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Day Month Year

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ULLEVÅL University Hospital

QUESTIONNAIRE FOR PATIENTS WITH MYASTHENIA GRAVIS

We want to learn more about the disease myasthenia gravis (myasthenia), and your answers to this questionnaire will give us a better understanding of the environmental and health factors that can influence the disease. Please answer the questions as well as you can, and take all the time you need. Your answers will be kept strictly confidential.

Thank you for your participation.

How to fill out the questionnaire:
Please tick in the middle of the boxes and write with capital letters as shown below.

Yes: X | O | S | L | O |

No: X | Ø | S | L | Ø |

If you do not wish to answer the questionnaire, tick the boxes below and return the questionnaire to us. By doing this you will avoid receiving a reminder.

☐ **Woman** ☐ **Man** **Age** **Years**

I do not wish to answer the questionnaire ☐

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BACKGROUND

1. Sex ☐ Woman ☐ Man

2. Age (years) ☐☐

3 a) Marital status *Tick only one box*

☐ Divorced/ separated ☐ Widow/ widower ☐ Married ☐ Boyfriend/ girlfriend ☐ Single

3 b) Do you live with: *Tick one or more boxes*

Spouse/ partner ☐ Parents ☐

Children/ stepchildren ☐ Live alone ☐

Sister/ brother ☐ Other relation ☐

4. Do you have children of your own? ☐ Yes ☐ No

If yes, number of children: ☐☐

5. Place of birth (country) ☐☐☐☐☐☐☐☐☐☐☐☐☐☐

6. Parents` and grandparents` places of birth (country):

Mother: ☐☐☐☐☐☐☐☐☐☐

Mother`s mother: ☐☐☐☐☐☐☐☐☐☐

Mother`s father: ☐☐☐☐☐☐☐☐☐☐

Father: ☐☐☐☐☐☐☐☐☐☐

Father`s mother: ☐☐☐☐☐☐☐☐☐☐

Father`s father ☐☐☐☐☐☐☐☐☐☐

BACKGROUND

7. What is the population of your municipality?

tick only one box

☐ 500 000 or more ☐ 100 000 - 500 000 ☐ 10 000 - 100 000 ☐ 1000 - 10 000 ☐ 1000 or less

8. Distance to the closest hospital you attend for follow-up for myasthenia

tick only one box

☐ 0 -10 km ☐ 10 - 50 km ☐ more than 50 km

FINANCIAL SITUATION

9 a) Are you receiving any of the following benefits? *Tick one or more boxes*

Sicknes/rehabilitation benefit/ Sick pay ☐

Benefit under vocational rehabilitation ☐

Disability pension ☐

Old age pension ☐

Welfare benefit ☐

Unemployment benefit ☐

Survivor`s benefit ☐

Other benefit ☐

I am not receiving any benefits ☐

9 b) During the past year, has the houshold had difficulty meeting running expenses for items like food, transport, housing?

Tick only one box

☐ Yes, often ☐ Yes, sometimes ☐ Yes, occationally ☐ No, never

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EDUCATION AND EMPLOYMENT

10. Indicate your level of education *Tick only one box*

- ☐ Primary school or lower (less than 7 years)
- ☐ Lower secondary school (7-10 years)
- ☐ Upper secondary school/vocational training (10-13 years)
- ☐ College/ university less than 4 years
- ☐ College/ university 4 or more years

11. What is your current work situation? *Tick only one box*

- ☐ Paid employment
- ☐ Self-employed
- ☐ Full-time work in the home
- ☐ Unemployed/laid off
- ☐ Receiving social security
- ☐ Pensioner
- ☐ Military service
- ☐ Education

If you currently are doing education, please go directly to question 17

12. What is your current or previous occupation?

Tick only one box

Answer even if you are receiving social security or pension

- ☐ Management, politics (manager, politician)
- ☐ Occupation requiring higher degree (engineer, doctor, lawyer, economist, secondary school teacher)
- ☐ Occupation requiring lower degree, technical qualification (nurse, police officer, school teacher)
- ☐ Office staff, customer service (secretary, working with accounts, receptionist)
- ☐ Sales, service occupation, care services (dealing with clients, care worker, hairdresser)
- ☐ Agriculture, forestry, fisheries
- ☐ Trade (mechanic, electrician, carpenter, housepainter, baker, butcher)
- ☐ Processing industry (machine operator, transport worker)
- ☐ Military occupation (recruit, non-commissioned officer, unspecified)
- ☐ Occupation not requiring qualifications (cleaner, messenger, refuse collector)

EDUCATION AND EMPLOYMENT

13 a) Has myasthenia influenced your choice of occupation?

☐ Yes ☐ No ☐ Not relevant ☐ Don`t know

13 b) Have you had to change your occupation because of myasthenia?

☐ Yes ☐ No ☐ Not relevant ☐ Don`t know

13 c) Have you had to stop working because of myasthenia?

☐ Yes ☐ No ☐ Not relevant ☐ Don`t know

14. Were you in paid employment before you developed myasthenia?

☐ Yes, full time ☐ Yes, part time ☐ No

15. Are you currently in paid employment?

☐ Yes, full time ☐ Yes, part time ☐ No ***If no, go to question 18***

16 a) During the last 12 months have you considered changing your occupation/job because of myasthenia?

☐ Yes ☐ No ☐ Don`t know

16 b) During the last 12 months have you had to take sick leave because of myasthenia?

☐ Yes ☐ No

If yes, for how long altoghether?

☐ 2 weeks or less

☐ 2 - 8 weeks

☐ More than 8 weeks

EDUCATION AND EMPLOYMENT

17. Questions regarding your education. Answer only if you are currently doing education

17 a) Has myasthenia influenced your choice of education?

☐ Yes ☐ No ☐ Not relevant ☐ Don`t know

17 b) Have you had to change your education because of myasthenia?

☐ Yes ☐ No ☐ Not relevant ☐ Don`t know

17 c) Have you had to quit your education because of myasthenia?

☐ Yes ☐ No ☐ Not relevant ☐ Don`t know

17 d) During the last 12 months have you considered changing type of education because of myasthenia?

☐ Yes ☐ No ☐ Don`t know

17 e) During the last 12 months did you have time off from school because of myasthenia?

☐ Yes ☐ No

If yes, for how long altoghether?

☐ 2 weeks or less

☐ 2 - 8 weeks

☐ More than 8 weeks

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MYASTHENIA

18 a) How old were you when you first noticed symptoms of myasthenia? ☐☐

18 b) When you first noticed myasthenia symptoms, were you: *Tick one box on each line*

Pregnant or had recently given birth?(women only)	☐ Yes	☐ No	☐ Don`t know
Undergoing medical treatment for another illness?	☐ Yes	☐ No	☐ Don`t know
Recently operated on?	☐ Yes	☐ No	☐ Don`t know
Recently diagnosed with another disease?	☐ Yes	☐ No	☐ Don`t know
Affected by some other event?	☐ Yes	☐ No	☐ Don`t know

If answer "other event", please add short explanation

19. How old were you when you were diagnosed with myasthenia by a doctor? ☐☐

20. What was the name of the hospital or neurologist where you were diagnosed?

Tick only one box

☐ Hospital/out-patient clinic

☐ Neurologist, private practice

Name, hospital

Name, city

21. Who follows up your myasthenia? *Tick only one box*

☐ Family doctor

☐ Neurologist

☐ Hospital doctor (not neurologist)

☐ Other doctor

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MYASTHENIA

22. How often have you had check-ups with a neurologist for myasthenia in the past 2 years?

Number of times ☐☐

23. How would you assess the follow-up by your doctor? *Tick only one box*

☐ Poor ☐ Medium ☐ Good

24 a) Which myasthenia symptoms did you have when the disease started?

Tick one box on every line.

Yes = I had the symptom
No = I did not have the symptom
Don't know = I don't know/can't remember whether I had the symptom

	Yes	No	Don`t know
Weak or droopy eyelids (eyelids hung down)	☐	☐	☐
Double vision (I saw double)	☐	☐	☐
Weak hand/arm muscles (difficulty carrying heavy objects)	☐	☐	☐
Weak legs (difficulty managing stairs and/or walking longer distances)	☐	☐	☐
Weak neck (difficulty holding your head up)	☐	☐	☐
Weakness in face, cheeks or lips (difficulty whistling or smiling)	☐	☐	☐
Speech difficulties (slurred, unclear speech)	☐	☐	☐
Chewing difficulties (difficulty chewing food)	☐	☐	☐
Difficulty swallowing (difficulty swallowing food and drink)	☐	☐	☐
Breathing difficulties (laboured breathing on slight effort)	☐	☐	☐

24 b) On a scale of 1 to 10, how serious did you feel your symptoms were when the disease started? *Tick only one box*

1 = very slight symptoms (did not affect daily life)
10= very serious symptoms (requiring hospitalisation)

1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Very slight symptoms — Very serious symptoms

MYASTHENIA

25 a) Which myasthenia symptoms have you had during the last 3 months?

Tick one box on every line.

Yes = I had the symptom
No = I did not have the symptom
Don't know = I don't know/can't remember whether I had the symptom

	Yes	No	Don`t know
Weak or droopy eyelids (eyelids hung down)	☐	☐	☐
Double vision (I saw double)	☐	☐	☐
Weak hand/arm muscles (difficulty carrying heavy objects)	☐	☐	☐
Weak legs (difficulty managing stairs and/or walking longer distances)	☐	☐	☐
Weak neck (difficulty holding your head up)	☐	☐	☐
Weakness in face, cheeks or lips (difficulty whistling or smiling)	☐	☐	☐
Speech difficulties (slurred, unclear speech)	☐	☐	☐
Chewing difficulties (difficulty chewing food)	☐	☐	☐
Difficulty swallowing (difficulty swallowing food and drink)	☐	☐	☐
Breathing difficulties (laboured breathing on slight effort)	☐	☐	☐

25 b) On a scale of 1 to 10, how serious were your symptoms during the last 3 months and up to the present? *Tick only one box*

1 = very slight symptoms (did not affect daily life)
10= very serious symptoms (requiring hospitalisation)

1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Very slight symptoms — Very serious symptoms

26. Have your myasthenia symptoms been worse during one or more periods since the disease started? *Tick only one box*

☐ Yes ☐ No ☐ Don`t know ***If no or don`t know go to question 29***

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MYASTHENIA

27 a) Which myasthenia symptoms did you have during your worst period?

Tick one box on every line.

Yes = I had the symptom
No = I did not have the symptom
Don't know = I don't know/can't remember whether I had the symptom

	Yes	No	Don`t know
Weak or droopy eyelids (eyelids hung down)	☐	☐	☐
Double vision (I saw double)	☐	☐	☐
Weak hand/arm muscles (difficulty carrying heavy objects)	☐	☐	☐
Weak legs (difficulty managing stairs and/or walking longer distances)	☐	☐	☐
Weak neck (difficulty holding your head up)	☐	☐	☐
Weakness in face, cheeks or lips (difficulty whistling or smiling)	☐	☐	☐
Speech difficulties (slurred, unclear speech)	☐	☐	☐
Chewing difficulties (difficulty chewing food)	☐	☐	☐
Difficulty swallowing (difficulty swallowing food and drink)	☐	☐	☐
Breathing difficulties (laboured breathing on slight effort)	☐	☐	☐

27 b) On a scale of 1 to 10, how serious did you feel your symptoms were when the disease was at its worst? *Tick only one box*

1 = very slight symptoms (did not affect daily life)
10= very serious symptoms (requiring hospitalisation)

1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Very slight symptoms — Very serious symptoms

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MYASTHENIA

28. Which of the following factors do you think could have made your myasthenia worse? *Tick one or more boxes*

- An infection ☐
- Stress- mental ☐
- Stress- physical ☐
- Season (temperature) ☐
- Medication ☐
- Other factors ☐

None of these factors made my myasthenia worse ☐

If answer "other factors", please add short explanation

29. Have you ever been admitted to hospital as an emergency patient because of myasthenia?

☐ Yes, 1-2 times ☐ Yes, 3-4 times ☐ Yes, more than 5 times ☐ No

30. Do you know whether you have tested positive for antibodies?

a) Antibodies against acetylcholine receptor (AchR) ☐ Yes ☐ No ☐ Don`t know

b) Antibodies against MuSK protein (anti-MuSK) ☐ Yes ☐ No ☐ Don`t know

31. Have you had a thymectomy (had your thymus removed)? ☐ Yes ☐ No

32. Do any other members of your family have myasthenia? ☐ Yes ☐ No

If yes, put a tick againts the family member

☐ Father ☐ Mother ☐ Siblings ☐ Grandparents ☐ Cousins

MYASTHENIA

33 a) Have you ever had any of the following medicines or treatments for myasthenia at any time? *Tick one or more boxes*

I have never taken medicines for myasthenia ☐ *(go to question **35**)*

Pyridostigmine (Mestinon) ☐
Prednisolone ☐
Azathioprine (Imuran) ☐
Ciclosporine A (Sandimmun) ☐
Myclofenolate mofetil (CellCept) ☐
Intravenous Immunglobolines ☐
Plasmapheresis /plasma exchange ☐
Other treatment ☐

If answer "other treatment", please add name of treatment

33 b) Which of the following medicines or treatments are you having <u>now</u> or have had in the <u>last 3 months</u>? *Tick one or more boxes*

I have not been treated or medicated in the last 3 months ☐

Pyridostigmine (Mestinon) ☐
Prednisolone ☐
Azathioprine (Imuran) ☐
Ciclosporine A (Sandimmun) ☐
Myclofenolate mofetil (CellCept) ☐
Intravenous Immunglobolines ☐
Plasmapheresis /plasma exchange ☐
Other treatment ☐

If answer "other treatment", please add name of treatment

34. Have you had to stop treatment or medication for myasthenia because of side effects?

☐ Yes ☐ No

If yes, treatment with:

MYASTHENIA

35. Are you in touch with any group or organisation for myasthenia patients?

☐ Yes ☐ No

If Yes, name:

If No, would you like to get in touch with a group/organisation?

☐ Yes ☐ No

36 a) How do you keep up to date on new information and treatment concerning myasthenia? *Tick one or more boxes*

Doctor ☐ I don't keep up to date ☐

Internet ☐

Medical journals/reference books ☐

Patient groups/organisations ☐

Other ☐

36 b) Are you satisfied with the information you receive? *Tick only one box*

☐ Yes ☐ No ☐ Not relevant

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OTHER DISEASES

37. Do you have any of the following diseases?

Tick one or more boxes

- ☐ **I have none of the diseases below**
- ☐ Type 1 diabetes
- ☐ Rheumatoid arthritis
- ☐ Coeliac disease
- ☐ Systemic lupus erythematosus (SLE)
- ☐ Crohn`s disease
- ☐ Autoimmune hepatitis
- ☐ Psoriasis
- ☐ Asthma
- ☐ Allergy
- ☐ Cancer
- ☐ Lung disease (not asthma)
- ☐ Type 2 diabetes
- ☐ Heart disease (heart failure)
- ☐ High blood pressure
- ☐ Mental health problems (anxiety, depression)

38. Metabolism

a) Have you ever been diagnosed with:

Tick one box on every line

	Yes	No	Don`t know
1. Hyperthyroidism	☐	☐	☐
2. Hypothyroidism	☐	☐	☐
3. Goitre	☐	☐	☐
4. Other thyroid disease	☐	☐	☐

If yes, how old were you when you were diagnosed the disease? ☐☐ **years**

b) Do you take or have you taken any of the following medicines:

	Yes	No	Don`t know
Thyroxin, Levaxin	☐	☐	☐
Neo-Mercazole	☐	☐	☐

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HEALTH

39. Indicate your present weight: ☐☐☐ **kg**

40. Indicate your present height: ☐☐☐ **cm**

41. Other medicines

For how many months during the past 12 months did you use the following medicines? Put **0** if you did not use any of the medicines.

Pain-killers	☐☐
Sleeping pills	☐☐
Tranquilisers	☐☐
Antidepressants	☐☐
Medicine for allergy	☐☐
Medicine for asthma	☐☐
Medicine for heart disease	☐☐

42. Smoking

a) Do you smoke now? *Tick one box on every line*

Cigarettes daily	☐ Yes	☐ No
Cigars/cigarillos daily	☐ Yes	☐ No
A pipe daily	☐ Yes	☐ No
I smoke every other day	☐ Yes	☐ No
I have <u>never</u> smoked daily	☐ Yes	☐ No

b) If you have previously smoked daily, how long ago did you stop? ☐☐ **years**

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HEALTH

43. Alcohol

a) Do you abstain completely from alcohol?

☐ Yes (go to question. **44**)

☐ No

b) How many times a month do you drink alcohol?

☐☐

Low-alcohol beer (less than 2 %) does not count. Put **0** if your answer is less than once a month.

c) How many glasses of beer, wine or spirits do you usually drink in the course of 2 weeks?

Enter the number of glasses. Low-alcohol beer does not count. Put **0** if you do not drink the type of alcohol

Beer ☐☐ **Glasses**

Wine ☐☐ **Glasses**

Spirits ☐☐ **Glasses**

44. How many cups of coffee/tea do you drink daily?

Put **0** if you don't drink coffee/tea daily

Number of cups of coffee: ☐☐

Number of cups of tea: ☐☐

45. Do you regularly take food supplements on a daily basis (e.g. cod liver oil, vitamins, mineral supplements)?

Tick only one box

☐ Yes, dailiy ☐ Now and then ☐ No

HEALTH

46. How much physical activity have you had over the past year in your free time?

Think of a weekly average for the year, e.g. working out, exercise, walking to work.

Tick one box on every line

	Hours per week			
Light exercise (no sweating/ no breathlessness)	☐ None	☐ Less than 1	☐ 1-2	☐ 3 or more
Hard exercise (sweating/ breathlessness)	☐ None	☐ Less than 1	☐ 1-2	☐ 3 or more

47. Physical activity at work. Answer only if you are employed.

How would you describe your job? *Tick only one box*

☐ Mostly sitting still (e.g. at a desk, assembling furniture)

☐ Requires a lot of walking (e.g. shop assistant, light industrial work)

☐ A lot of walking and lifting heavy objects (e.g. delivering mail, nursing, construction work)

☐ Heavy physical work (e.g. logging, agricultural work, heavy construction work)

48. Vaccination

a) Did you follow the normal vaccination programmes as a child?

☐ Yes ☐ No ☐ Don`t know

b) Have you been vaccinated since the age of 18?

☐ Yes ☐ No ☐ Don`t know

MEN ONLY

49. How old were you (years) when you reached puberty? ☐☐ **years**
(voice breaking, growth of body hair, etc.)

WOMEN ONLY

50. How old were you (years) when you had your first menstruation?

☐☐ **years** put **0** if you have never menstruated

51. If you are no longer menstruating, how old were you (years) when you stopped?

☐☐ **years** put **0** if you are still menstruating

Is other reason (e.g. hysterectomy, surgery) the cause of no longer menstruating?

☐ Yes ☐ No ☐ Not relevant

52. Are you pregnant? ☐ Yes ☐ No ☐ Don`t know ☐ Not relevant

53 a) How many children have you had? Put **0** if you have never had a child and go directly to question **54** on the next page

Number of children ☐☐

b) How old were you when your first child was born? ☐☐

c) How old were you when your last child was born? ☐☐

d) Were any of your children born with symptoms of myasthenia?

☐ Yes ☐ No ☐ Don`t know

e) Were there complications at any of the births?

☐ Yes ☐ No ☐ Don`t know

WOMEN ONLY

54. Have you had any miscarriages? Put **0** if you have not had any miscarriages

Number of miscarriages: ☐☐

55. Have you ever had treatment for infertility/IVF treatment? ☐ Yes ☐ No

56. Do you use/have you ever used the following medicines? *Tick one box on every line*

Contraceptive pills/mini-pills/injection	☐ Now	☐ Before, not now	☐ Never
IUD/contraceptive coil	☐ Now	☐ Before, not now	☐ Never
Hormone therapy (Oestrogen)	☐ Now	☐ Before, not now	☐ Never

57. If you are using/have used hormone therapy (the most common names are e.g. Cyclabil, Estraderm, Kilogest, Ovesterin) how long have you been using them?

☐ Less than 1 year ☐ 1-5 years ☐ More than 5 years

58. In what ways have the following factors affected the course of your myasthenia?

Tick one box on every line

Change of life (menopause)	☐ not relevant	☐ better	☐ no change	☐ worse	☐ don`t know
Menstruation	☐ not relevant	☐ better	☐ no change	☐ worse	☐ don`t know
Pregnancy	☐ not relevant	☐ better	☐ no change	☐ worse	☐ don`t know
First six months after giving birth	☐ not relevant	☐ better	☐ no change	☐ worse	☐ don`t know
Hormonal contraceptives/ hormone therapy	☐ not relevant	☐ better	☐ no change	☐ worse	☐ don`t know

THANK YOU FOR TAKING THE TIME TO ANSWER THE QUESTIONS

PLEASE ADD COMMENTS IF NEEDED