

Survey on Stigma and Neurological Disorder

	1	2	3	4	5	TOTAL	SCORE
Fear of being discriminated against	16.98% 9	16.98% 9	20.75% 11	28.30% 15	16.98% 9	53	2.89
Being made fun of or humiliated	21.82% 12	12.73% 7	14.55% 8	23.64% 13	27.27% 15	55	2.78
Fear of not getting promotions	5.26% 3	19.30% 11	26.32% 15	26.32% 15	22.81% 13	57	2.58
Worried they will think less of me/that I am not capable	41.07% 23	19.64% 11	10.71% 6	16.07% 9	12.50% 7	56	3.61
Fear of losing my job	16.07% 9	30.36% 17	25.00% 14	3.57% 2	25.00% 14	56	3.09

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

Answered: 68 Skipped: 27

ANSWER CHOICES	RESPONSES
Negatively	28.30% 15
It made no difference	54.72% 29
Positively	16.98% 9
TOTAL	53

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

Answered: 67 Skipped: 28

ANSWER CHOICES	RESPONSES
Yes	68.66% 46
No	31.34% 21
TOTAL	67

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

Answered: 59 Skipped: 36

ANSWER CHOICES	RESPONSES	
Work performance	64.41%	38
Work relationships	32.20%	19
Leave days	32.20%	19
Capability to work	57.63%	34
Opportunity for promotions	47.46%	28
Other (please specify)	13.56%	8
Total Respondents: 59		

#	OTHER (PLEASE SPECIFY)	DATE
1	Fitting work into a 9-5	6/8/2020 1:07 PM
2	motywację	5/26/2020 9:49 PM
3	Mi devo limitare per non sentirmi male e la cosa e' umiliante per me stesso,sapere di essere limitato.	5/3/2020 12:31 PM
4	A volte è difficile rispondere con un sorriso ai dolori..ma aiuta	5/3/2020 11:42 AM
5	Mental Health	4/27/2020 4:36 PM
6	Concentrarea către sfârșitul săptămânii	4/22/2020 6:55 PM
7	Mental health	4/6/2020 8:46 PM
8	Everything, from what type of work i feel i can apply for, to what hours i am capable of doing, the realisation that i am never going to get promoted because of people's attitudes, and that i am always going to be considered to be 'a risk' and so not get appointed in the first place. These are not just feelings, this has happened already.	3/16/2020 2:56 PM

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?

Answered: 39 Skipped: 56

#	RESPONSES	DATE
1	Read the information I give them and listen to me. Original management was supportive and welcomed information current do not	6/13/2020 3:17 PM
2	Address my workload	6/9/2020 7:52 PM
3	They already done everything they can, and more..	6/8/2020 5:15 PM
4	Flexible working, rest place at work, more home working	6/8/2020 1:07 PM
5	show more empathy	6/8/2020 1:00 PM
6	Zapewnić spokój i ciszę w miejscu pracy	6/5/2020 8:16 PM
7	They should let me work lesser ours	6/4/2020 1:46 AM
8	I wish there was a clear and simple understanding that when a person with a brain disorder says they need a day off because of sudden and debilitating symptoms, they're not skiving or less productive than other workers.	5/29/2020 12:42 AM
9	Dostosować wymagania do możliwości chirehi	5/27/2020 7:00 PM
10	Nothing	5/27/2020 12:46 PM
11	Zmienić właściciela	5/27/2020 8:17 AM
12	nie chorować	5/26/2020 9:49 PM
13	Be more tolerant	5/26/2020 6:28 PM
14	Nothing	5/5/2020 7:04 PM
15	I am self-employed. I wish I could fall back on savings or some form of support when I am too unwell to work. I have to work sometimes when I should be resting.	5/5/2020 11:01 AM
16	Mine are very supportive	5/5/2020 8:50 AM
17	Flessibilità negli orari di lavoro	5/3/2020 8:31 PM
18	Not apply	5/3/2020 2:42 PM
19	Essere più disponibile riguardo le ferie	5/3/2020 12:31 PM
20	Farmi fare una visita prima dell'assunzione e prendere in carico subito i criteri annitati sulla schede delle capacita' tecniche in modo da rispettare i punti stabiliti.	5/3/2020 12:31 PM
21	I don't know	5/3/2020 12:16 PM
22	..	5/3/2020 11:42 AM
23	n/a	4/28/2020 7:36 AM
24	Dont apply	4/28/2020 6:05 AM
25	Open and regular discussion on health	4/27/2020 9:54 PM
26	Embrace neurodiversity.	4/27/2020 4:36 PM
27	Do not ask about it, otherwise people will look to us like we are wrong	4/27/2020 12:18 PM
28	They did what they could.	4/27/2020 11:25 AM
29	Sa intelega ca poti sa fii o persoana potrivita pentru companie chiar dacă ai probleme de sanatate	4/22/2020 7:35 PM
30	Scurtarea sau flexibilitatea programului de lucru	4/22/2020 6:55 PM
31	Information, adaptation	4/22/2020 5:34 PM
32	Since I have an invisible disease no one knows how I fell, if I am momentarily with vertigo, pain, brain for or with my eyesight blurred so it is sometimes hard to explain that I need some time ant that I cannot work for a little bit.	4/17/2020 3:51 PM
33	There exist no Diversity and Inclusion guidelines. Best practice would include having clear procedures. As mentioned before my direct supervisor is overwhelmed and does not know how to deal with the situation. If policies were in place, they would have a reference on how to manage these kind of situations.	4/15/2020 12:42 PM
34	Right now I am happy with the situation because I am able to everything but I am just	4/7/2020 10:13 AM

worried about the future. What if the negative days come?

35	Ask me what I need	4/6/2020 8:46 PM
36	A work day from home would be so beneficial for rest and recuperation but still being productive.	3/17/2020 5:30 PM
37	To understand more	3/16/2020 6:58 PM
38	If they don't discriminate me and don't hate my condition everything will be ok.	3/16/2020 5:54 PM
39	Some training for managers about 'invisible conditions', mental health and so on would be a good start. Training occupational health to understand that putting in a wheelchair ramp is not the only thing that people might need to help them to work. Listen to us! Let us tell you what works!	3/16/2020 2:56 PM

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

Answered: 69 Skipped: 26

ANSWER CHOICES	RESPONSES	
Yes	52.00%	13
No	48.00%	12
TOTAL		25

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

Answered: 25 Skipped: 70

ANSWER CHOICES	RESPONSES	
disagree	16.00%	4
neither agree or disagree	52.00%	13
agree	16.00%	4
strongly agree	16.00%	4
TOTAL		25

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

Answered: 25 Skipped: 70

ANSWER CHOICES	RESPONSES	
disagree	36.00%	9
Neither agree or disagree	36.00%	9
agree	20.00%	5
strongly agree	8.00%	2
TOTAL		25

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

Answered: 25 Skipped: 70

ANSWER CHOICES	RESPONSES	
Yes	28.00%	7
No	56.00%	14
Maybe	16.00%	4
TOTAL		25

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

Answered: 25 Skipped: 70

ANSWER CHOICES	RESPONSES	
Yes	28.00%	7
No	72.00%	18
TOTAL		25

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

Answered: 69 Skipped: 26

ANSWER CHOICES	RESPONSES	
Yes	44.93%	31
No	55.07%	38
TOTAL		69

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

Answered: 69 Skipped: 26

ANSWER CHOICES	RESPONSES	
Yes	18.84%	13
No	57.97%	40
Not sure	23.19%	16
TOTAL		69

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

Answered: 69 Skipped: 26

ANSWER CHOICES	RESPONSES	
Yes, always	42.03%	29
Sometimes	44.93%	31
No, never	13.04%	9
TOTAL		69

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

Answered: 68 Skipped: 27

ANSWER CHOICES	RESPONSES	
I would not discuss it	11.76%	8
Uncomfortable, but I would discuss it	48.53%	33
Comfortable, it's not a problem	39.71%	27
TOTAL		68

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

Answered: 69 Skipped: 26

ANSWER CHOICES	RESPONSES	
strongly disagree	4.35%	3
disagree	28.99%	20
neither agree or disagree	21.74%	15
agree	27.54%	19
strongly agree	17.39%	12
TOTAL		69

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

Answered: 68 Skipped: 27

ANSWER CHOICES	RESPONSES	
strongly disagree	16.18%	11
disagree	20.59%	14
neither agree or disagree	22.06%	15
agree	35.29%	24
strongly agree	5.88%	4
TOTAL		68

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

Answered: 69 Skipped: 26

ANSWER CHOICES	RESPONSES	
strongly disagree	14.49%	10
disagree	28.99%	20
neither agree or disagree	27.54%	19
agree	23.19%	16
strongly agree	5.80%	4
TOTAL		69

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

Answered: 65 Skipped: 30

ANSWER CHOICES	RESPONSES	
Yes	17.24%	5
No	82.76%	24
TOTAL		29

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

Answered: 68 Skipped: 27

ANSWER CHOICES	RESPONSES	
Yes	95.59%	65
No	4.41%	3
TOTAL		68

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

Answered: 68 Skipped: 27

ANSWER CHOICES	RESPONSES	
Yes	19.12%	13
No	80.88%	55
TOTAL		68

Q34 Are you currently taking prescription medication for your condition?

Answered: 68 Skipped: 27

ANSWER CHOICES	RESPONSES	
Yes	83.82%	57
No	16.18%	11
TOTAL		68

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

Answered: 68 Skipped: 27

ANSWER CHOICES	RESPONSES	
Yes	7.35%	5
No	92.65%	63
TOTAL		68

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

Answered: 68 Skipped: 27

ANSWER CHOICES	RESPONSES	
Not at all	10.29%	7
Somewhat	42.65%	29
Well	27.94%	19
Very well	19.12%	13
TOTAL		68

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

Answered: 68 Skipped: 27

ANSWER CHOICES	RESPONSES	
Yes	61.76%	42
No	38.24%	26
TOTAL		68

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

Answered: 68 Skipped: 27

ANSWER CHOICES	RESPONSES	
Yes	57.35%	39
No	42.65%	29
TOTAL		68

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

Answered: 68 Skipped: 27

ANSWER CHOICES	RESPONSES	
Yes	48.78%	20
No	51.22%	21
TOTAL		41

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

Answered: 68 Skipped: 27

ANSWER CHOICES	RESPONSES	
Yes	61.76%	42
No	14.71%	10
Not sure	23.53%	16
TOTAL		68

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

Answered: 68 Skipped: 27

ANSWER CHOICES	RESPONSES	
strongly disagree	5.88%	4
disagree	14.71%	10
neither agree or disagree	32.35%	22
agree	32.35%	22
strongly agree	14.71%	10
TOTAL		68

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

Answered: 67 Skipped: 28

ANSWER CHOICES	RESPONSES	
Not at all	13.43%	9
A little	62.69%	42
Very much	23.88%	16
TOTAL		67

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)

Answered: 65 Skipped: 30

	1	2	3	4	5	6	TOTAL	SCORE
The name of the condition	15.00% 9	6.67% 4	10.00% 6	15.00% 9	18.33% 11	35.00% 21	60	2.80
The symptoms of the condition	9.68% 6	12.90% 8	17.74% 11	29.03% 18	19.35% 12	11.29% 7	62	3.31
Lack of understanding of the condition	24.59% 15	19.67% 12	11.48% 7	24.59% 15	11.48% 7	8.20% 5	61	3.97
The invisible nature of the condition	28.57% 18	28.57% 18	14.29% 9	7.94% 5	9.52% 6	11.11% 7	63	4.25
Misconceptions/myths about the condition	23.73% 14	16.95% 10	27.12% 16	10.17% 6	8.47% 5	13.56% 8	59	3.97
Because it is a brain disorder	3.23% 2	16.13% 10	20.97% 13	11.29% 7	29.03% 18	19.35% 12	62	2.95

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

Answered: 63 Skipped: 32

	1	2	3	4	5	6	7	TOTAL	SCORE
During education	13.79% 8	8.62% 5	10.34% 6	12.07% 7	12.07% 7	12.07% 7	31.03% 18	58	3.40
In employment	34.48% 20	20.69% 12	12.07% 7	5.17% 3	5.17% 3	12.07% 7	10.34% 6	58	4.97
In romantic relationships	13.56% 8	13.56% 8	20.34% 12	11.86% 7	15.25% 9	13.56% 8	11.86% 7	59	4.10
In friendships	5.08% 3	18.64% 11	13.56% 8	23.73% 14	20.34% 12	13.56% 8	5.08% 3	59	4.03
Interaction with family	8.47% 5	8.47% 5	18.64% 11	11.86% 7	20.34% 12	22.03% 13	10.17% 6	59	3.66
Interaction with medical professionals	10.17% 6	16.95% 10	6.78% 4	16.95% 10	15.25% 9	13.56% 8	20.34% 12	59	3.68
Interaction with the public	17.24% 10	15.52% 9	17.24% 10	20.69% 12	6.90% 4	13.79% 8	8.62% 5	58	4.40

Q45 Please rate the following

Answered: 67 Skipped: 28

	NEVER	RARELY	SOMETIMES	OFTEN	ALWAYS	TOTAL
Because of my illness, some people seemed uncomfortable with me.	17.91% 12	25.37% 17	43.28% 29	13.43% 9	0.00% 0	67
Because of my illness, some people avoided me.	32.84% 22	23.88% 16	34.33% 23	8.96% 6	0.00% 0	67
Because of my illness, I felt left out of things.	22.39% 15	19.40% 13	35.82% 24	22.39% 15	0.00% 0	67
Because of my illness, people were unkind to me.	49.25% 33	26.87% 18	17.91% 12	5.97% 4	0.00% 0	67
Because of my illness, people avoided looking at me.	58.21% 39	13.43% 9	22.39% 15	5.97% 4	0.00% 0	67
I felt embarrassed about my illness.	31.34% 21	13.43% 9	34.33% 23	16.42% 11	4.48% 3	67
Some people acted as though it was my fault I have this illness.	47.76% 32	19.40% 13	19.40% 13	11.94% 8	1.49% 1	67