

Survey on Stigma and Neurological Disorder

62	Flexible timetable	3/16/2020 8:27 PM
63	Adaptar las condiciones laborales	3/16/2020 7:40 PM
64	Work from home.	3/16/2020 6:44 PM
65	Understand the conditions and ask the sufferer how they are affected and their concerns.	3/16/2020 6:31 PM
66	Not applicable since I can't work, but if the degree of my impairment was considerably lower: (1) an accommodation that would allow me to work while lying down (because of orthostatic intolerance), (2) an office for myself to shield me from visual and auditory overstimulation	3/16/2020 6:10 PM
67	I had hoped to try working part time, but they wouldn't do that	3/16/2020 5:10 PM
68	I am unable to work anymore. This disease is so debilitating and there are currently no treatments for it, research is grossly underfunded. I am housebound and bedridden.	3/16/2020 4:49 PM
69	Follow through on short day, (tell other staff that part hours and reduced hours for health are 2 very different and independent issues	3/16/2020 4:12 PM
70	My workplace had supported me extremely well.	3/16/2020 2:47 PM
71	My employee is a friend so it's hard to say In case I work in a company: leave days, rests during the day, easier tasks, flexible schedule and work hours	3/16/2020 2:40 PM
72	Give me a support worker understand that I simply cannot communicate at times understand the variability and plan for that	3/16/2020 2:24 PM
73	Be non judgmental Sympathetic Accommodate me and my illness Not discriminate Have empathy Research my illnesses Educate themselves Make changes to my job and the work place	3/16/2020 1:46 PM
74	Flexible working hours.	3/16/2020 1:06 PM

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

Answered: 250 Skipped: 152

ANSWER CHOICES	RESPONSES	
Yes	96.88%	93
No	3.13%	3
TOTAL		96

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

Answered: 103 Skipped: 299

ANSWER CHOICES	RESPONSES	
strongly disagree	22.33%	23
disagree	28.16%	29
neither agree or disagree	38.83%	40
agree	10.68%	11
TOTAL		103

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

Answered: 100 Skipped: 302

ANSWER CHOICES	RESPONSES	
strongly disagree	22.00%	22
disagree	28.00%	28
Neither agree or disagree	38.00%	38
agree	11.00%	11
strongly agree	1.00%	1
TOTAL		100

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

Answered: 101 Skipped: 301

ANSWER CHOICES	RESPONSES	
Yes	68.32%	69
No	13.86%	14
Maybe	17.82%	18
TOTAL		101

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

Answered: 97 Skipped: 305

ANSWER CHOICES	RESPONSES	
Yes	52.58%	51
No	47.42%	46
TOTAL		97

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

Answered: 249 Skipped: 153

ANSWER CHOICES	RESPONSES	
Yes	97.59%	243
No	2.41%	6
TOTAL		249

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

Answered: 249 Skipped: 153

ANSWER CHOICES	RESPONSES	
Yes	63.45%	158
No	11.65%	29
Not sure	24.90%	62
TOTAL		249

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

Answered: 248 Skipped: 154

ANSWER CHOICES	RESPONSES	
Yes, always	30.65%	76
Sometimes	60.89%	151
No, never	8.47%	21
TOTAL		248

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

Answered: 232 Skipped: 170

ANSWER CHOICES	RESPONSES	
I would not discuss it	6.90%	16
Uncomfortable, but I would discuss it	75.43%	175
Comfortable, it's not a problem	17.67%	41
TOTAL		232

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

Answered: 246 Skipped: 156

ANSWER CHOICES	RESPONSES	
strongly disagree	15.45%	38
disagree	22.76%	56
neither agree or disagree	17.07%	42
agree	31.71%	78
strongly agree	13.01%	32
TOTAL		246

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

Answered: 246 Skipped: 156

ANSWER CHOICES	RESPONSES	
strongly disagree	12.20%	30
disagree	14.23%	35
neither agree or disagree	15.04%	37
agree	40.65%	100
strongly agree	17.89%	44
TOTAL		246

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

Answered: 247 Skipped: 155

ANSWER CHOICES	RESPONSES	
strongly disagree	7.29%	18
disagree	14.57%	36
neither agree or disagree	14.98%	37
agree	41.70%	103
strongly agree	21.46%	53
TOTAL		247

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

Answered: 242 Skipped: 160

ANSWER CHOICES	RESPONSES	
Yes	51.96%	53
No	48.04%	49
TOTAL		102

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

Answered: 247 Skipped: 155

ANSWER CHOICES	RESPONSES	
Yes	26.72%	66
No	73.28%	181
TOTAL		247

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

Answered: 246 Skipped: 156

ANSWER CHOICES	RESPONSES	
Yes	54.47%	134
No	45.53%	112
TOTAL		246

Q34 Are you currently taking prescription medication for your condition?

Answered: 247 Skipped: 155

ANSWER CHOICES	RESPONSES	
Yes	51.82%	128
No	48.18%	119
TOTAL		247

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

Answered: 241 Skipped: 161

ANSWER CHOICES	RESPONSES	
Yes	10.79%	26
No	89.21%	215
TOTAL		241

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

Answered: 247 Skipped: 155

ANSWER CHOICES	RESPONSES	
Not at all	68.42%	169
Somewhat	29.55%	73
Well	1.21%	3
Very well	0.81%	2
TOTAL		247

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

Answered: 247 Skipped: 155

ANSWER CHOICES	RESPONSES	
Yes	95.14%	235
No	4.86%	12
TOTAL		247

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

Answered: 247 Skipped: 155

ANSWER CHOICES	RESPONSES	
Yes	95.14%	235
No	4.86%	12
TOTAL		247

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

Answered: 244 Skipped: 158

ANSWER CHOICES	RESPONSES	
Yes	55.36%	62
No	44.64%	50
TOTAL		112

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

Answered: 245 Skipped: 157

ANSWER CHOICES	RESPONSES	
Yes	73.47%	180
No	13.47%	33
Not sure	13.06%	32
TOTAL		245

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

Answered: 245 Skipped: 157

ANSWER CHOICES	RESPONSES	
strongly disagree	2.86%	7
disagree	5.31%	13
neither agree or disagree	22.86%	56
agree	31.84%	78
strongly agree	37.14%	91
TOTAL		245

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

Answered: 240 Skipped: 162

ANSWER CHOICES	RESPONSES	
Not at all	0.42%	1
A little	25.42%	61
Very much	74.17%	178
TOTAL		240

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: 240 Skipped: 162

	1	2	3	4	5	6	TOTAL	SCORE
The name of the condition	10.53% 24	11.40% 26	14.04% 32	27.19% 62	27.63% 63	9.21% 21	228	3.22
The symptoms of the condition	1.29% 3	6.90% 16	15.52% 36	28.45% 66	40.09% 93	7.76% 18	232	2.78
Lack of understanding of the condition	26.92% 63	33.76% 79	18.80% 44	9.83% 23	4.27% 10	6.41% 15	234	4.50
The invisible nature of the condition	20.78% 48	21.21% 49	27.27% 63	19.05% 44	8.66% 20	3.03% 7	231	4.17
Misconceptions/myths about the condition	33.19% 77	23.71% 55	22.41% 52	11.21% 26	6.03% 14	3.45% 8	232	4.56
Because it is a brain disorder	7.52% 17	2.65% 6	1.77% 4	3.54% 8	12.83% 29	71.68% 162	226	1.73

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: 240 Skipped: 162

	1	2	3	4	5	6	7	TOTAL	SCORE
During education	7.44% 16	10.23% 22	9.77% 21	9.77% 21	11.63% 25	17.67% 38	33.49% 72	215	3.05
In employment	10.36% 23	18.92% 42	13.51% 30	13.06% 29	10.36% 23	18.02% 40	15.77% 35	222	3.89
In romantic relationships	6.28% 14	6.73% 15	14.35% 32	14.35% 32	11.66% 26	23.32% 52	23.32% 52	223	3.18
In friendships	6.87% 16	12.88% 30	21.89% 51	24.46% 57	20.17% 47	9.87% 23	3.86% 9	233	4.17
Interaction with family	5.63% 13	16.45% 38	15.15% 35	19.05% 44	20.78% 48	12.99% 30	9.96% 23	231	3.88
Interaction with medical professionals	56.36% 133	15.25% 36	9.75% 23	4.66% 11	4.66% 11	3.39% 8	5.93% 14	236	5.80
Interaction with the public	7.76% 18	22.41% 52	17.67% 41	15.52% 36	19.83% 46	11.64% 27	5.17% 12	232	4.27

Q45 Please rate the following

Answered: 239 Skipped: 163

	NEVER	RARELY	SOMETIMES	OFTEN	ALWAYS	TOTAL
Because of my illness, some people seemed uncomfortable with me.	4.18% 10	19.67% 47	46.86% 112	25.52% 61	3.77% 9	239
Because of my illness, some people avoided me.	5.88% 14	23.11% 55	40.76% 97	24.79% 59	5.46% 13	238
Because of my illness, I felt left out of things.	2.10% 5	5.46% 13	18.49% 44	47.90% 114	26.05% 62	238
Because of my illness, people were unkind to me.	12.18% 29	27.31% 65	36.13% 86	21.01% 50	3.36% 8	238
Because of my illness, people avoided looking at me.	41.84% 100	27.20% 65	22.18% 53	7.11% 17	1.67% 4	239
I felt embarrassed about my illness.	12.55% 30	17.15% 41	31.38% 75	26.78% 64	12.13% 29	239
Some people acted as though it was my fault I have this illness.	4.60% 11	12.13% 29	36.40% 87	35.98% 86	10.88% 26	239