



Bell's Palsy Survey
28 February – 30 March 2014

Worldwide Demographic
384 initial participants

About the survey

Facial Palsy UK conducted a survey during March 2014 to try and better understand the issues faced by people with Bell's palsy. Data was collected using an online survey which was advertised via UK facial palsy clinics, social media, our website and a Google Adwords campaign.

We asked people how health specialists referred to their condition to filter out answers not specifically related to Bell's palsy. Some people mistakenly think the names facial palsy and Bell's palsy are interchangeable. Facial palsy is a condition which has a number of different causes; Bell's palsy is just one of at least thirty different causes including tumours, congenital birth anomalies and more.

Responses

We collected a total of 431 responses, 384 of which were specific to Bell's palsy and the other 47 were filtered out for the purpose of this survey.

251 Bell's palsy specific responses were from the UK and 133 were from the rest of the world.






We included all geographical responses in this report to establish how Bell's palsy affects the individual.

Location (UK and other)

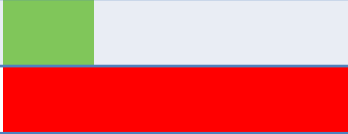
Response	Chart	Percentage	Count
East Anglia		4.7%	18
Greater London		6.2%	24
Midlands		10.2%	39
North East England		2.3%	9
North West England		6.0%	23
Northern Ireland		2.1%	8
Scotland		7.3%	28
South East England		13.8%	53
South West England		5.7%	22
Wales		2.3%	9
Yorkshire and the Humber		4.7%	18
Other, please specify...		34.6%	133
Total Responses			384

133 'other responses' were collected from outside the UK. USA (60%), Australia (8%), Canada (7%) and South Africa (5%) make up 80% of other responses. Denmark, Gibraltar, Hong Kong, India, Iraq, Ireland, Malaysia, Nigeria, Singapore, South Africa, the Netherlands and the United Arab Emirates account for the remaining 20%.

Age of Participants





Response	Chart	Percentage	Count
Under 13		1.0%	4
13-17		3.4%	13
18-24		7.6%	29
25-44		51.0%	196
45-54		19.5%	75
55-64		12.8%	49
65-74		4.7%	18
75-84		0.0%	0
85 and over		0.0%	0
Total Responses			384

Gender

Response	Chart	Percentage	Count
Male		19.8%	76
Female		80.2%	308
Total Responses			384

The large majority of respondents was female

Number of episodes of Bell's palsy

Response	Chart	Percentage	Count
This is the first time		82.3%	316
Twice		10.2%	39
Three times		4.4%	17
More than three times		3.1%	12
Total Responses			384

***17.7% of survey participants
have had a repeat episode of
Bell's palsy***

Any other health issues at the time of diagnosis?

Response	Percentage	Count
NO OTHER HEALTH PROBLEMS	54.2%	208
Pregnant	10.4%	40
Head cold/throat infection/sinus infection	7.8%	30
Cold sores (Herpes simplex virus)	5.7%	22
Shingles (Herpes varicella-zoster virus)	4.7%	18
Diabetes	4.7%	18
Ear infection	4.2%	16
Stress	1.8%	7
Chickenpox (Herpes varicella-zoster virus)	1.3%	5
Had just had a baby (post-partum)	1.3%	5
High blood pressure	1%	4
Pneumonia	0.8%	3
Dental problems	0.8%	3
Trauma	0.8%	3
Other health problems (less than 0.6% ea)	6.5%	25
(% refers to the proportion of people that reported each health problem)	Total Respondents	384



More about other health issues

Nearly half of all respondents had **no other health problems** at the time of diagnosis.

308 initial survey respondents were female, thus the actual percentage of women who were pregnant when diagnosed was 13%. This was the largest single health issue reported.

Head colds, sinus, throat and ear infections combined accounted for 12% of other health problems reported.

Have they had any ongoing problems caused by Bell's palsy?

Response	Chart	Percentage	Count
Yes		67.7%	260
No		32.3%	124
Total Responses			384

At this point we screened out anyone who had not had ongoing problems caused by Bell's palsy (32.3% of our sample)

What physical issues have they experienced?

Response	Percentage	Count
Face feeling tight or tense	79%	205
Unwanted facial movements/twitching	68%	176
Excessive watering of the eye	65%	170
Dry/sore eye	62%	160
Eating/drinking difficulties	60%	155
Inability/difficulty to blink or close eye for sleeping	57%	149
Difficulties with speech	57%	148
Inability/difficulty expressing emotions	52%	136
Drooling	52%	134
Altered taste	41%	107
Dry mouth	31%	80
Breathing difficulties	11%	28
Facial pain	10%	27
Other less common issues	10%	26
(% refers to the proportion of people that reported a symptom)	Total Respondents	260

Does the participant have one sided nasal obstruction?

Response	Percentage	Count
Yes	29.6%	77
No	70.4%	183
Total Responses		260

Is the nasal obstruction on the same side as the palsy?

Response	Percentage	Count
Yes	99%	76
No	1%	1
Total Responses		77

Was the nasal obstruction present before the palsy started?

Response	Percentage	Count
Yes	14%	11
No	86%	66
Total Responses		77

17% of the 384 participants of this survey have nasal obstruction which was not present before their Bell's palsy diagnosis

What impact, if any, has Bell's palsy had on the participant socially and/or psychologically?

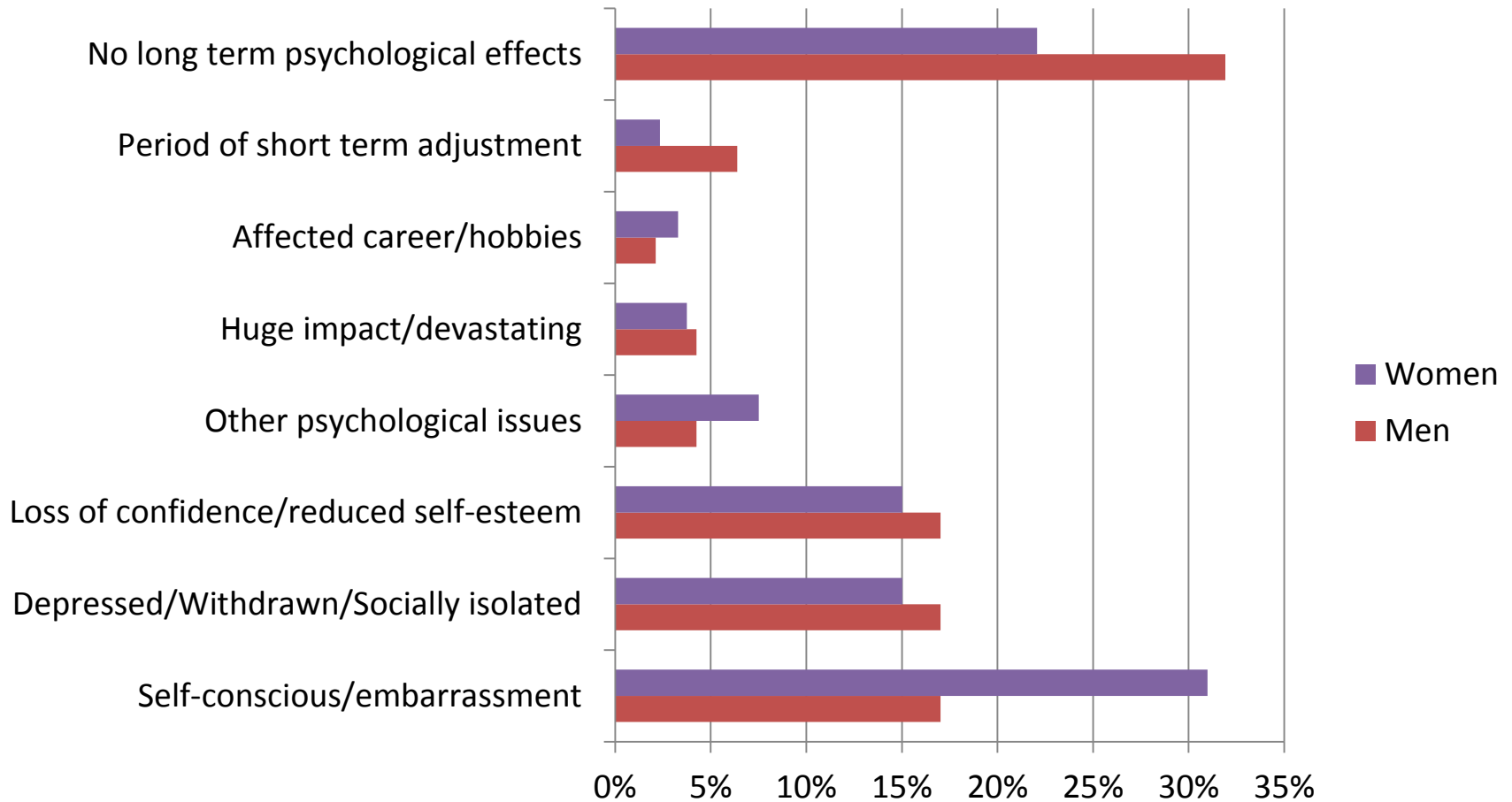
Responses were free form, we then grouped similar ones into categories.

Response	Percentages	Count
Self-conscious/embarrassment	28.5%	74
Declined to answer	20%	53
Depressed/Withdrawn/Socially isolated	15.5%	40
Loss of confidence/reduced self-esteem	15.5%	40
Other psychological issues	7%	18
Huge impact/devastating	4%	10
No real impact	3.5%	9
Affected career/hobbies	3%	8
Short term adjustment	3%	8
Total Respondents		260

More on the psychological and social effects

- 44% (nearly half of those with ongoing problems) reported problems with self-esteem, feelings of embarrassment and loss of confidence.
- One fifth said they have either become withdrawn, socially isolated or depressed, or feel completely devastated by the condition.
- Nearly a quarter reported no long-term psychological and social effects and 3% reported a period of short-term adjustment.
- 3% said that it affected their career; notable professions were acting, musician, jobs which involved computer screen work and jobs which involved speaking.

Social and psychological impact by gender



This is a Word Cloud created from the free form responses received in the previous question



A representative sample of responses about the physical effects

“My life divides into ‘before Bell’s’ and ‘after Bell’s’. Although people say it is barely noticeable, I am a changed person. I laugh less because it increases the lop-sidedness of my face and causes eye closure and pulsing in my ear. I suffer constant discomfort and pain from tightness, synkinesis and dry eye.”

“I have suffered from repeated drooping of the right side of my face, mainly the mouth and eye area. My face feels particularly heavy and uncomfortable. My tongue is also affected and feels heavy, it feels as if my face is falling in.”

“I am a Business Development Manager so talk for a living. Four months later I still can’t say my name properly!”

A representative sample of responses about psychological effects

“I don’t smile and laugh like I used to, I hate what I see in the mirror. If I could see myself when I talk, I would never talk.”

“Difficult to explain the impact to others who minimise it.”

“It has made me anxious and depressed. I don’t want to go out socially, especially if it means having a meal. I have lost all confidence in myself and I am also unable to do my job.”

“In the beginning it was terrible, I found it hard to deal with day to day life and lost my confidence which affected my work. It’s now been 4 years and I can finally talk about it!”

“I’m a positive person so it’s only made me stronger.”

Survey limitations

The respondents are not a true representation of the whole population as the survey was more widely advertised online rather than offline, for example, this approach to recruitment is likely to have influenced the age profile of respondents.

We cannot assume the gender bias shown in the survey is an accurate representation of the number of women compared to men affected by Bell's palsy, although medical research shows that pregnancy is a high risk factor.

People who are aware of our charity and have long term problems with Bell's palsy are more likely to have responded to the survey than those who have made a full recovery.

Conclusions

- There are a wide range of chronic physical symptoms
- Approximately one fifth of those surveyed said they have nasal obstruction after Bell's palsy although only approximated one tenth reported breathing difficulties.
- Approximately three quarters of participants with ongoing problems reported psychological issues.
- Overall men reported much fewer psychological issues, but slightly more men than women reported problems with depression and social isolation, loss of confidence and reduced self-esteem.