

SURVEY ON STIGMA AND NEUROLOGICAL DISORDER RESULTS



JULY 2020

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ABOUT THIS SURVEY

The European Federation of Neurological Associations [EFNA] represents 19 European and International associations across a wide variety of neurological disease areas, such as multiple sclerosis, epilepsy, migraine and ADHD.

In 2018 EFNA conducted [a pan-European survey of 18 – 35 year olds living with neurological disorders](#). The survey explored problems faced by this age group, as well as their feelings around levels of understanding of their disorder and their engagement in advocacy work or patient groups.

Following closely behind ‘access to medication and treatment’, two of the biggest issues reported were ‘stigma’ and ‘isolation’.

Given these results, EFNA has chosen to delve further into the stigma suffered by those with neurological disorders, by commissioning this survey into its causes and effects.

The Cambridge English Dictionary defines stigma as:

a strong feeling of disapproval that most people in a society have about something, especially when this is unfair

According to the World Health Organisation, stigma is a major cause of discrimination and exclusion: it affects people’s self-esteem, helps disrupt their family relationships and limits their ability to socialise and obtain housing and jobs.

This report presents the results of our research. By ascertaining when, where and how stigma arises, we will be able to develop strategies to address this problem.

For more on this survey or EFNA’s work, please see efna.net or contact communications@efna.net.

SUMMARY

Between March and June of 2020, 1373 responses to the survey were received from 37 countries.

80% of the respondents were female and the majority were aged between 35 and 54 years old.

Responses came from a diverse range of neurological conditions, though the greatest numbers came from the below disease areas:

- Myalgic Encephalomyelitis (ME)
- Dystonia
- Migraine or headache
- Chronic pain
- Restless Legs Syndrome (RLS)
- Epilepsy
- ADHD
- Multiple Sclerosis
- Parkinson's Disease

Results for these specific areas can be found on page 28 of this report.

92% of respondents report feeling affected by stigma on account of the neurological disorder with which they live. Lack of understanding is seen as the biggest cause of this, followed by myths/misconceptions about these disorders and their invisible nature. The highest levels of stigma are experienced by those respondents whose disorders are considered 'invisible', suggesting a lack of societal empathy for symptoms that cannot be seen. This is supported by the fact that 32% report regularly being made to feel that their condition is their fault.

The issue of stigma has proved most problematic during interactions with medical professionals. 74% felt that a medical professional did not believe the extent or severity of their symptoms and the same percentage feel they did not receive adequate or appropriate treatment because a medical professional did not take them seriously. Worryingly, over 35% avoided seeking medical advice because they felt embarrassed. Given the importance of early intervention in many of these conditions we can see that stigma poses a risk to people's health outcomes.

The financial impact of living with neurological disorder results in increased hardship for those affected. Over 55% believe their living costs are higher on account of their condition, while 47% report that the associated costs are a burden on their life. Over 30% have been denied insurance or a mortgage on account of their neurological condition.

Stigma is also prevalent within families and in social situations. 49% say their families sometimes make them feel that they exaggerate their condition and, sadly, 32% of respondents with children have been made to feel that they are inadequate parents. Almost half of respondents who lived with a neurological disorder during childhood found it difficult to make friends or maintain friendships at school, and a similar number were excluded from school events on account of their condition.

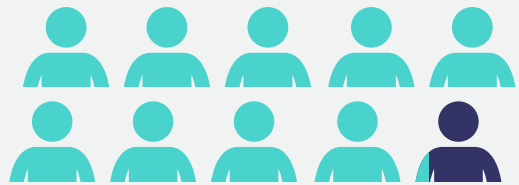
44% reported feeling that people were sometimes unkind to them on account of their illness, with 13% reporting that people are frequently unkind. Over 20% feel that people avoid them often or always and 45% feel that they are regularly left out of things.

From these results we can see that the need for increased understanding is clear.

EFNA plans to prioritise actions to deal with stigma in our 2021 workplan. We hope that, in partnership with our member organisations and other interested stakeholders, we can use these findings to develop strategies that will combat stigma where it arises, thereby improving the quality of life of people living with neurological disorder.

KEY FINDINGS

92% of those living with a neurological disorder feel affected by stigma



Chronic Pain: 100% (80% very much)

Myalgic Encephalomyelitis: 99.6% (74% very much)

Migraine/headache: 96% (58% very much)

ADHD: 91% (49% very much)

Dystonia: 89% (31% very much)

Multiple Sclerosis: 87% (24% very much)

Epilepsy: 86% (27% very much)

Parkinson's Disease: 85% (34% very much)

74% felt they did not receive adequate treatment because a medical professional **did not believe** the severity of their symptoms.

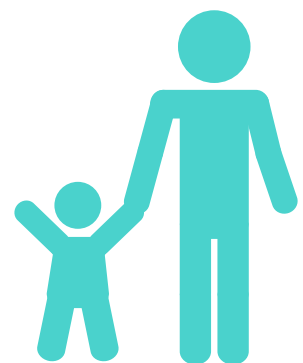


35% have avoided seeking medical advice because they felt **embarrassed**.

13% feel people are often **unkind** to them on account of their condition.



Over 30% have been **denied** insurance or a mortgage on account of their condition



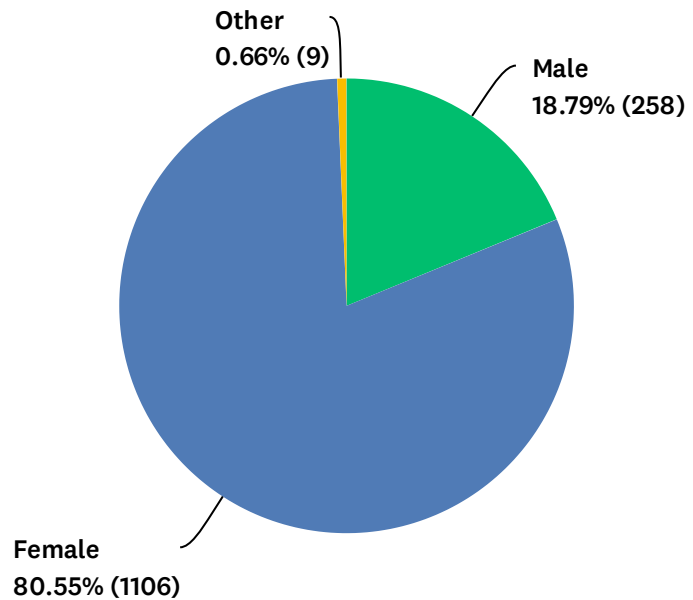
32% have been made to feel they are **inadequate** parents

20% feel people **avoid** them on account of their condition.

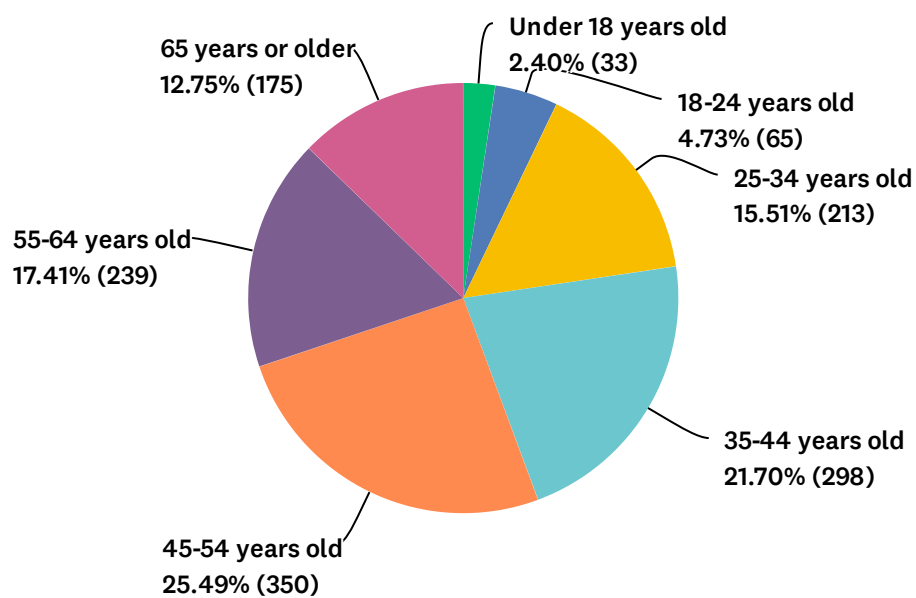
RESULTS OF THE SURVEY

SECTION 1: GENERAL INFORMATION

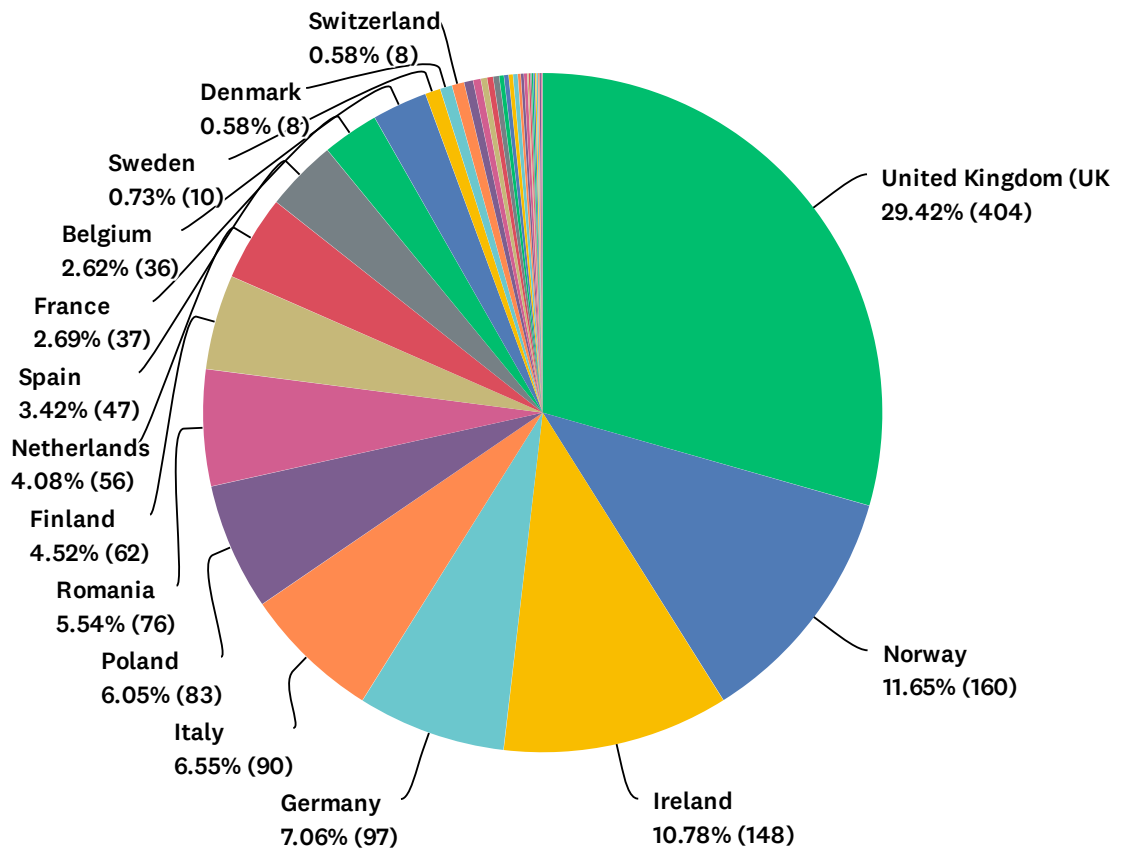
Q1. Sex:



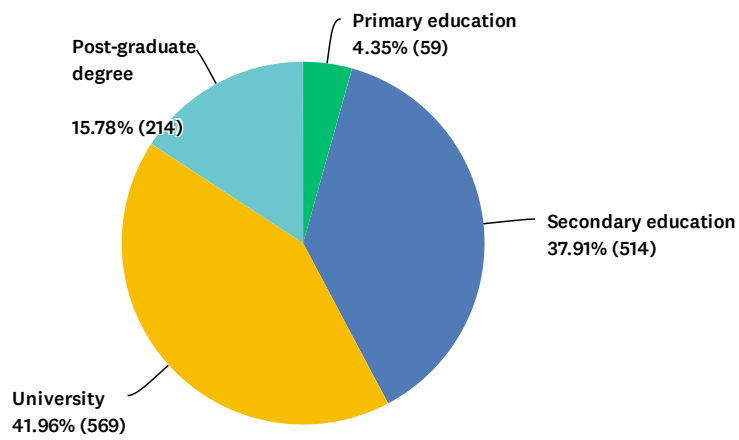
Q2. Age:



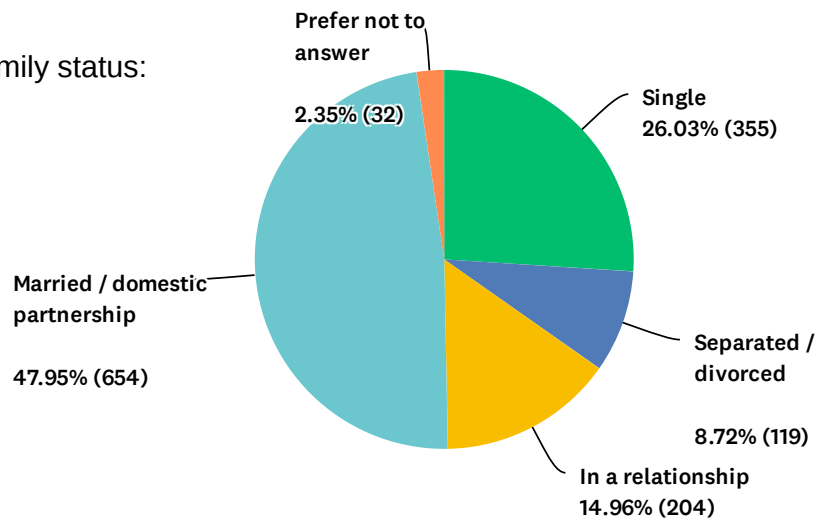
Q3. Country of residence:



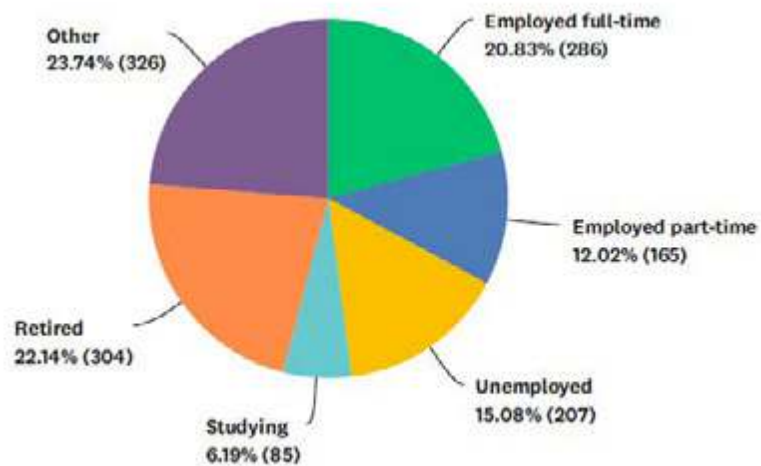
Q4. Educational Level:



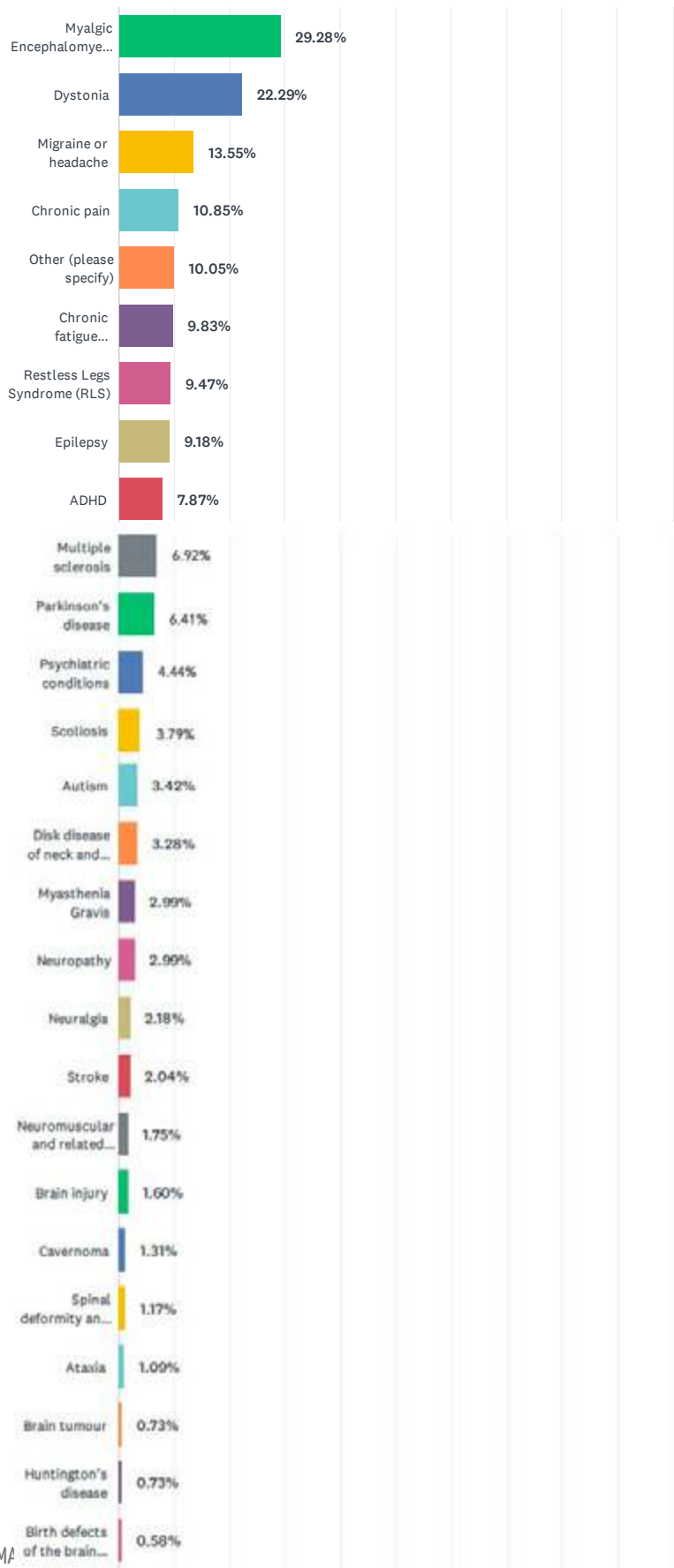
Q5 Family status:



Q6. Employment status:

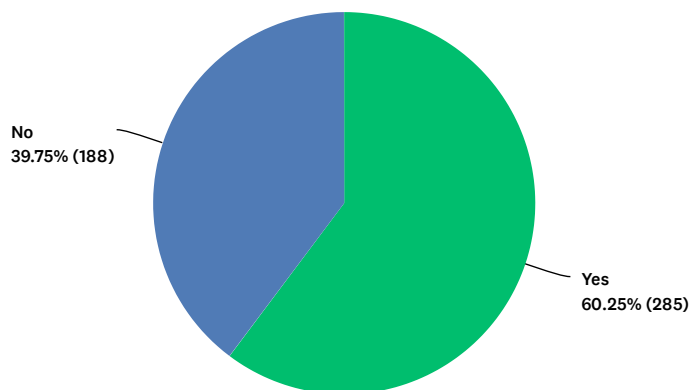


Q7. What is the neurological disorder/condition(s) you are living with? Please tick all that apply.

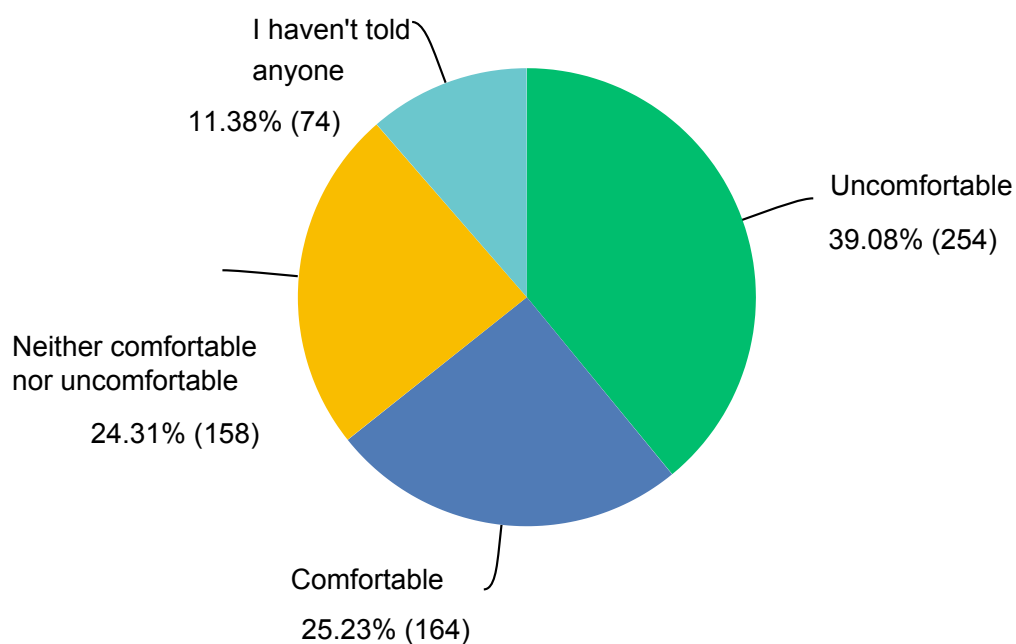


SECTION 2: EMPLOYMENT

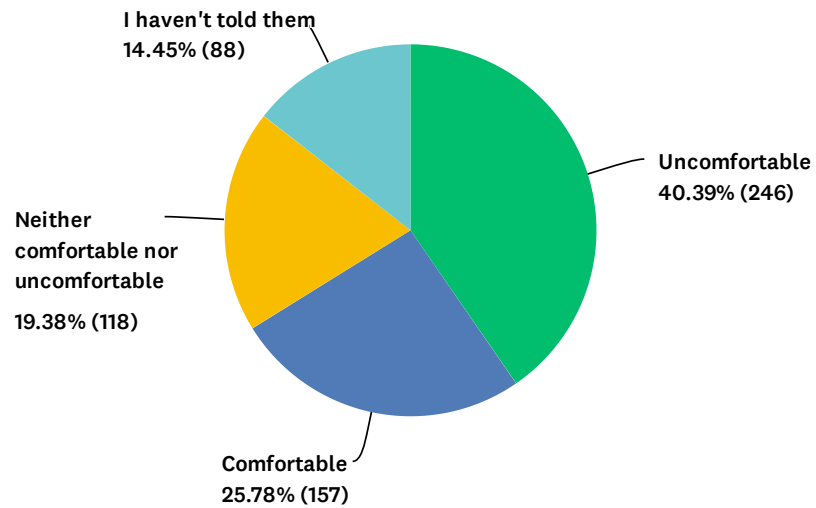
Q8. If you are currently employed, have you taken time off in the last 12 months because of your health issue?



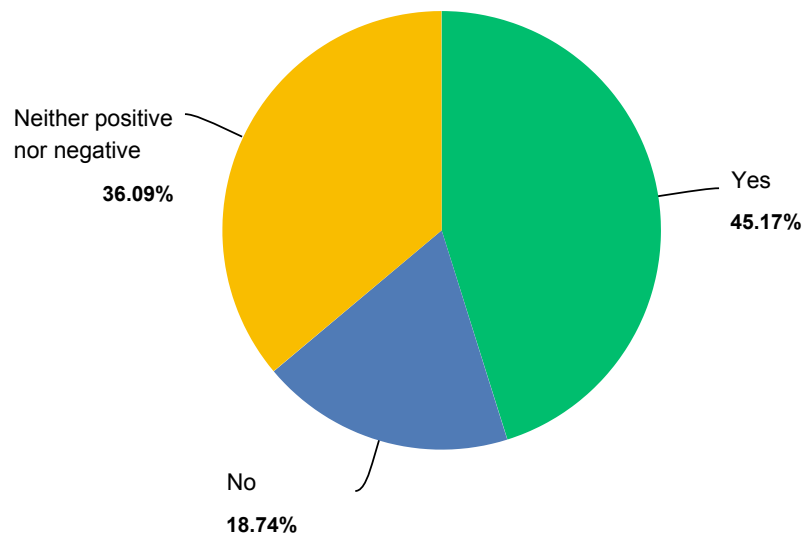
Q9. How comfortable did you feel disclosing your brain health issue to a co-worker?



Q10. How comfortable did you feel disclosing it to your manager/supervisor?



Q11. Did your manager respond in a positive or helpful way when you disclosed your brain health issue?



Q12. If your manager/supervisor responded in a positive way, what did they say/do to help you feel more comfortable?

[Please click here for individual responses.](#)



Q13. If your manager/supervisor responded in a negative way, please describe their reaction

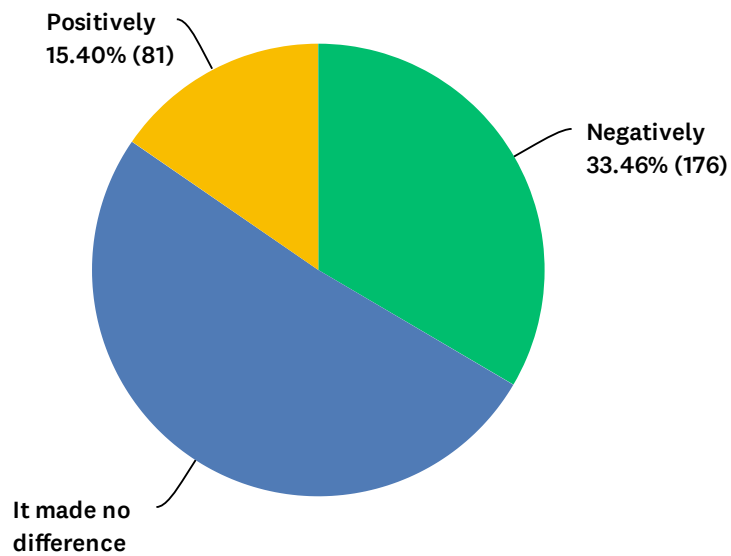
[Please click here for individual responses.](#)



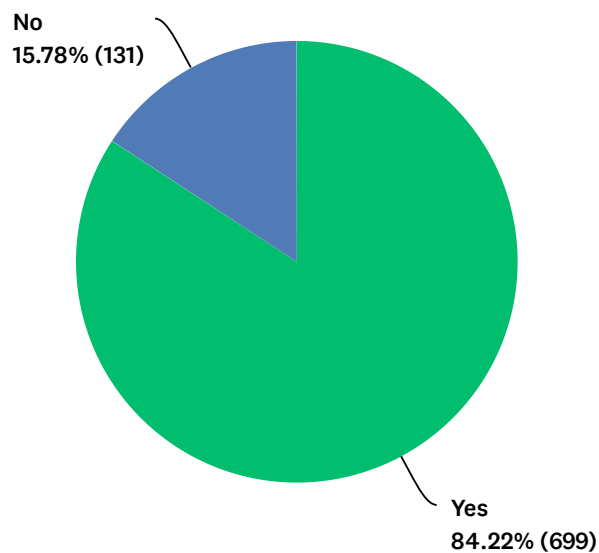
Q14. If you had concerns about disclosing your brain health issue at work, please rank those concerns from 1-5 below, with 1 being your biggest concern and so on.



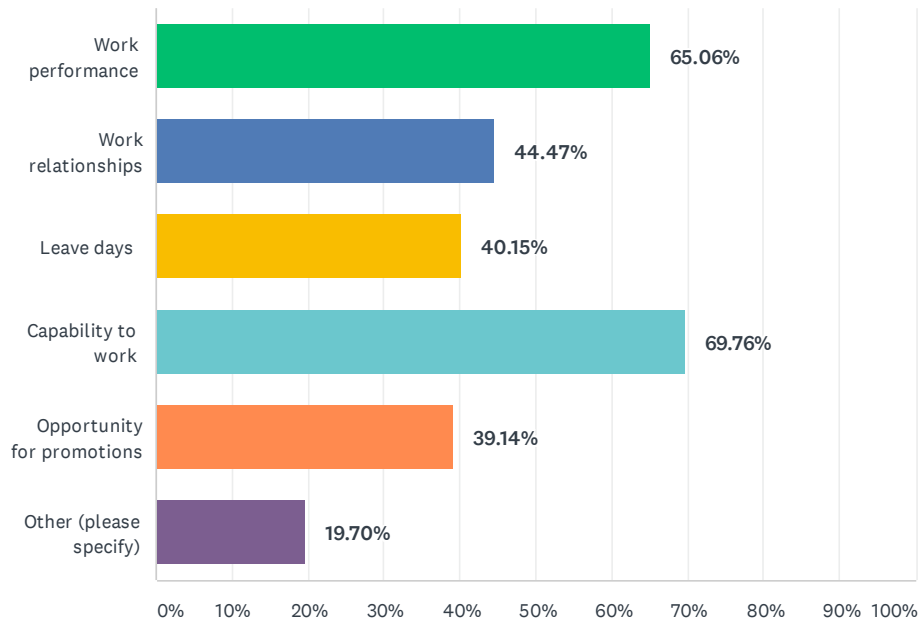
Q15. How were your relationships within the workplace affected after you disclosed your health issue?



Q16. Does having a brain disorder make your work life more difficult?



Q17. Do you feel having a brain disorder affects your... (tick all that apply)



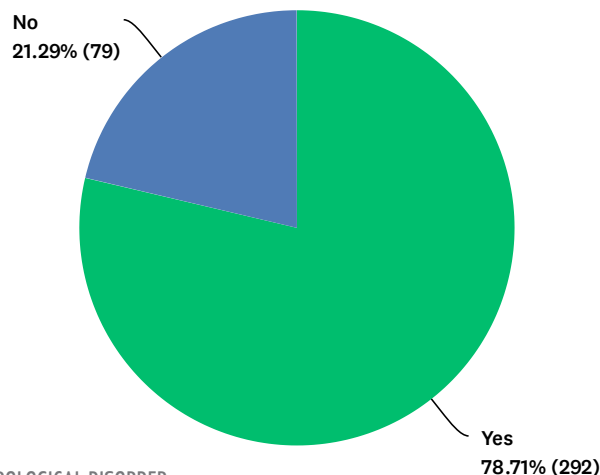
Q18. What do you believe your company should do to help you cope better with the effects of your brain health issue in the Workplace?

[Please click here for individual responses.](#)



SECTION 3: EDUCATION

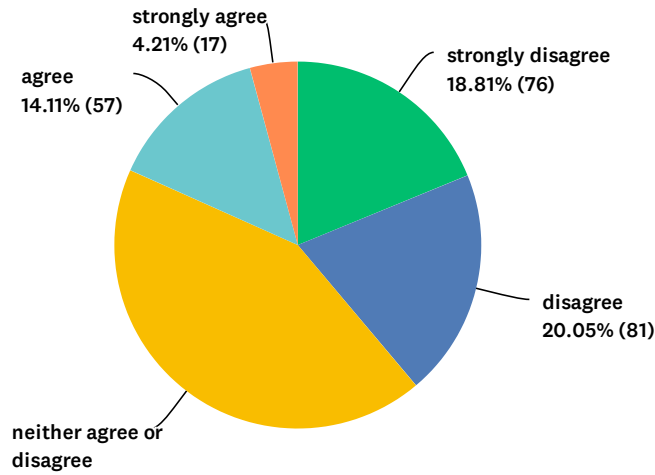
Q19. Did having a brain disorder make your education more difficult?



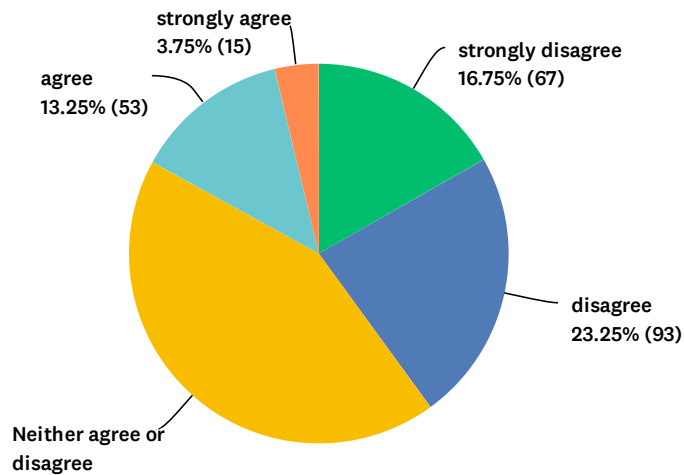
Note:

As some respondents' neurological disorders developed later in life, the questions in this section have been answered only by those to whom they are relevant.

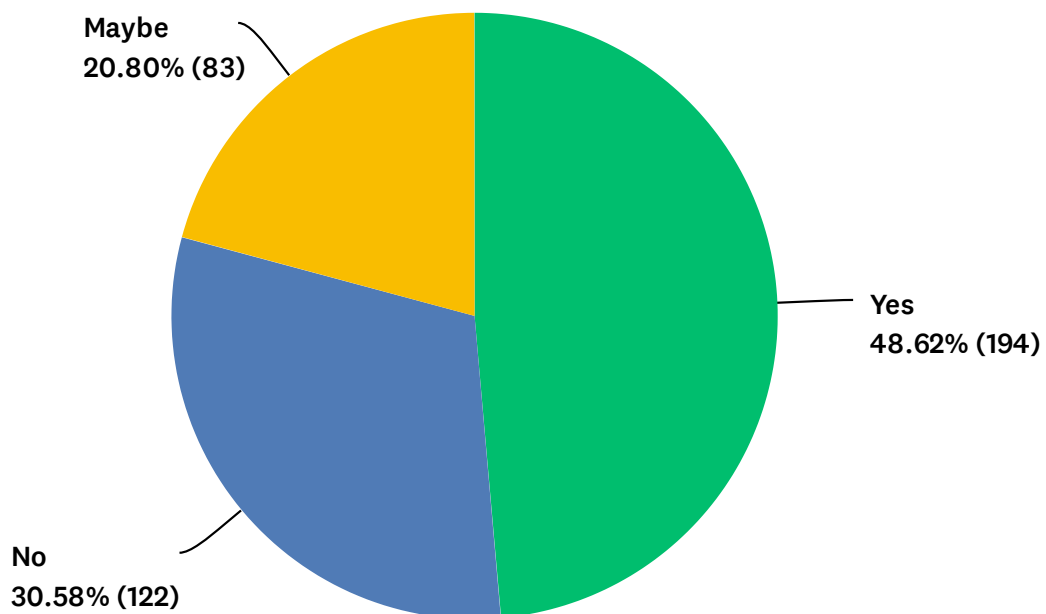
Q20. How much do you agree with this statement:
“Teachers were very understanding about my health condition.”



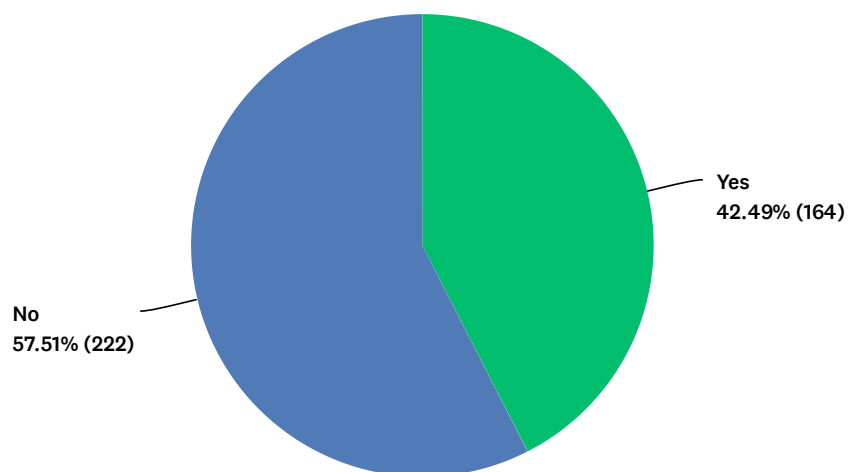
Q21. How much do you agree with this statement:
“The other students were very understanding about my health condition.”



Q22. Did your condition make it difficult to make friends/
maintain friendships at school?

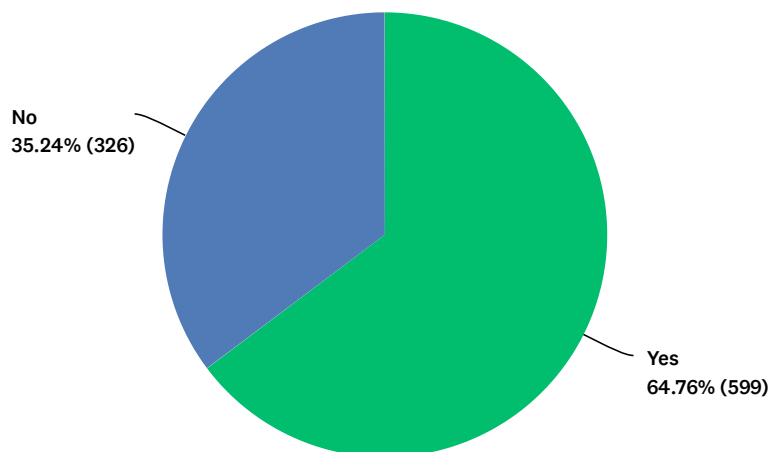


Q23. Were you ever excluded from activities at school, such as trips or sports?

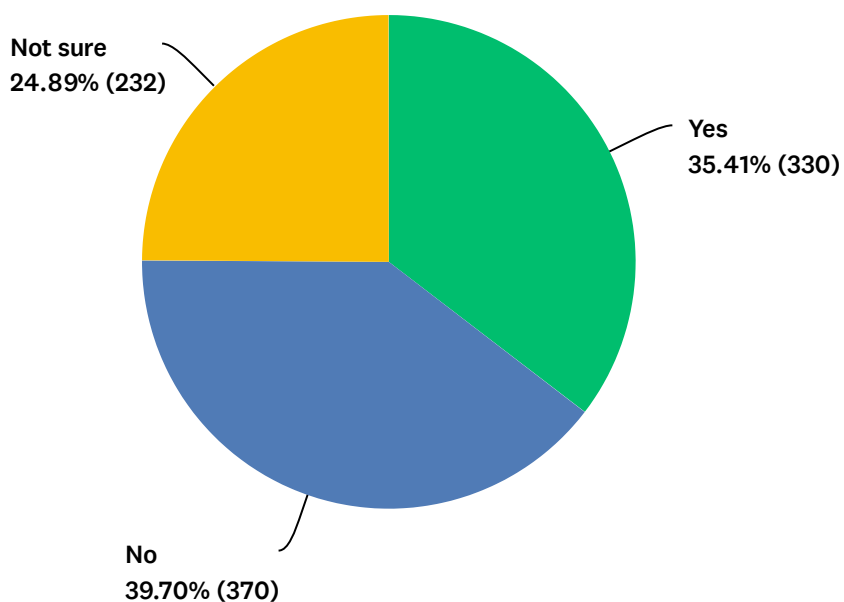


SECTION 4: RELATIONSHIPS AND FAMILY

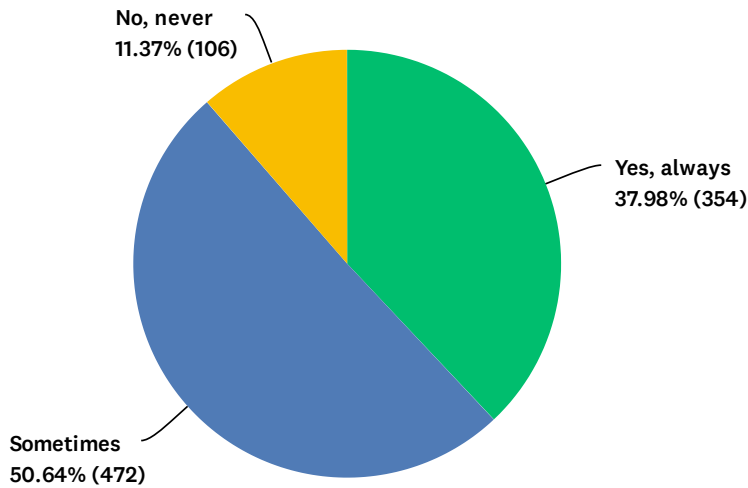
Q24. In the past 4 weeks, have you missed any social occasions or activities on account of your neurological condition



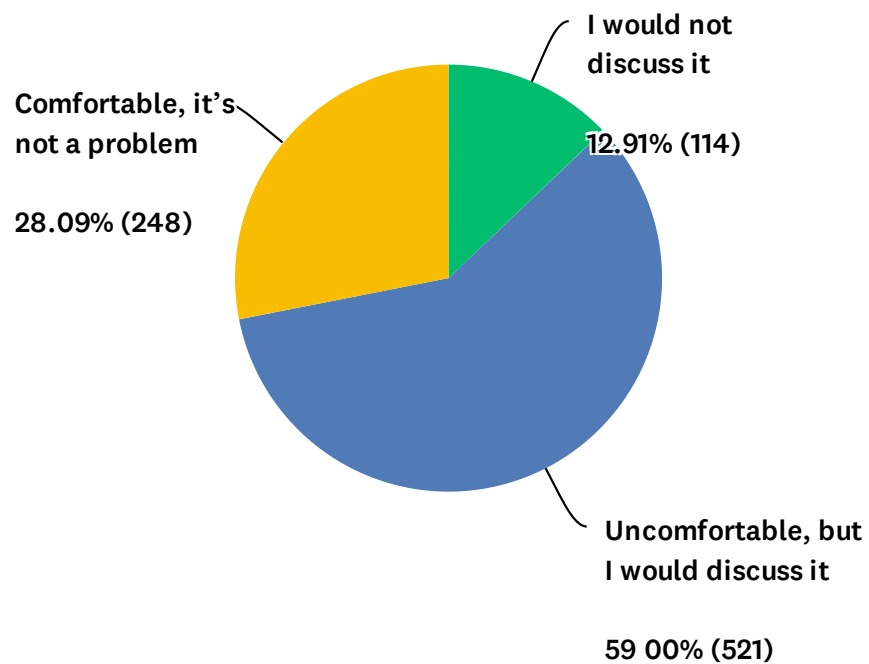
Q25. Are you ever been excluded from invitations to social events by family or friends?



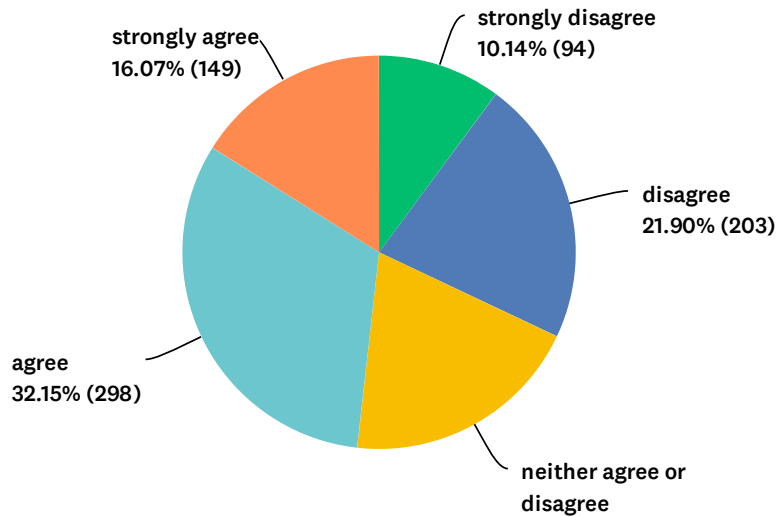
Q26. Do you feel comfortable discussing issues relating to your neurological condition with your partner/family?



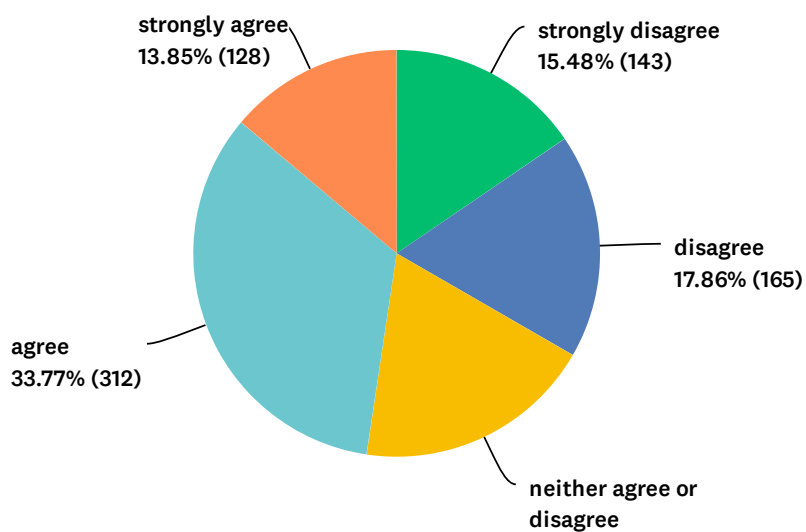
Q27. In a new romantic relationship, how comfortable would you feel discussing your neurological disorder and its impact?



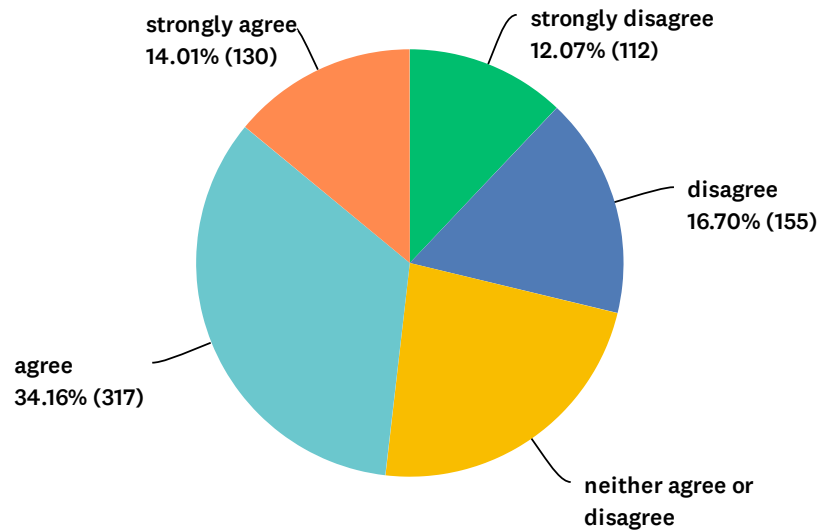
Q28. How much do you agree with this statement: “My family understand the consequences of my health problems.”



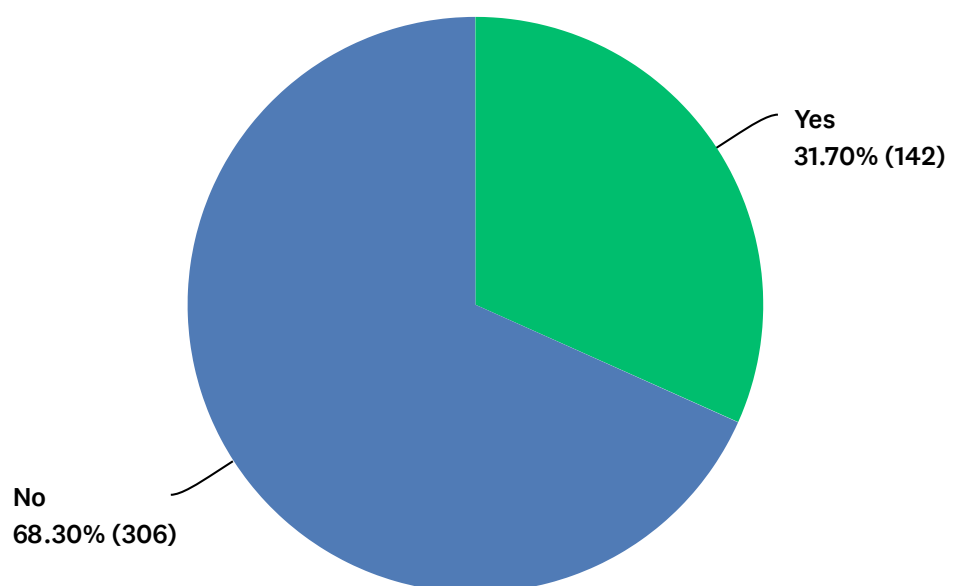
Q29. How much do you agree with this statement: “My family can sometimes make me feel like I am exaggerating about my condition.”



Q30. How much do you agree with this statement: “My family think I can do more than I feel able to.”

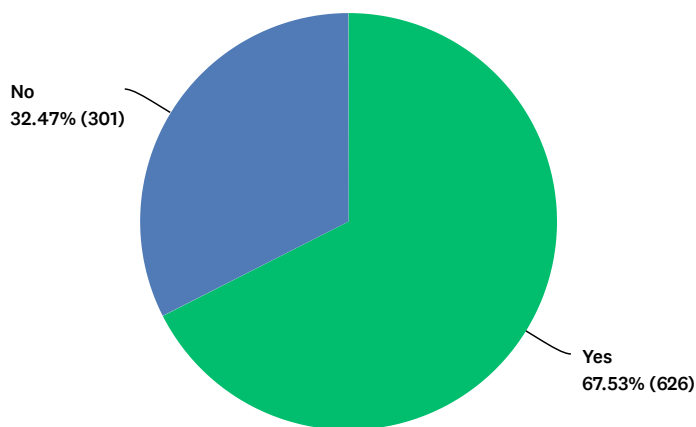


Q31. If you have children, has anyone ever made you feel that you are not an adequate parent because of your health issue?

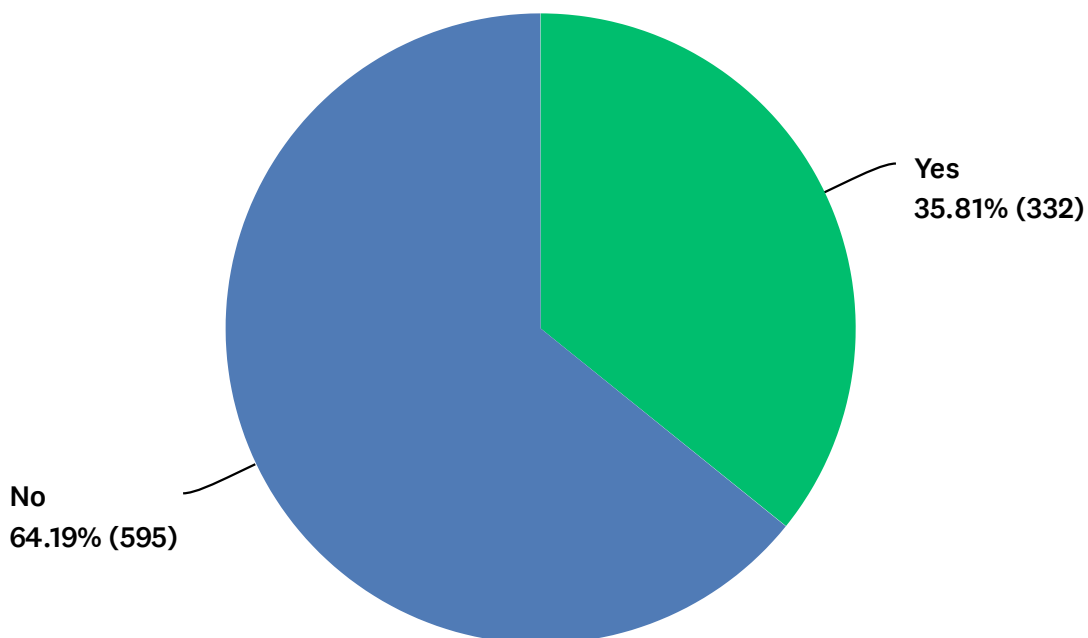


SECTION 5: MEDICAL TREATMENT

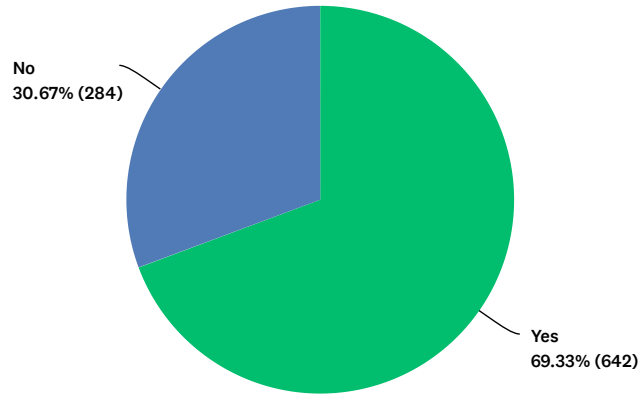
Q32. Are you under the treatment of a specialist or neurologist for your condition?



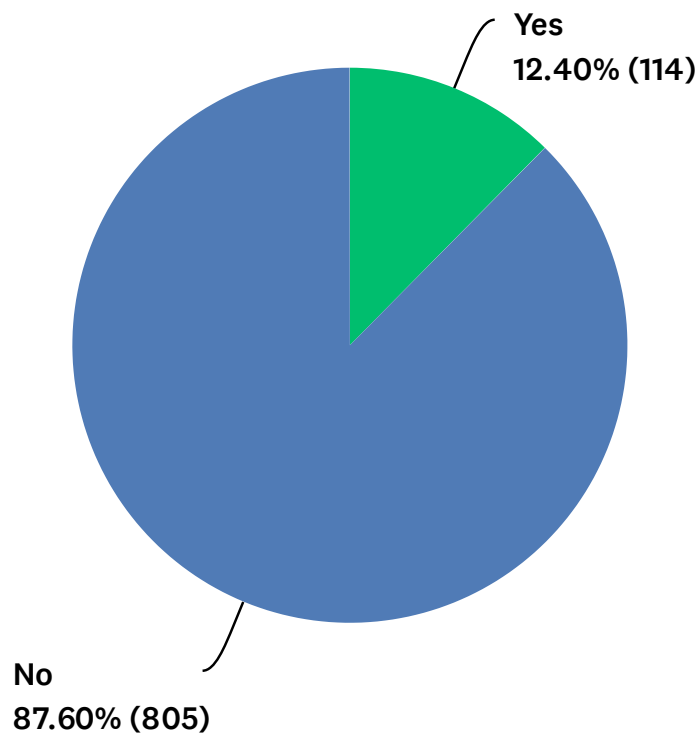
Q33. Have you ever delayed or avoided seeking medical advice because you felt embarrassed about your condition?



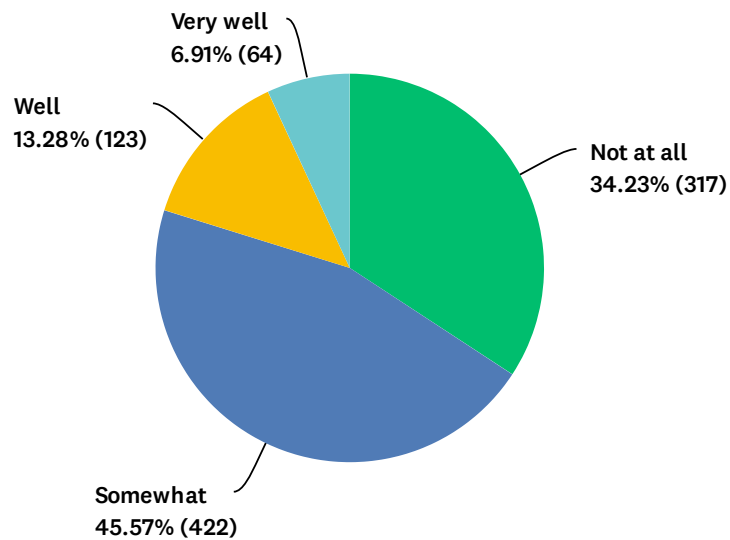
Q34. Are you currently taking prescription medication for your condition?



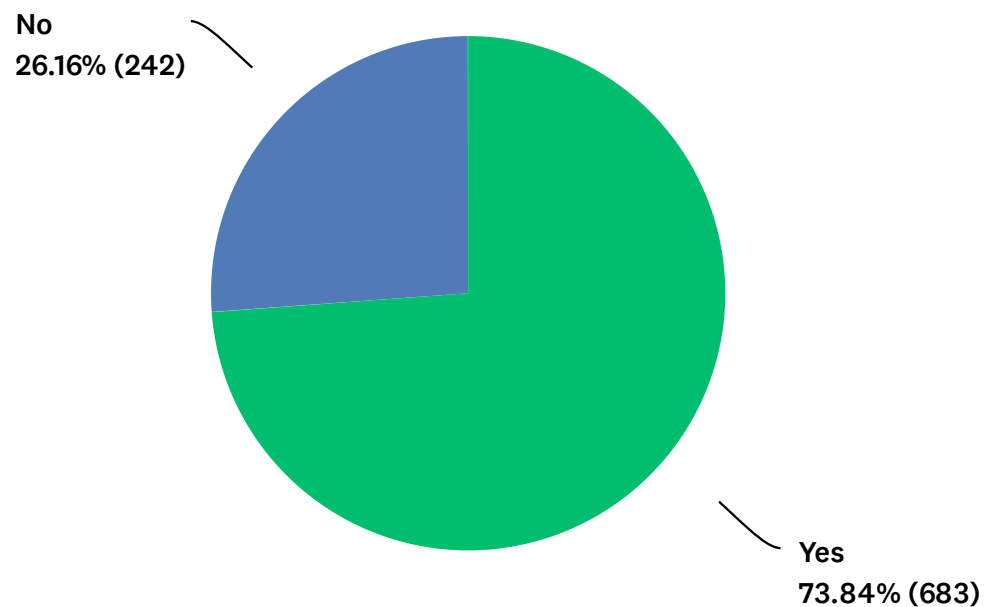
Q35. Have you ever avoided taking medication because you felt embarrassed?



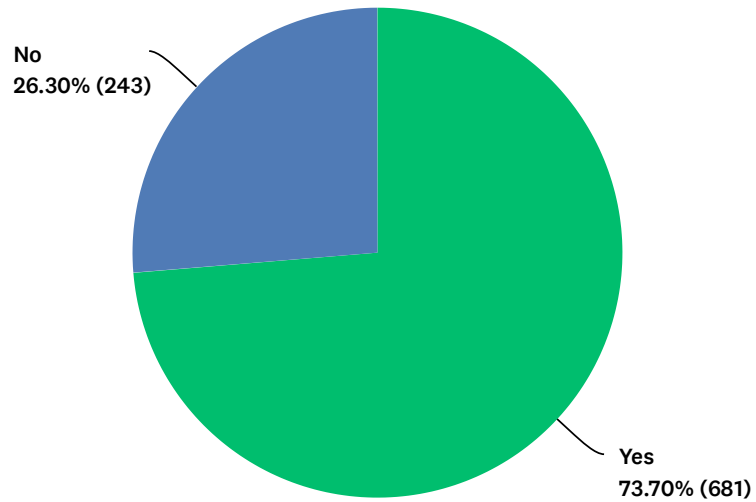
Q36. How well do you feel medical professionals understand what it is like to live with your condition?



Q37. Have you ever felt that a medical professional did not believe the extent or severity of your symptoms?

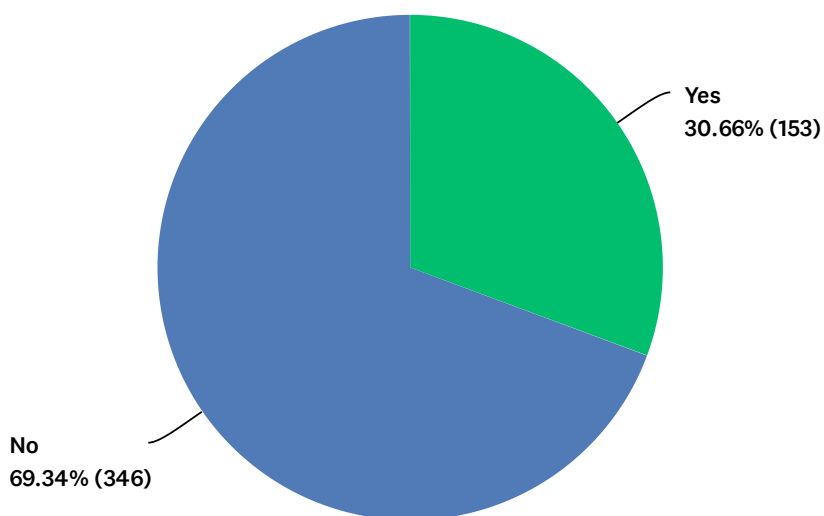


Q38. Have you ever felt that you did not receive adequate or appropriate treatment because a medical professional did not take you seriously?

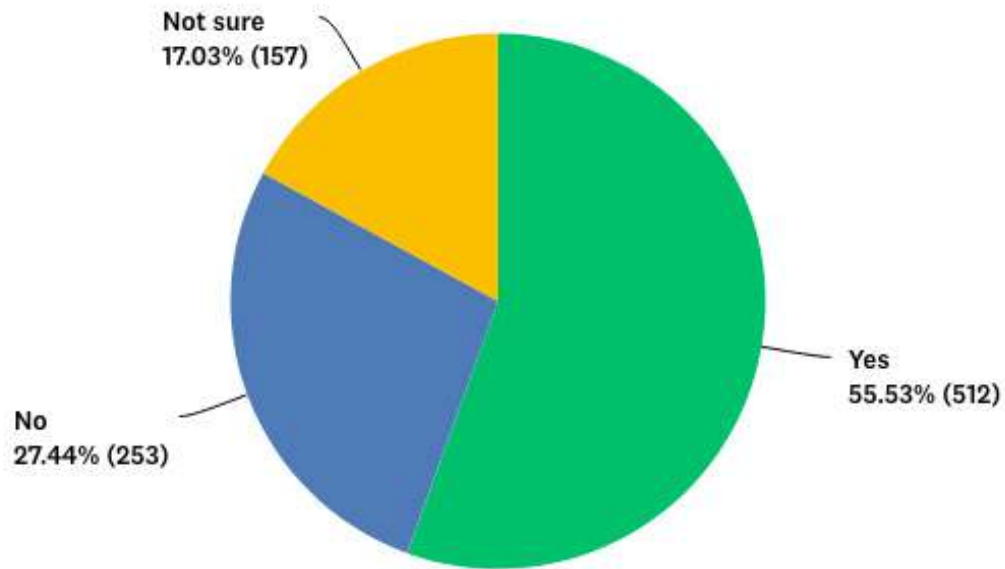


SECTION 6: SOCIAL AND ECONOMIC

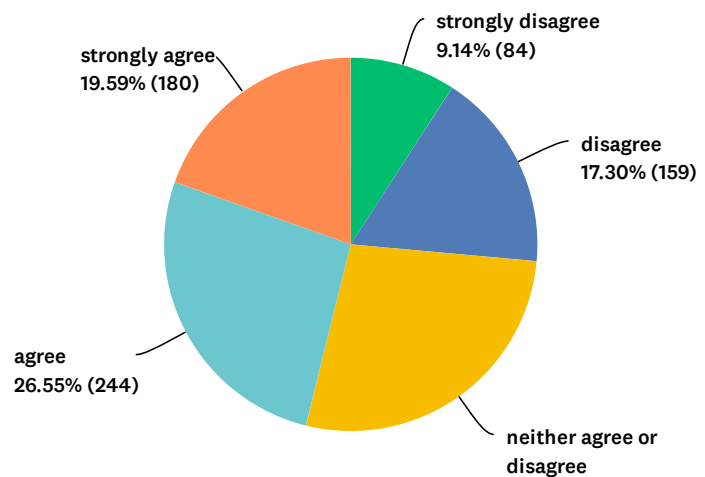
Q39. Have you ever been denied insurance or a mortgage on account of your neurological condition?



Q40. Do you feel that your living costs are higher on account of your health issue?

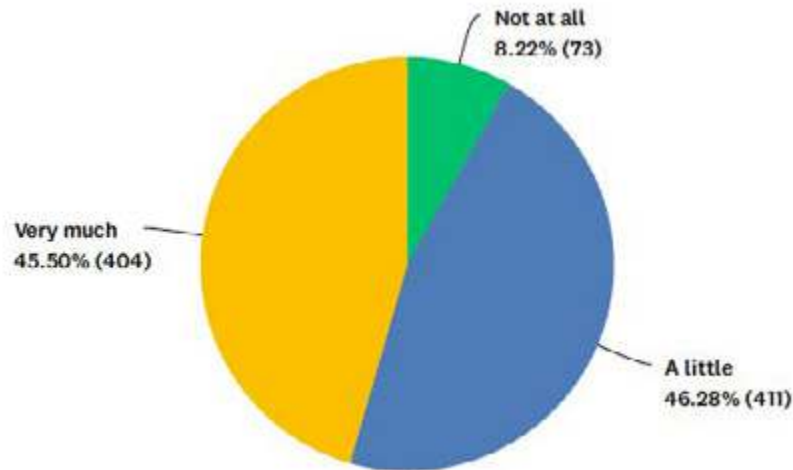


Q41. How much do you agree with this statement: "The costs associated with my condition are a burden in my life."



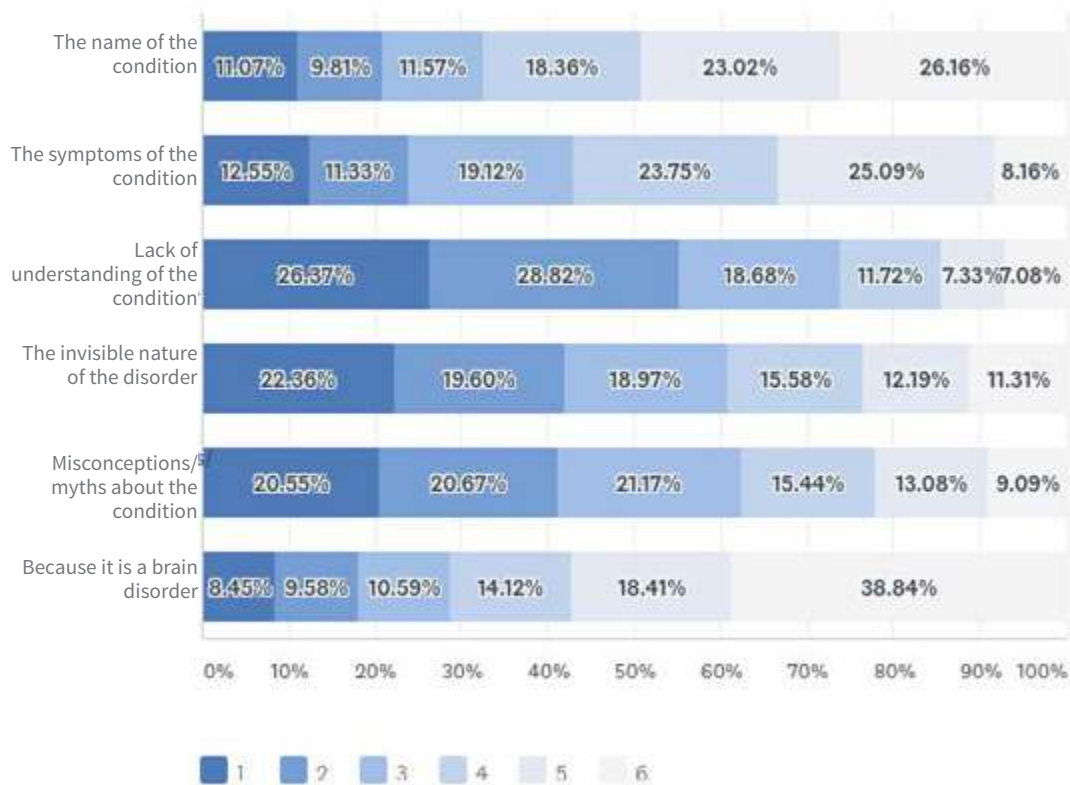
SECTION 7: STIGMA

Q42. To what extent do you feel affected by stigma on account of your illness?



Q43. What do you believe is the root cause of stigma toward your illness?

(Please rank from 1 to 6 with the biggest cause first)



Q44. In which area of your life has stigma been most problematic?
 (Please rank from 1 to 7 with the most problematic area first)



Q45. Please rate the following



- Because of my illness, some people seemed uncomfortable with me.
- Because of my illness, some people avoided me.
- Because of my illness, I felt left out of things.
- Because of my illness, people were unkind to me.
- Because of my illness, people avoided looking at me.
- I felt embarrassed about my illness.
- Some people acted as though it was my fault I have this illness.

RESPONSES BY DISEASE AREA

A complete list of results is available for disease areas with sufficient responses to the survey:

- [ADHD](#)
- [Chronic Pain](#)
- [Dystonia](#)
- [Epilepsy](#)
- [Migraine](#)
- [Multiple Sclerosis \(MS\)](#)
- [Myalgic Encephalomyelitis \(ME\)](#)
- [Parkinson's Disease](#)
- [Restless Legs Syndrome \(RLS\)](#)

COMPARISON OF DISEASE AREAS

[Click here](#) to view a comparison of responses from the major disease areas.

Survey authored by Elizabeth Cunningham, on behalf of the European Federation of Neurological Associations [EFNA].

For further information please visit our website at efna.net or email communications@efna.net.

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