

Adult Nystagmus Quality of Life Questionnaire (NYS-29)

Version January 2016

Instructions for Patient

The NYS-29 is a questionnaire about how nystagmus may affect your everyday life. The NYS-29 includes a list of statements which involve your nystagmus or feelings about your nystagmus.

Please take as much time as you need to respond to each statement. If you are unable to complete this on your own then please ask for someone to assist you.

INSTRUCTIONS

1. Please respond to **every** statement by circling the response that best reflects how you feel
2. Below each statement there is a choice of five responses. Please circle only **one** of the responses
3. If you wear glasses or contact lenses please respond to each statement as if you are wearing them
4. If you are unsure of your response then please choose the response you think is most appropriate and make a comment in the left margin
5. If you have any questions then please ask

Thank you for completing this questionnaire

NSY-29 QUESTIONNAIRE

Name:

Date:

1. Having nystagmus does not help me to form close personal relationships

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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2. I am less confident because I have nystagmus

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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3. I find it difficult to form new relationships because I have nystagmus

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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4. I feel self-conscious because I have nystagmus

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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5. I find it difficult maintaining friendships because I have nystagmus

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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6. I find that family relationships are difficult because I have nystagmus

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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7. I find it difficult to maintain relationships with people at work because I have nystagmus

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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8. I find meeting new people is difficult because I have nystagmus

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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9. I will be excluded by others because I have nystagmus

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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10. I feel less able because I have nystagmus

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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11. I will always be isolated because I have nystagmus

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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12. Nystagmus makes me feel I don't want to try new things

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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13. I will always miss out because I have nystagmus

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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14. I feel stressed because I have nystagmus

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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15. Having nystagmus makes me stand out from other people

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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16. I feel vulnerable because I have nystagmus

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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17. Having nystagmus makes me different to other people

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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**18. I have difficulty finding or exploring new places because I have
nystagmus**

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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19. I have to rely on others because I have nystagmus

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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20. I struggle in crowded places because I have nystagmus

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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21. I struggle to get to places on my own because I have nystagmus

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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22. I am generally limited by day to day travel because I have nystagmus

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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23. I have to use things that make me stand out from other people (large print books, monocular) because I have nystagmus

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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24. Nystagmus makes it hard for me to read facial expressions

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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25. I have to ask for additional help because I have nystagmus

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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26. I am restricted in terms of leisure and social activities because I have nystagmus

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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27. Nystagmus blurs my vision

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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28. Nystagmus affects what I do in the day

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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29. I was/am/will be restricted in my choice of occupation because I have nystagmus

Not at all	A Little	Somewhat/moderately	Quite a Lot	Very Much So
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Instructions for Investigator

The adult nystagmus questionnaire (NYS-29) has been developed in order to accurately measure how nystagmus impacts upon quality of life. The NYS-29 is intended to be used in both a clinical setting and also as a research tool.

Patients should review the questionnaire instructions before responding to each statement. The NYS-29 should be completed by the patient, with help, if necessary. Patients should be encouraged to respond to every statement.

For each of the 29 items the following scoring system is used for each response:

Response Given	Score
Not at all	100
A Little	75
Somewhat/Moderately	50
Quite a Lot	25
Very Much So	0

A score can be calculated as an overall mark or subscales scores in the following manner:

Overall Score

The overall NYS-29 score is calculated as a mean of all the 29 item scores.

Whereby any items are unanswered the overall score is calculated as the mean of all answered items

Best quality of life is measured as the maximum score of 100 and worst quality of life as the minimum of 0.

Personal and Social Subscale

The personal and social subscale score is calculated as a mean of items 1 through to 17.

Whereby any items are unanswered the personal and social score is calculated as the mean of all answered items

Maximum personal and social score is 100 and worst is 0

Physical and Environmental Subscale

The physical and environmental subscale score is calculated as a mean of items 18 through to 29.

Whereby any items are unanswered the physical and environmental score is calculated as the mean of all answered items

Maximum physical and environmental score is 100 and worst is 0