wellbeing.

Tip: Remaining symptoms refers to symptoms that occur despite treatment for gMG.

No impact-1 2 3 4 5 6 7 8 Maximal impact - 9

* 40. 13. c) Please provide your rationale for the rating you provided for the impact of **intensity** of your symptoms.

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* 41. 13. d) Please provide your rationale for the rating you provided for the impact of **unpredictability** of your symptoms.

[illegible]

Our initial research has identified that remaining symptoms and changes in the intensity and unpredictability of symptoms of gMG can lead to feelings of anxiety and frustration in patients as many perceive gMG to be limiting their independence. In addition, symptoms of gMG reportedly impacted the way patients perceive themselves.

In this section we would like to explore the impact that remaining symptoms and changes in the intensity and unpredictability of symptoms of gMG have on your mental wellbeing.

- Tip: Remaining symptoms refers to symptoms that occur despite treatment for gMG.

[illegible]

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- [illegible]

Our initial research has identified that remaining symptoms and changes in the intensity and unpredictability of symptoms of gMG can lead to feelings of anxiety and frustration in patients as many perceive gMG to be limiting their independence. In addition, symptoms of gMG reportedly impacted the way patients perceive themselves.

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[illegible]

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[illegible]

Our initial research identified that remaining symptoms and changes in the intensity and unpredictability of symptoms of gMG can have a substantial impact on patients' ability to work and study. For example, learning new skills, studying and commuting to work or education institutions were often cited as being made more difficult for patients with gMG.

In this section we would like to explore the impact that remaining symptoms and changes in the intensity and unpredictability of symptoms of gMG have on your education, training and/or employment.

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Tip: Remaining symptoms refers to symptoms that occur despite treatment for gMG.

No impact-1 2 3 4 5 6 7 8 Maximal impact - 9

* 54. 18. c) Please provide your rationale for the rating you provided for the impact of **intensity** of your symptoms.

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In this section we would like to explore the impact that remaining symptoms and changes in the intensity and unpredictability of symptoms of gMG have on your education, training and/or employment.

- ☐ In education (Full-time)
- ☐ In training (Full-time)
- ☐ Employed (Full time)
- ☐ Employed (Part time)
- ☐ Retired
- ☐ Long-term sick-leave
- ☐ Unemployed (previously employed)
- ☐ Unemployed (no prior work history)
- ☐ Other (Please specify) _____

☐ Yes

☐ No

1 2 3 4 5 6 7 8 9

No impact Maximal impact

[illegible][illegible]

NOTE : Answer the below question only if answer to (Q#57 is Yes)

* 61. Please provide your rationale for the rating you provided for the impact of **unpredictability** of your symptoms.

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In this section we would like to explore the impact that remaining symptoms and changes in the intensity and unpredictability of symptoms of gMG have on your education, training and/or employment.

NOTE : Answer the below question only if answer to((Q#56 is In education (Full-time) OR In training (Full-time) OR Employed (Full time) OR Employed (Part time) OR Retired OR Long-term sick-leave OR Unemployed (previously employed)))

- * 62. 20. Please describe any impact that **remaining symptoms** of gMG have on your ability to apply for or accept a new job or promotion. Please also include the impact of **unpredictable** symptoms and any variations in their **intensity**.

Tip: Remaining symptoms refers to symptoms that occur despite treatment for gMG.

NOTE : Answer the below question only if answer to((Q#56 is In education (Full-time) OR In training (Full-time) OR Employed (Full time) OR Employed (Part time) OR Retired OR Long-term sick-leave OR Unemployed (previously employed)))

- * 63. 21. Please describe the impact that **remaining symptoms** of gMG have on your ability to complete your work-related training requirements. Please also include the impact of **unpredictable** symptoms and any variations in their **intensity**.

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In this section we would like to explore the impact that remaining symptoms and changes in the intensity and unpredictability of symptoms of gMG have on your education, training and/or employment.

Tip: Remaining symptoms refers to symptoms that occur despite treatment for gMG.

65. 22. b) Please rank on a scale of 1-9 (with 1 being no impact and 9 being maximal impact) the impact that changes in the **intensity and unpredictability** of your symptoms have on your ability to commute to work or education/training facility.

* 66. 22. c) Please provide your rationale for the rating you provided for the impact of **intensity** of your symptoms.

[illegible]

* 67. 22. d) Please provide your rationale for the rating you provided for the impact of **unpredictability** of your symptoms.

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- Tip: Remaining symptoms refers to symptoms that occur despite treatment for gMG.

[illegible]

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- [illegible]

[illegible]

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* 74. 26. a) Are you currently in receipt of financial support/benefits following your gMG diagnosis and due to still experiencing gMG symptoms despite therapy? (Select one option)

- ☐ Yes
- ☐ No

* 75. 26. b) Do changes in the intensity and unpredictability of your symptoms affect your eligibility for financial support/ benefits?

Our initial research identified that patients have difficulties in being able to plan for the future due to remaining symptoms and changes in the intensity and unpredictability of symptoms of gMG. In particular, planning to have children and furthering one's career were noted to be particularly difficult.

In this section we would like to explore the impact that remaining symptoms and changes in the intensity and unpredictability of symptoms of gMG have on your ability to plan for the future.

1 2 3 4 5 6 7 8 9

○ ○ ○ ○ ○ ○ ○ ○ ○

No impact Maximal impact

[illegible][illegible][illegible]

Our initial research identified that patients have difficulties in being able to plan for the future due to remaining symptoms and changes in the intensity and unpredictability of symptoms of gMG. In particular, planning to have children and furthering one's career were noted to be particularly difficult.

In this section we would like to explore the impact that remaining symptoms and changes in the intensity and unpredictability of symptoms of gMG have on your ability to plan for the future.

Tip: Remaining symptoms refers to symptoms that occur despite treatment for gMG.

No impact-1 2 3 4 5 6 7 8 Maximal impact - 9

* 82. 29. c) Please provide your rationale for the rating you provided for the impact of **intensity** of your symptoms.

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- This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

- [illegible]

Our initial research highlighted that certain factors, including weather, hot/cold temperatures, and personal stress can have an impact on symptom intensity and unpredictability. In this section we would like to explore the impact that certain factors have on the **intensity and unpredictability** of **remaining** symptoms of gMG.

[illegible]

* 87. Please provide rationale for your above ranking of how the time since treatment affects the intensity of your symptoms of gMG.

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* 88. Please provide rationale for your above ranking on how your time in menstrual cycle affects the intensity of your symptoms of gMG.

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NOTE : Answer the below question only if answer to (Q#86(c) is No impact- 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR Maximal impact-9)

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