

# Accessing health care for facial palsy via the NHS and the impact of living with the condition

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Facial Palsy UK

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## What is facial palsy?

The term facial palsy generally refers to weakness of the facial muscles, mainly resulting from temporary or permanent damage to the facial nerve. When a facial nerve is either non-functioning or missing, the muscles in the face do not receive the necessary signals in order to function properly. This results in paralysis of the affected part of the face, which can affect movement of the eye(s) and/or the mouth, as well as other areas. There are different degrees of facial paralysis: sometimes only the lower half of the face is affected, sometimes one whole side of the face is affected and, in some cases, both sides of the face are affected.

## About the survey

This survey was developed to better understand how people access health care for facial palsy via the NHS and the impact of living with the condition. Responses were gathered through an online survey from people who have or have had facial palsy, are aged 18 and over, all live in the UK and are eligible for NHS health care. There were 421 respondents. Due to rounding, some percentages may not add up exactly to 100%.

## About Facial Palsy UK

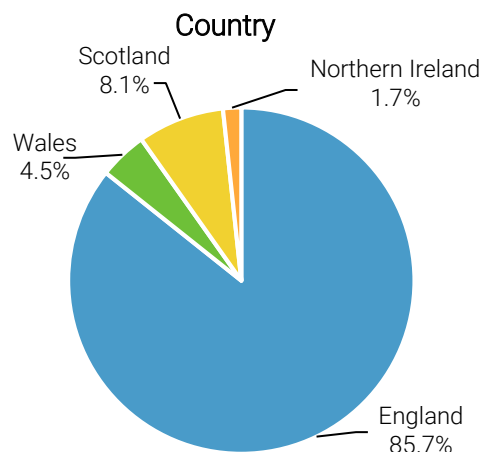
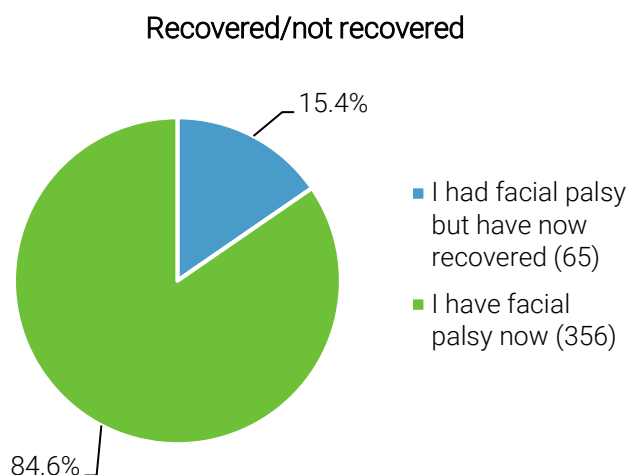
Facial Palsy UK is a charity registered in England & Wales (1148115) and Scotland (SC045086). Our mission is for every person in the UK affected by facial palsy to be given access to the best information, treatment and support available. Website: [www.facialpalsy.org.uk](http://www.facialpalsy.org.uk).

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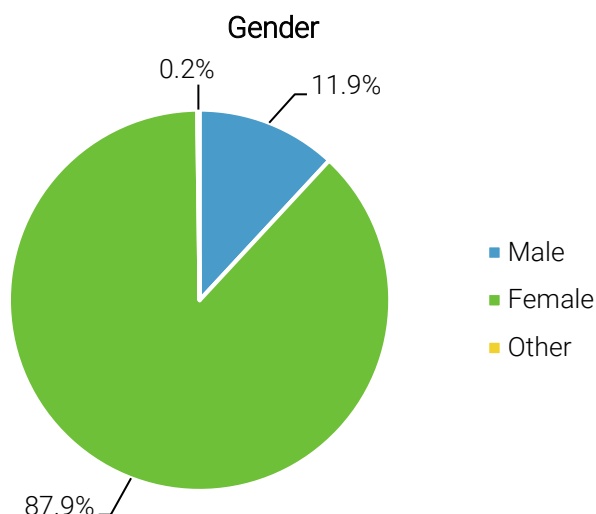
## Who completed the survey?

We wanted to know who was living with facial palsy now, who had recovered and demographics.



Age of respondents		
Age bracket	Percent	Number
18-24	4.8%	20
25-34	14.9%	63
35-44	23.9%	101
45-54	27.1%	114
55-64	20.9%	88
65-74	7.4%	31
75+	1.0%	4
Total respondents		421

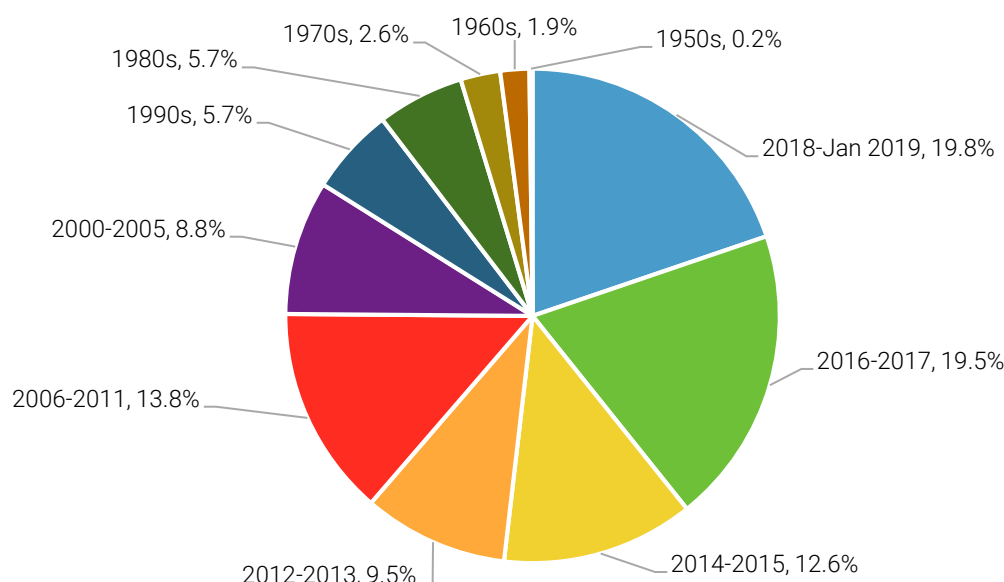
Respondents were asked how they would like their gender to be designated in our analysis with options for male, female and a freeform write-in box. 370 respondents identified as female, 50 as male and 1 requested to be identified as 'other'.



## Diagnosis

It was important to know when the facial palsy first occurred when completing the survey as some respondents were newly diagnosed, whilst others had been diagnosed much longer.

### When respondents were first diagnosed



- The earliest anyone was diagnosed was in the 1950s.
- 38.7% of respondents were diagnosed before the Facial Palsy UK charity launched in 2012.
- 41.6% were diagnosed between 2012 and 2017.
- 19.8% were diagnosed between Jan 2018 and Jan 2019; respondents told us whether they were diagnosed in Jan-Jul 2018 (10.2%), Aug-Oct 2018 (4.8%) or Nov 18-Jan 19 (4.8%).

### Age of respondent

We asked what age respondents were when first diagnosed with a form of facial palsy and stipulated this was not necessarily when the correct diagnosis of cause was made.

Age of respondent when first diagnosed with a form of facial palsy		
Age bracket	Percent	Responses
Diagnosed at birth or a few days after	4.3%	18
0-5	4.5%	19
6-11	1.0%	4
12-17	5.0%	21
18-24	8.3%	35
25-34	19.2%	81
35-44	19.0%	80
45-54	23.8%	100
55-64	12.6%	53
65-74	1.7%	7
75+	0.7%	3
Total respondents		421

## Initial diagnosis

The table below details the initial diagnosis given by the health care professional when the facial paralysis first occurred.

Diagnosis	Percent	Responses
Bell's palsy	59.9%	252
Bell's palsy in pregnancy/postnatal	6.9%	29
Acoustic neuroma/vestibular schwannoma	9.3%	39
Ramsay Hunt syndrome	4.3%	18
Cause as yet unknown	3.8%	16
Congenital facial palsy	2.6%	11
Birth trauma	2.4%	10
Stroke	1.9%	8
Surgical injury	1.2%	5
Ear infection	1.0%	4
Facial nerve neuroma	1.0%	4
Salivary gland/parotid tumour	1.0%	4
Guillain-Barré syndrome	0.7%	3
Head injury	0.7%	3
Moebius syndrome	0.7%	3
Virus	0.5%	2
Allergy	0.2%	1
Asymmetric crying facies	0.2%	1
Blocked saliva gland	0.2%	1
Cholesteatoma	0.2%	1
Craniectomy to remove epidermoid	0.2%	1
Labrynthitis	0.2%	1
Meningitis	0.2%	1
Migraines	0.2%	1
Squamous cell carcinoma	0.2%	1
Other tumour	0.2%	1
Total respondents		421

More than two thirds (66.8%) of those surveyed were given an initial diagnosis of Bell's palsy; 6.9% of those were diagnosed during pregnancy.

## Diagnosing health professional

We asked which health professional(s) made the diagnosis giving people the option to select more than one type of health professional if relevant (sometimes an initial diagnosis by a GP needs confirming by a consultant):

- 41.8% - GP/doctor
- 36.4% - Accident and Emergency department at hospital (33.3%) / NHS Walk-in centre (3.1%)
- 21.1% - Ear, Nose & Throat (ENT) consultant
- 20.2% - Neurologist

Others named as being involved in the diagnosis (in less than 5% of cases) were: other consultants/specialists, midwives, surgeons, dentist, dermatologist, practice nurse, radiologist, and a rare disease specialist.

## Misdiagnosis

We wanted to understand how many respondents had been incorrectly diagnosed.

### Respondents misdiagnosed

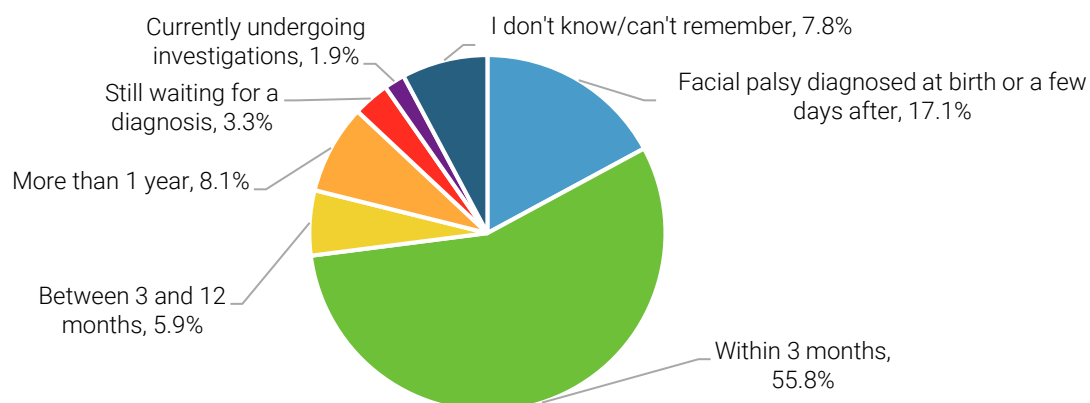
80 respondents overall (19%) had their diagnosis changed at a later date. Of those, the most commonly misdiagnosed causes were:

- Ramsay Hunt syndrome (51.3%)
- Bell's palsy (21.3%)
- Tumours (8.8%)

The following table shows what the diagnosis was changed to:

Diagnosis changed at a later date to	Percent	Responses
Ramsay Hunt syndrome	51.3%	41
Bell's palsy	21.3%	17
Facial nerve neuroma	5.0%	4
Cause now unknown	5.0%	4
Melkersson-Rosenthal syndrome	2.5%	2
Stroke	2.5%	2
Acoustic neuroma	1.3%	1
Congenital facial palsy	1.3%	1
Moebius syndrome	1.3%	1
Myasthenia gravis	1.3%	1
Sarcoidosis	1.3%	1
Surgical injury	1.3%	1
Tumour at birth	1.3%	1
Migrainous infarction	1.3%	1
Multiple sclerosis	1.3%	1
Osteosarcoma of temporal skull base	1.3%	1
<b>Total respondents where diagnosis changed at later date</b>		<b>80</b>

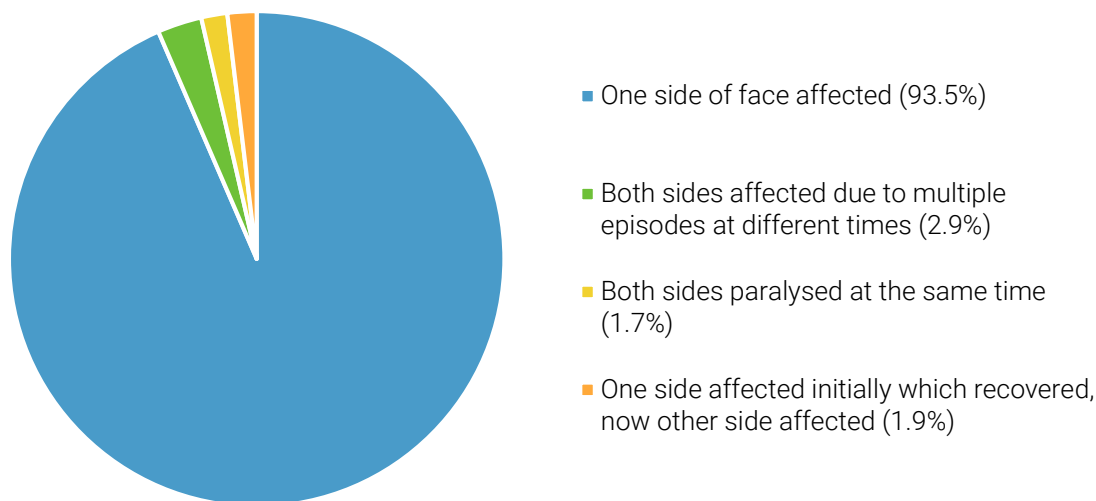
How soon was a correct diagnosis made by a health professional after the facial palsy began?



14% of respondents said it took three months or longer to receive a correct diagnosis.

## Physical issues

Understanding how the face was affected by the paralysis



We asked all 421 respondents about physical issues they encountered as a result of facial palsy now or in the past.

Physical issues experienced now or in the past as a result of facial palsy			Issues still ongoing	
Issue	%	Number	%	Number
Difficulty smiling in the expected way	95.5%	402	84.6%	356
Muscle tightness/tension	76.5%	322	65.1%	274
Uncontrolled facial movements/twitching, e.g. eye closes when I smile	75.3%	317	64.6%	272
Frequently watering eye	72.9%	307	59.6%	251
Dry and painful eye(s)	71.7%	302	52.3%	220
Difficulty speaking clearly	66.7%	281	36.8%	155
Tiredness	63.7%	268	49.9%	210
Numb feeling in the face	63.7%	268	40.1%	169
Facial/neck pain	62.0%	261	46.6%	196
Struggle to keep food in my mouth	58.2%	245	24.2%	102
Having to drink with a straw	58.0%	244	19.5%	82
Find it difficult to kiss someone	56.3%	237	37.8%	159
Difficulty chewing	56.3%	237	29.7%	125
Vision problems caused by the facial palsy	53.2%	224	37.1%	156
Retention of food in the cheek area	49.4%	208	31.4%	132
Hearing difficulties	47.5%	200	32.5%	137
Difficulty cleaning teeth	46.3%	195	21.9%	92
Altered taste	44.4%	187	23.3%	98
Altered sense of smell	27.3%	115	17.1%	72
Breathing difficulties	16.4%	69	12.4%	52
Tooth decay associated with facial palsy	16.2%	68	11.9%	50
Don't know/not sure	0.7%	3	0.7%	3
No longer experience any physical issues	NA	NA	1.4%	6

## Ongoing physical issues

Out of 21 different reported physical issues, the top five issues experienced were also the 'top five' ongoing issues:

- Difficulty smiling in the expected way (84.6%).
- Muscle tightness/tension (65.1%).
- Uncontrolled facial movements/twitching (64.6%).
- Frequently watering eye (59.6%).
- Dry/painful eye (52.3%).

The following functional problems are also an issue for many:

- More than a third have ongoing vision problems (37.1%).
- More than a third have difficulty speaking clearly (36.8%).
- A third have hearing difficulties (32.5%).

At least one in five respondents are still affected by eating and drinking difficulties:

- Struggling to chew (29.7%).
- To keep food in the mouth (24.2%).
- Have to drink with a straw (19.5%).
- Food retention in the cheek area (31.4%).
- Altered taste (23.3%).

Eating difficulties, decreased saliva production and difficulties brushing teeth can lead to an increase in tooth decay (11.9%).

Pain and tiredness are ongoing problems for almost half of respondents:

- Facial/neck pain (46.6%).
- Tiredness (49.9%).

More than a third still find it difficult to kiss someone (37.8%).

At the beginning of the survey, 65 respondents stated that they had had facial palsy but now recovered. Exploring just their responses: 9.2% said they no longer experience ANY physical issues, 58.5% were still suffering with uncontrolled facial movements and 46.2% were still experiencing muscle tightness/tension in the face; 41.5% said they still struggled with tiredness and 44.6% still experienced a frequently watering eye. It's clear that although some respondents considered themselves recovered from their initial episode of facial palsy, many continue to live with long term effects of the condition.

"There are lots of people in the medical profession that need to be aware of this condition. I was once turned away from donating blood just because my eye wouldn't open and that is so embarrassing." Survey respondent

"I had to leave my job as a trainer in the police force as I can no longer talk out loud to a training group in a classroom all day. The facial palsy has ruined my career and I strongly believe I wasn't given the best chance of recovery because I wasn't given antivirals when I should have been. Doctors need to have more information on facial palsy and what help is available to patients rather than treating them as a collection of parts." Survey respondent



## Psychological impact

### Understanding the psychological issues that arise with facial palsy

We asked all 421 respondents about psychological issues they encountered as a result of facial palsy now or in the past. 17 respondents who had not experienced psychological issues as a result of facial palsy were excluded from the 'ongoing' results.

Psychological issues experienced now or in the past as a result of facial palsy			Issues still ongoing	
Issue	%	Number	%	Number
Self-consciousness	91.2%	384	82.9%	335
Low self-esteem	76.0%	320	56.4%	228
Grief for way face looked before or way it would have looked if not paralysed	71.0%	299	58.7%	237
Anxiety	58.4%	246	46.8%	189
Depression	52.0%	219	34.7%	140
Loss of identity	42.5%	179	28.7%	116
Mood swings	38.2%	161	26.7%	108
Anger	36.1%	152	22.3%	90
Panic attacks	24.2%	102	18.1%	73
Not experienced any psychological issues as a result of facial palsy	4.0%	17	NA	NA
I've recovered from the psychological issues I experienced	NA	NA	6.2%	25

The top five psychological issues reported were: self-consciousness, low self-esteem, grief, anxiety and depression. These were also the top five ongoing issues.

- 91.2% of respondents reported they had felt self-conscious in the past due to having facial palsy and 82.9% stated this was still an ongoing issue.
- 76% had suffered with low self-esteem in connection with facial palsy and over half (56.4%) said this was an ongoing problem for them.
- 71% reported experiencing grief for the way the face looked before or should have looked if not paralysed and over half (58.7%) said this was an ongoing issue.
- More than half of those surveyed had suffered with anxiety and depression directly linked to having facial palsy. Anxiety was still a problem for almost half (46.8%) and depression was an ongoing problem for more than one in three (34.7%).
- A 2014 study<sup>1</sup> found that in England, overall, one in six adults (one in five women/one in eight men) met the criteria for a common mental disorder (such as anxiety and depression). More than one in three respondents with facial palsy (34.7%) stated they had ongoing problems with depression. Almost half (46.8%) reported problems with anxiety.
- Only 4% reported they had never had psychological issues as a result of facial palsy and 6.2% recovered from the psychological issues they had previously experienced.

Exploring responses of 65 participants who at the beginning of the survey stated they had recovered from facial palsy: 23.7% said they have recovered from psychological issues, 62.7% still struggled with self-consciousness, 49.2% had low self-esteem and 44.1% were struggling with anxiety. We know from our support enquiries that people are often anxious about facial palsy happening again.

<sup>1</sup> McManus S, Bebbington P, Jenkins R, Brugha T. (eds.) (2016). Mental health and wellbeing in England: Adult psychiatric morbidity survey 2014. Leeds: NHS digital.

## Living with facial palsy

### Social impact when facial palsy impacted lives the most

As part of the survey we wanted to explore the social impact of living with facial palsy. We asked respondents to think about **when facial palsy impacted their life the most** and consider whether they agreed or disagreed with the following statements.

Statement	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree	Not applicable	Total responses
I enjoy eating out in restaurants	45 (10.7%)	64 (15.2%)	52 (12.4%)	88 (20.9%)	159 (37.8%)	13 (3.1%)	421 (100%)
I have an active social life away from my home	37 (8.8%)	66 (15.7%)	15 (12.1%)	96 (22.8%)	158 (37.5%)	13 (3.1%)	421 (100%)
I use social media to keep in contact with friends and/or family	133 (31.6%)	126 (29.9%)	59 (14.0%)	40 (9.5%)	31 (7.4%)	32 (7.6%)	421 (100%)
I like being in photographs	5 (1.2%)	6 (1.4%)	25 (5.9%)	47 (11.2%)	335 (79.6%)	3 (0.7%)	421 (100%)
I enjoy attending special events such as weddings	18 (4.3%)	59 (14.0%)	50 (11.9%)	101 (24.0%)	184 (43.7%)	9 (2.1%)	421 (100%)
I feel comfortable speaking to new people	17 (4.0%)	47 (11.2%)	51 (12.1%)	124 (29.5%)	180 (42.8%)	2 (0.5%)	421 (100%)
New people know when I am happy or sad	24 (5.7%)	48 (11.4%)	130 (30.9%)	82 (19.5%)	119 (28.3%)	18 (4.3%)	421 (100%)
People assume I have difficulty understanding them	25 (5.9%)	77 (18.3%)	121 (28.7%)	72 (17.1%)	93 (22.1%)	33 (7.8%)	421 (100%)

"Whilst I completely underestimated the impact of my Bell's palsy and its associated symptoms (pain, etc.) my GP supported me at this time. I completely underestimated the psychological impact 'losing my smile' had. I didn't leave the house for six weeks." Survey respondent

"This is a lonely, frustrating condition, made all the worse when medical professionals can offer no help, advice or support as they don't know enough about it! Add that to the amount of staring and comments when out in public, it's a wonder people don't become a recluse." Survey respondent

## Social impact now

We then asked respondents to think about **how they feel now** about the same set of statements and whether they agreed or disagreed with them.

Statement	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree	Not applicable	Total responses
I enjoy eating out in restaurants	79 (18.8%)	108 (25.7%)	64 (15.2%)	74 (17.6%)	89 (21.1%)	7 (1.7%)	421 (100%)
I have an active social life away from my home	63 (15.0%)	104 (24.7%)	57 (13.5%)	84 (20.0%)	106 (25.2%)	7 (1.7%)	421 (100%)
I use social media to keep in contact with friends and/or family	149 (35.4%)	134 (31.8%)	60 (14.3%)	30 (7.1%)	28 (6.7%)	20 (4.8%)	421 (100%)
I like being in photographs	13 (3.1%)	29 (6.9%)	29 (6.9%)	80 (19.0%)	266 (63.2%)	4 (1.0%)	421 (100%)
I enjoy attending special events such as weddings	46 (10.9%)	88 (20.9%)	69 (16.4%)	95 (22.6%)	114 (27.1%)	9 (2.1%)	421 (100%)
I feel comfortable speaking to new people	35 (8.3%)	90 (21.4%)	65 (15.4%)	125 (29.7%)	103 (24.5%)	3 (0.7%)	421 (100%)
New people know when I am happy or sad	38 (9.0%)	60 (14.3%)	144 (34.2%)	94 (22.3%)	70 (16.6%)	15 (3.6%)	421 (100%)
People assume I have difficulty understanding them	17 (4.0%)	55 (13.1%)	139 (33.0%)	69 (16.4%)	109 (25.9%)	32 (7.6%)	421 (100%)

"The combination of one sided hearing loss, facial palsy and the sight issues caused by eye drops has made me feel removed from my environment and isolated. On the plus side I am now more understanding of shyness in others and the friends I have are incredibly supportive once they understand." Survey respondent.

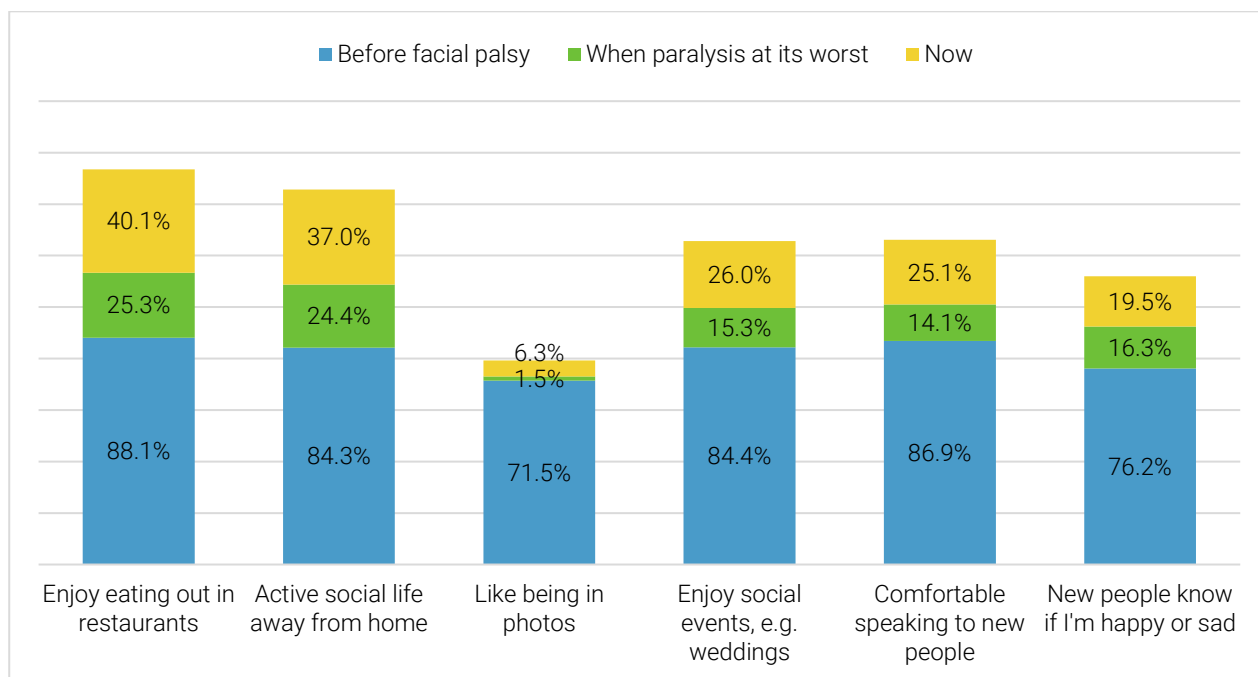
"I would LOVE to be able to smile again." Survey respondent.

"It is 8 years since the impact of Ramsay Hunt syndrome. The mental scars of the resulting depression, the loss of my career and my outgoing personality, will never totally recover. Only now am I receiving the specialist physiotherapy. It is a very lonely road." Survey respondent.

## How had life changed?

We also wanted to understand how life had changed for respondents after being diagnosed with facial palsy. We analysed 319 responses where people strongly agreed or somewhat agreed with each statement, these excluded:

- Those born with facial palsy.
- Those who couldn't remember a time before having facial palsy.
- Those who had recovered.



As shown in the chart above, for a proportion of respondents, their lives have changed considerably:

- Non-verbal communication is more difficult with new people.
- Communicating verbally with new people is challenging.
- Eating out in restaurants and general social activities away from home are less enjoyable.
- Social gatherings such as weddings have become less enjoyable.
- Enjoyment of being photographed has changed the most therefore it is unsurprising that so many people no longer enjoy events such as weddings.

## Improving the quality of life for people with facial palsy

All respondents (421) were asked what could improve their quality of life with reference to facial palsy:

- Routine access to health care for people with facial palsy (84.1%)
- More psychological support for people with facial palsy (83.8%)
- More awareness of facial palsy among the general public to improve attitudes and understanding (81%)

Respondents also suggested the following ways to improve their situation:

GPs and Emergency Care:

- More information from health professionals at point of diagnosis.
- More training for GPs who don't understand the long-term impact of facial palsy.
- Better understanding, diagnosis and treatment from health professionals.

Specialist health care:

- A complete overhaul of the system for treating facial palsy in the UK to create fairness and equal access to care, as in some areas it is considered cosmetic and funding denied.
- Better pathways of care to reduce likelihood of complications such as synkinesis.
- Improved access to specialists plus more specialist clinics and therapists trained in facial paralysis so people can access help locally.

Research:

- More research into causes, treatments and cures.
- More collaboration of expertise to avoid duplication of effort.

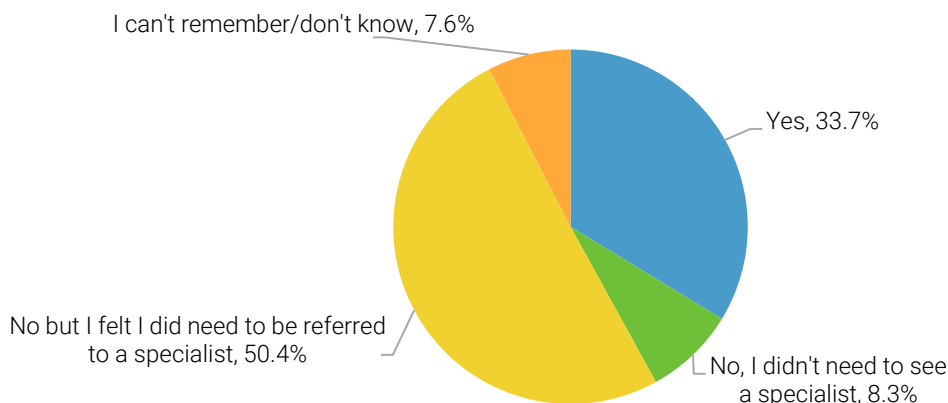
Other:

- Greater employer awareness.
- Ensure pregnant women are made aware of Bell's palsy at pre/post-natal appointments.
- More understanding among dentists.
- Access to complementary therapies, e.g. acupuncture.

## Accessing follow-up health care

We were interested in understanding treatment pathways and which specialists people with facial palsy are being referred to.

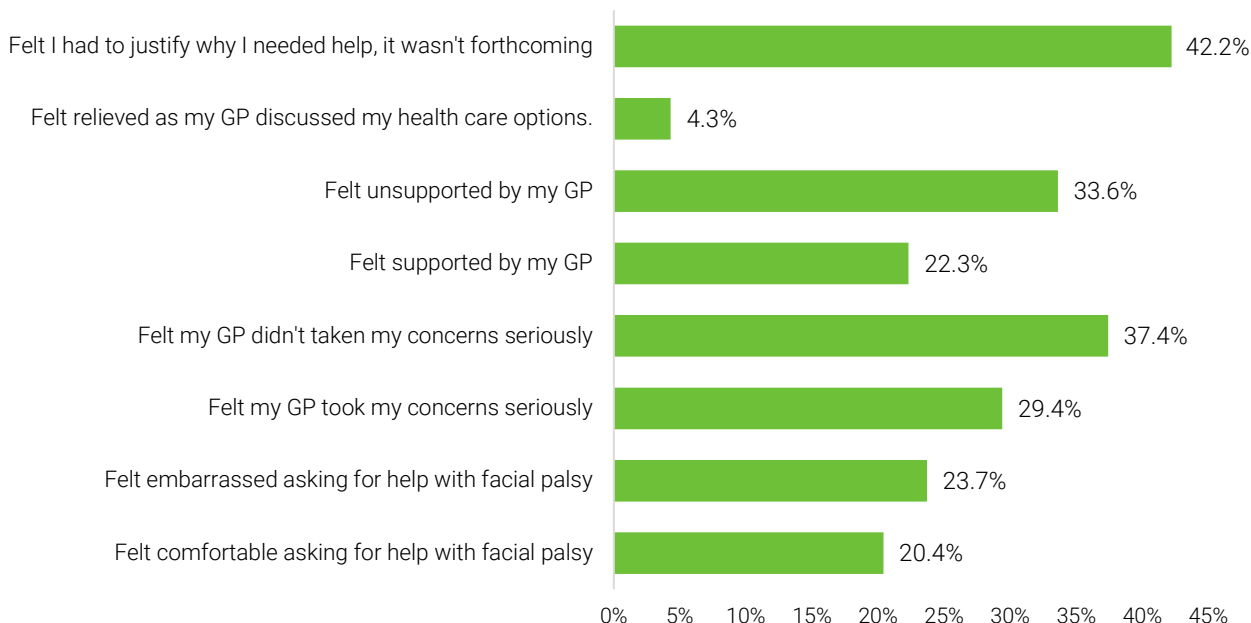
We asked the 421 respondents if their GP or hospital clinic immediately referred them to a specialist for further help when they were initially diagnosed with facial palsy.



Excluding those immediately referred to a specialist, we asked the remaining 279 respondents whether they needed to later request follow-up health care: 211 (76%) confirmed that they needed to request follow-up health care.

## Initial communications with the GP/Doctor

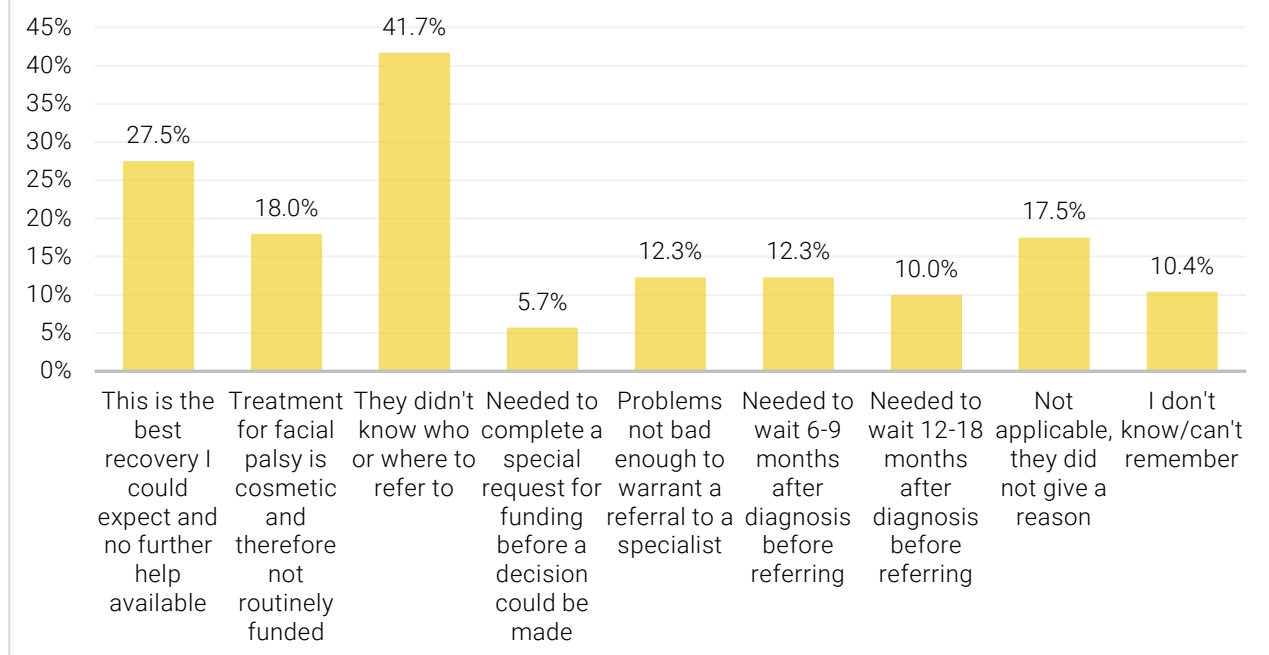
### How did people feel when approaching their GP?



Of the 211 respondents who requested follow-up health care, the biggest problem faced by more than a third (89 respondents) was feeling that they had to justify to their GP why they needed help.

*"I am under the impression that knowledge of this illness is limited and we are just expected to get on with our lives, in other words shut up and put up." Survey respondent.*

### Reasons given by GPs for not referring patients



For more than a third (88 respondents, 41.7%), they found that their GP did not know who or where to refer patients to. Similarly, 47 respondents were told they needed to wait either 6-9 (12.3%) or 12-18 (10%) months before they could be referred; 50 respondents were not referred immediately due to funding constraints (23.7%); and 58 were refused a referral and told they could not expect any further recovery (27.5%). 29 respondents (5.7%) were told they would need to complete a special request for funding in order to be considered for follow-up treatment for facial palsy.

These findings have illustrated that a significant barrier to receiving specialist health care for facial palsy is lack of awareness within the NHS about what is available.

"GPs should be better informed about the care available. I saw three GPs who didn't help at all, I had to research the care available and ask for a referral to a specialist I found. This took two years as I was dealing with a new baby and the psychological effects of Bell's palsy. I felt I had to just 'get on with it' but my family talked me into seeking further help as I had low self-esteem." Survey respondent.

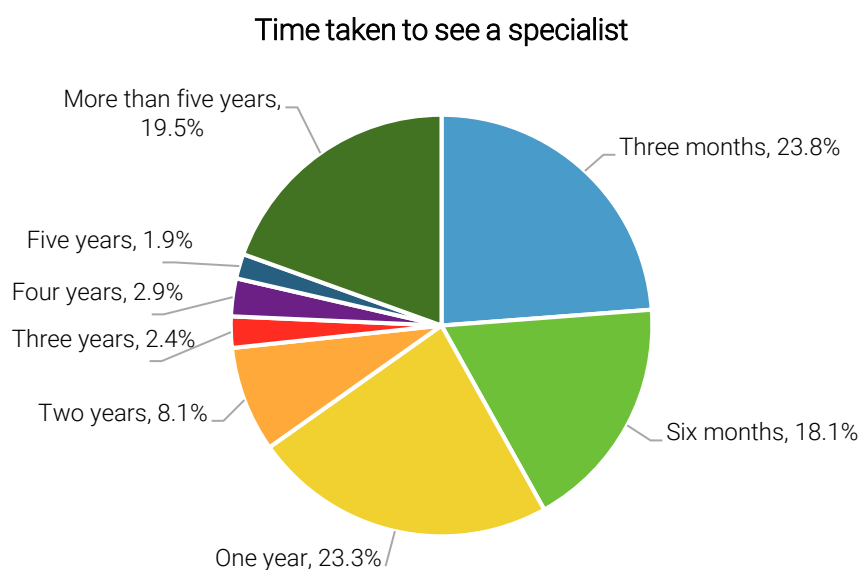
## Obtaining a referral to secondary care

Out of 211 respondents who were not given a routine referral:

- 34.8% were only given a referral after doing their own research and giving their GP the name of a specialist.
- 21.4% were referred only after several requests for help.
- 6.7% were only given a referral after changing their GP and 2.9% were referred after a successful request for funding.
- 9.5% are still waiting for a referral to a specialist and 1.4% had their funding request declined.

"When I saw my GP and handed her the contact details of a specialist NHS facial palsy team, it was dismissed and the information was given back to me. I then emailed the facial palsy clinic at my chosen hospital to try to refer myself, however I was advised I could not self-refer and to go back and request referral from my GP, who will not help with referral. I have therefore still not seen a specialist and have instead had to self-treat by reviewing the information on the Facial Palsy UK website and working with a private physiotherapist." Survey respondent.

We wanted to find out how long it took to see a specialist after respondents were initially diagnosed.



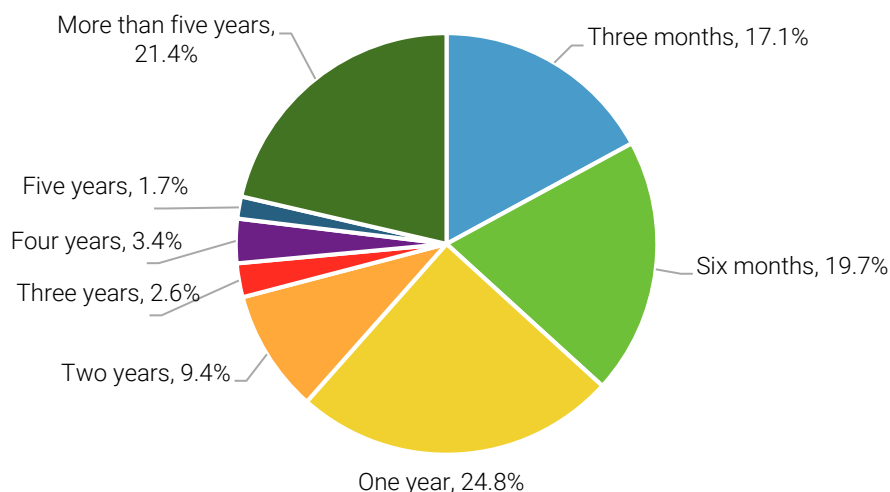
Of 211 respondents not routinely referred, one in five (21.4%) waited five years or more to see a specialist. Only 41.9% managed to see a specialist within a year. Over half (58.1%) were waiting a year or more to see a specialist.



## Bell's palsy and NICE guidelines

Current NICE guidelines\* state that someone with Bell's palsy should be referred to a facial nerve specialist if there is doubt about the diagnosis or a person with Bell's palsy has had incomplete recovery three months after the initial onset of symptoms. The following chart refers to 117 respondents who had a Bell's palsy diagnosis, stated that they were not automatically referred to a specialist, and have not recovered. We excluded people diagnosed August 2018 – January 2019, because they may have had Bell's palsy less than three months at the time of completing the survey.

Time taken to see a specialist - Bell's palsy



74 respondents (63.3%) waited a year or more for a referral. One in five (23.1%) waited five years or more.

"I acquired my facial palsy following surgery to remove a vestibular schwannoma. This had been badly spidtered around my facial nerve resulting in the nerve being stretched. My neurosurgeon was reluctant to diagnose the facial palsy as being permanent and I had to fight for over a year to get to see a consultant who was able to refer me to a specialist facial physio. The physio I was seeing at my local hospital had no specialist training in facial palsy treatment and was unable to help me. I repeatedly also asked to see a specialist clinical psychologist as I have severe depression. The hospital referred me to a psychologist who specialises in cancer related depression. I felt that he simply did not understand the impact that the facial palsy had upon my mental wellbeing." Survey respondent.

We asked respondents to briefly describe what issues they were asking for help with in relation to their facial palsy. The word cloud summarises these (210) responses:



\*<https://cks.nice.org.uk/bells-palsy/#scenario>

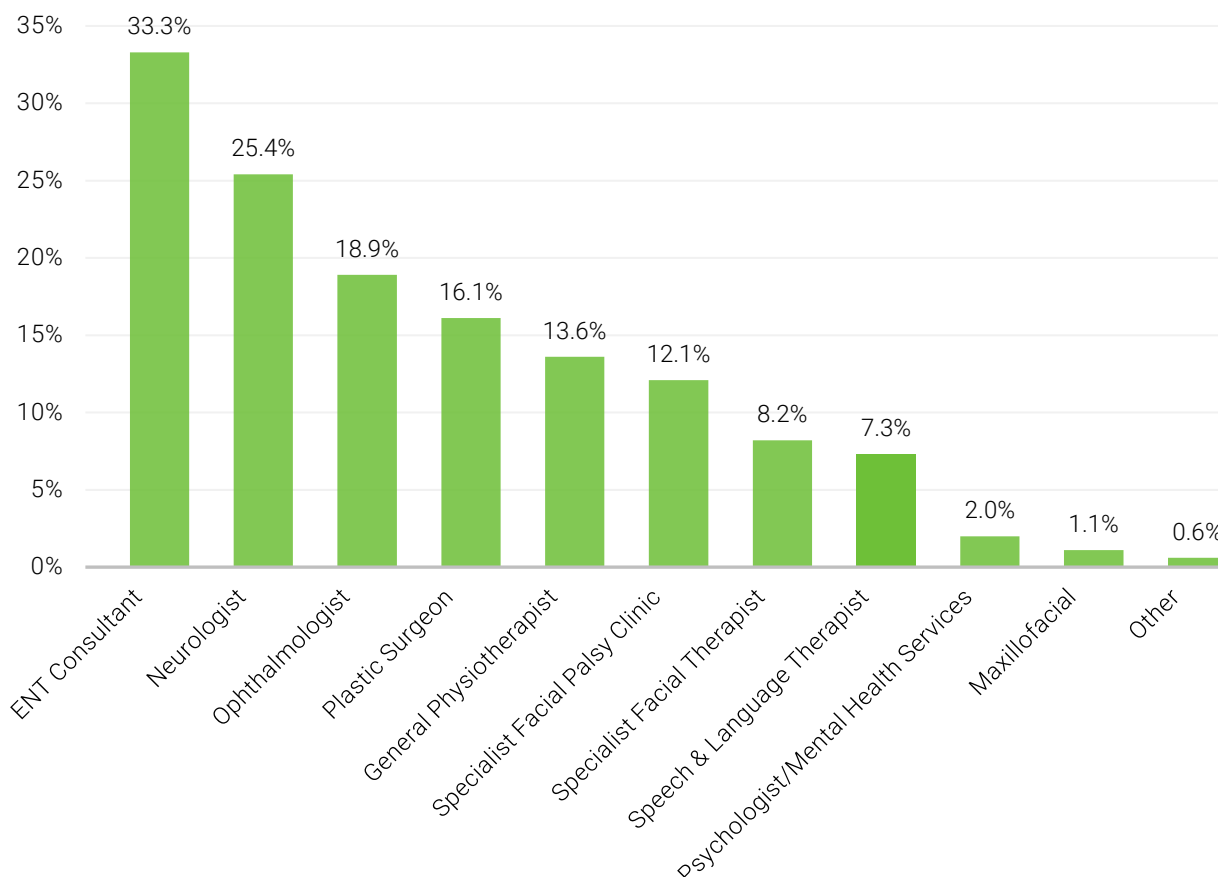


## Referrals

We were interested in understanding where 354 respondents who accessed secondary care were referred to for their initial appointment.

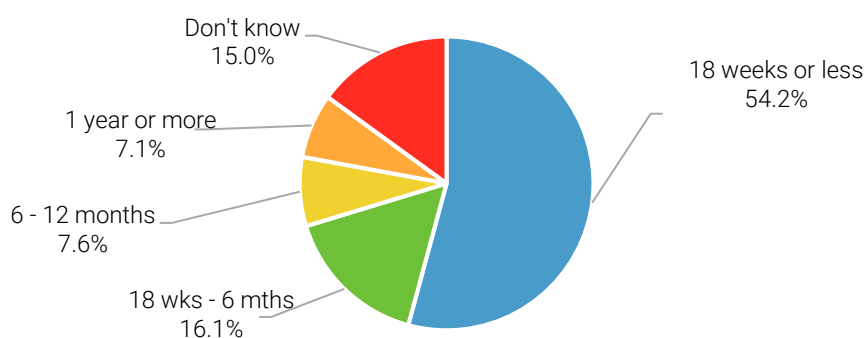
Over half (58.7%) were referred to either an Ear Nose & Throat (ENT) consultant or a Neurologist.

**Which clinics were patients referred to initially?**



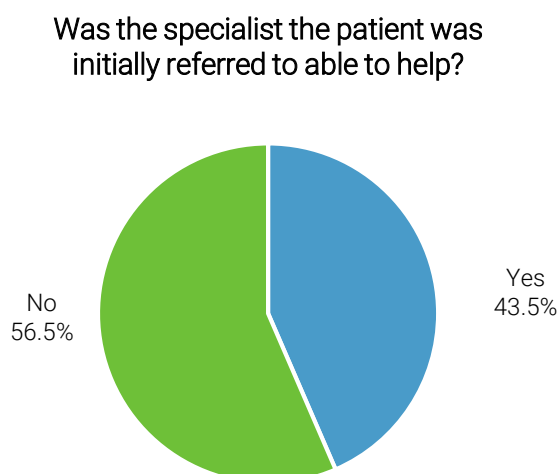
Approximately half (54.2%) had a wait time of 18 weeks or less. The maximum waiting time for non-urgent consultant-led treatment in the NHS is 18 weeks from the day the appointment was booked through the NHS e-Referral Service. 30.8% had to wait longer than 18 weeks.

**Length of time waiting for the appointment**



## Referral appointments (first referral)

Of 354 respondents accessing secondary care, 200 (56.5%) were referred to someone who could not help them for this first appointment.



The reasons for the specialist not being able to help varied:

What reasons were given for why the specialist could not help?	%	Number
They were not experienced in facial palsy and offered no onward referral to a specialist	36.5%	73
They didn't know of any surgeries or treatments that could help	34.5%	69
They wanted to refer patient to another hospital/consultant with more experience	12.5%	25
The facial palsy happened too long ago	11.0%	22
Surgery/treatment for facial palsy is cosmetic and not funded	10.0%	20
It was too early/it would get better in time	5.5%	11
Condition unlikely to improve	2.0%	4
Felt no further help was required	1.5%	3

"It hadn't been long enough since diagnosis to treat. It had been 4 months." Survey respondent.

"Said it would just take time to heal. They said nothing could be done for my initial bout which happened 14 years ago which has not healed properly." Survey respondent.

"She told me give it some time and it would correct itself. That was two years ago and I still have it." Survey respondent.

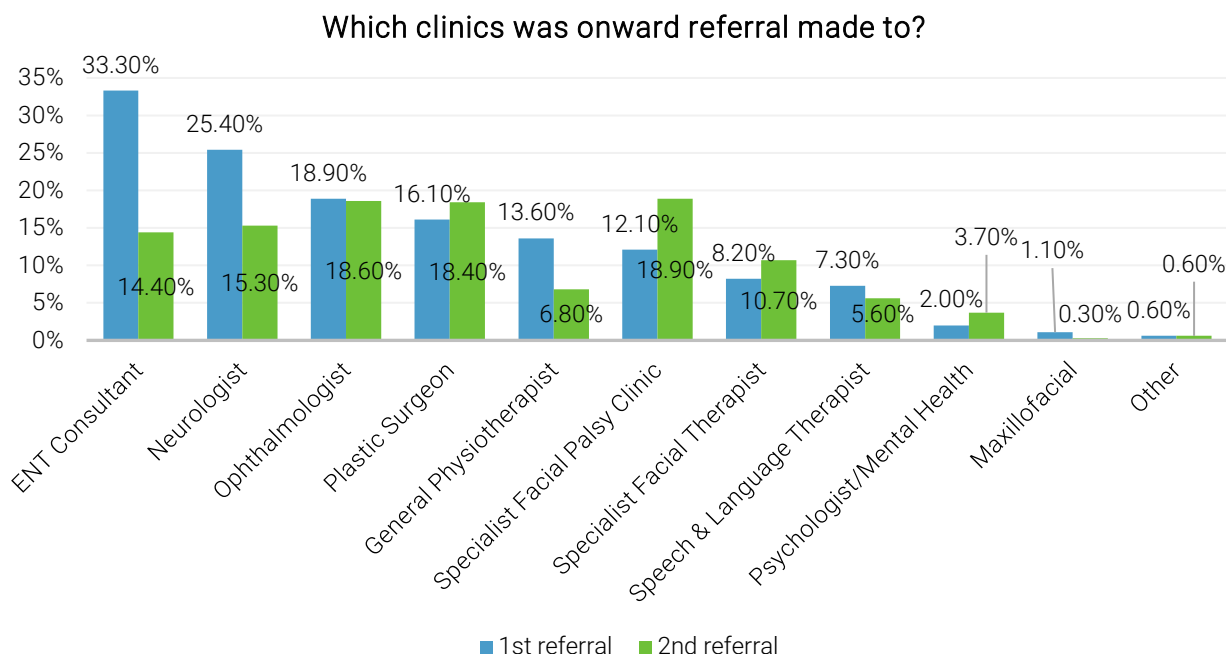
"They gave me a diagnosis and ruled out anything sinister with scans but said I had to wait to heal. No other help was offered." Survey respondent.

"They said it's an unknown condition, therefore couldn't treat it." Survey respondent.

"Reassuring to have ENT, eye and CT scan appointments to rule out other issues, but frustrating that no advice was offered on Bell's palsy at these appointments. Most useful advice came from GP." Survey respondent.

## Onward referrals

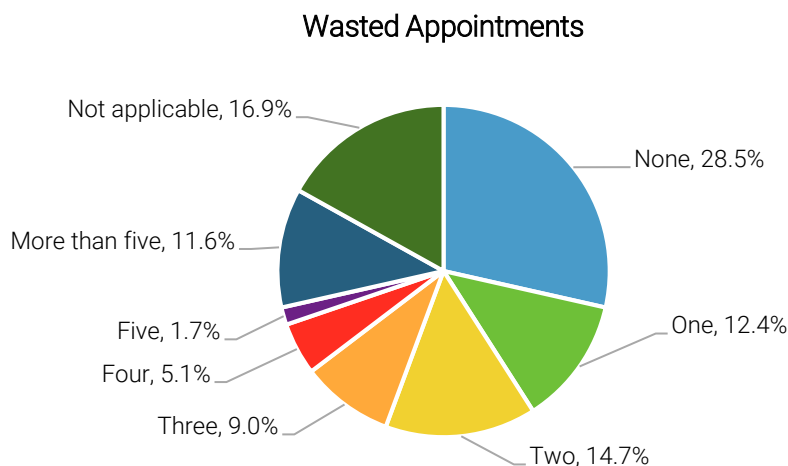
We wanted to understand where further referrals were made to after the initial referral.



The chart above shows where initial referrals were made to compared to where second referrals were made to. Less 'second' referrals were made to ENT and Neurology but more were made to plastic surgeons, specialist facial palsy clinics and specialist facial therapists. The number of general physiotherapy appointments also reduced for 'second' referrals. It's difficult to pin down exactly where first and second referrals come from. Many of the first referrals will be made by GPs and A&E but a few may be referrals via secondary care, for example when a patient has facial palsy due to tumour removal. Some ENT consultants but not all are facial palsy specialists.

## NHS waste: Wasted Appointments

We asked the 354 respondents who accessed follow-up health care to consider the NHS hospital appointments they attended with a consultant, surgeon or therapist. We asked these respondents how many they attended which they felt were of no benefit to them because the person was not an expert and therefore unable to help.



All types of facial palsy			Bell's palsy cases 2012-2018	
Number of appointments with non-expert in facial palsy	Percent	Responses	Percent	Responses
None – immediately referred to an expert	28.5%	101	22.8%	36
One	12.4%	44	13.9%	22
Two	14.7%	52	19.6%	31
Three	9.0%	32	8.2%	13
Four	5.1%	18	5.7%	9
Five	1.7%	6	2.5%	4
More than five	11.6%	41	10.8%	17
Not applicable	16.9%	60	16.5%	26
<b>Totals</b>	<b>100%</b>	<b>354</b>	<b>100%</b>	<b>158</b>

Just over a quarter (28.5%) got to the right place first time although 16.9% said the question was not applicable to them. 193 respondents (54.5%) said they had attended at least one appointment with either a consultant, surgeon or therapist which was of no benefit to them because the person was not an expert in facial palsy. This was more than half of those who accessed secondary care. For those not directly referred to a facial palsy specialist, there was an average of 2.5 wasted appointments.

We also reported on statistics for more recent cases of Bell's palsy from 2012-2018 showing an average of 2.8 wasted appointments. 60.7% had at least one appointment with a consultant, surgeon or therapist who couldn't help them because they weren't an expert.

### Feedback about NHS appointments:

"Attitude from neurologists and ENT consultants was 'we don't know what's caused it or what to do about it'. One actually said 'You should be grateful you were pretty to start with'". Survey respondent.

"If someone has no expertise in facial palsy, it is a waste of NHS resources to issue appointments." Survey respondent.

"Three ENT appointments, told to smile, told no improvement and left, each appointment lasted less than one minute." Survey respondent.

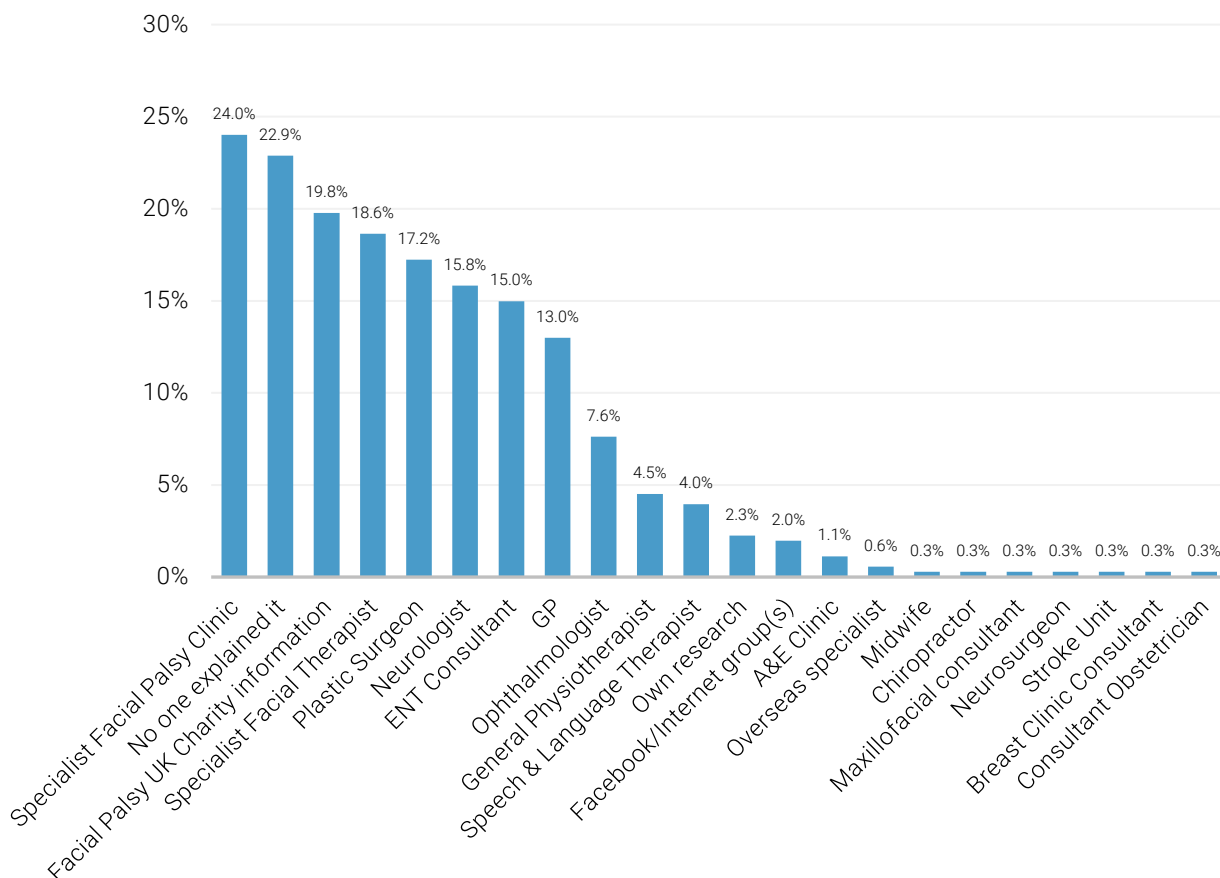
"The neurologist was dismissive - said I had little chance of recovery and he could do nothing for me." Survey respondent.

## Treatments, Therapies & Surgeries

### Information

Many people who contact Facial Palsy UK appear to have been given very little information about the condition. We wanted to understand who was being most helpful to respondents in terms of delivering good quality information about their facial palsy.

#### Who is explaining facial palsy fully and in a way you can understand?



81 respondents (22.9%) said that no one had explained their condition to them in a way they could understand.

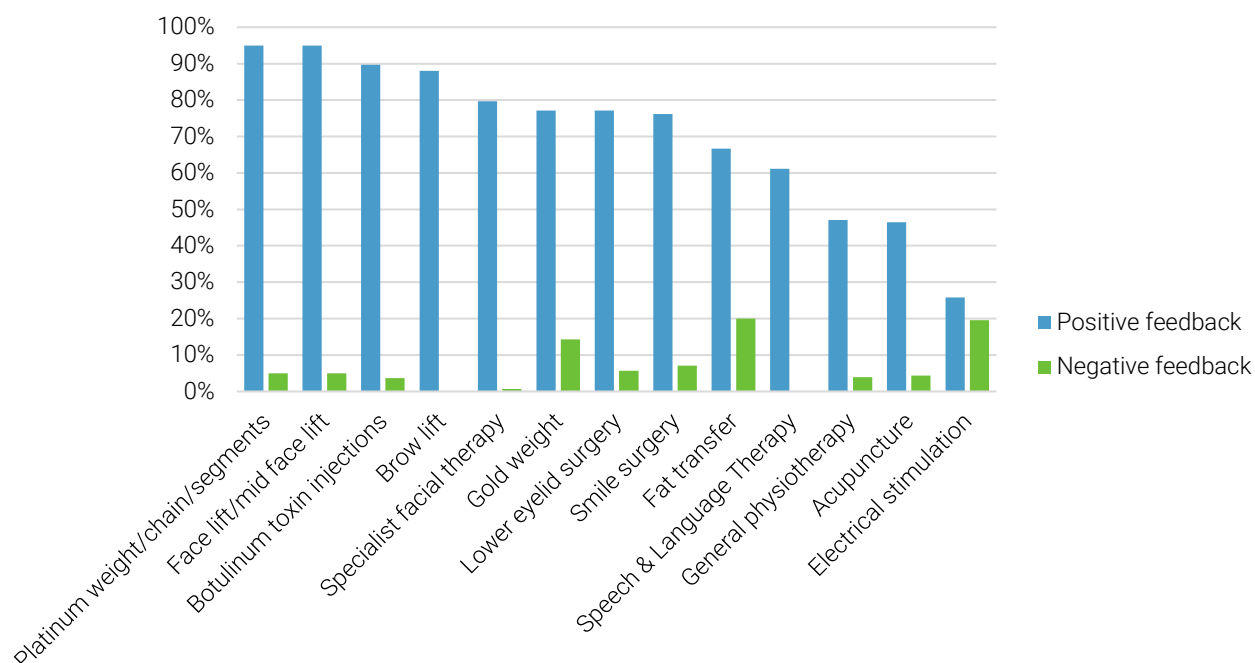
"A&E need to offer more help and explain the condition maybe at least send you home with information leaflets with support phone numbers." Survey respondent

"I feel I have had to research the Internet and social media to find out all about facial paralysis and Bell's palsy and Ramsey Hunt syndrome, as no professional has told me anything or pointed me in the right direction." Survey respondent.

## How helpful are health care options?

We were interested in which surgeries, treatments and therapies patients had accessed and how helpful or unhelpful they were. Facial Palsy UK does not necessarily endorse these.

The graph below details comparison of positive and negative feedback by 354 respondents who accessed follow-up care. Total figures are based on a percentage of who tried each health care option. However, support enquiries received by Facial Palsy UK demonstrate that many people are not able to access specialist health care. Less than half of respondents had accessed any of the different options. For example, specialist facial therapy was accessed by 41.8%, general physiotherapy by 44.4%.



### Positive feedback:

The options with the most positive outcomes were: Platinum weights in the eyelid (95%), face lift (95%), botulinum toxin injections (89.7%), brow lift (88%), specialist facial therapy (79.7%), gold weights in the eyelid (77.1%), lower eyelid surgery (77.1%) and smile surgery (76.2%). More than three quarters of respondents who tried these options found they helped.

Approximately two thirds said that fat transfer (66.7%) and speech and language therapy (61.1%) had helped. Approximately half said general physiotherapy (47.1%) and acupuncture (46.5%) had helped. A quarter (25.8%) said electrical stimulation had helped.

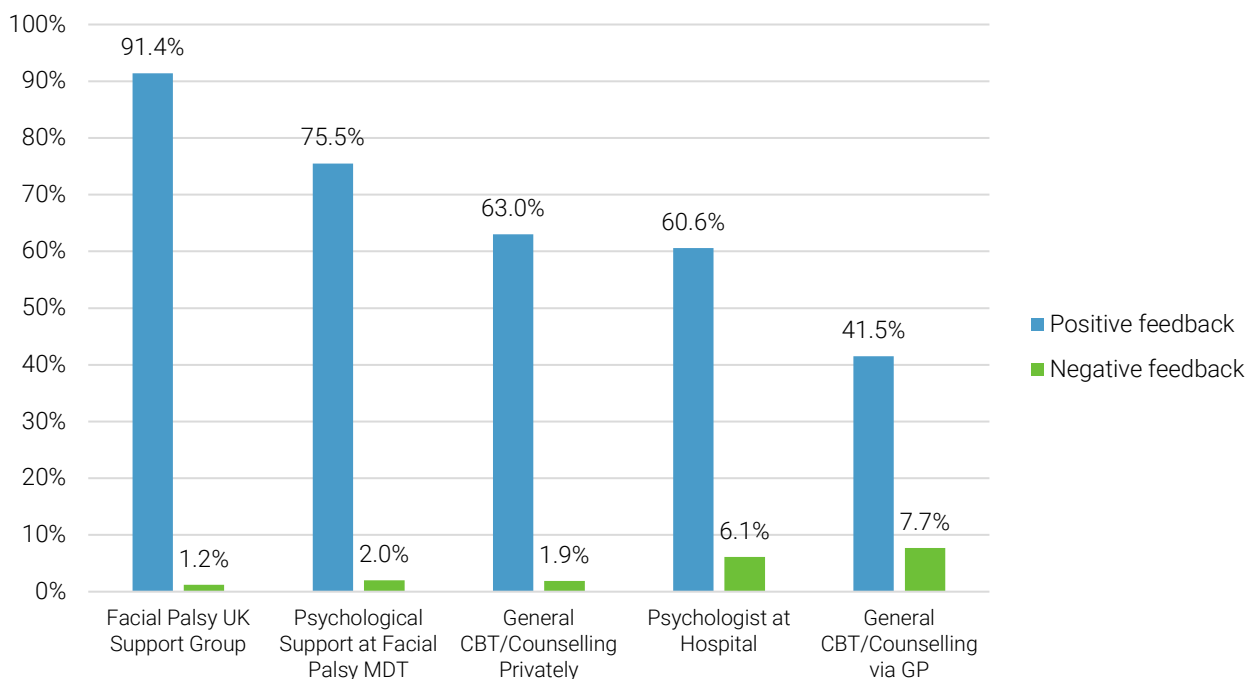
### Negative feedback:

Options receiving negative feedback of more than 10% were: fat transfer (20%), electrical stimulation therapy (19.6%) and gold weights in the eyelid (14.3%).

Small numbers of respondents also gave overall positive feedback about: selective neurectomy; platysma resection; upper eyelid lift/excess skin removal; temporary external eyelid weights; scleral contact lenses, and facial massage (as per Facial Palsy UK website videos). Some respondents had tried a mixture of homeopathic remedies, different types of massage therapies and osteopathic treatments with mixed results.

## Psychotherapies and peer support

We were interested in the helpfulness of psychotherapies, peer support and other support aids.



The graph above details comparison of positive and negative feedback by all 421 respondents. Total figures are based on a percentage of who tried each health care option.

The options with the most positive outcomes were: Facial Palsy UK Support Group (91.4%) and psychological support given as part of a facial palsy multidisciplinary team in secondary care (75.5%).

Almost two thirds who accessed CBT (Cognitive behavioural therapy) or counselling privately (63%) found it helpful. 60.6% of respondents who accessed psychotherapies via a hospital also found it helpful.

There were less respondents who found general CBT and counselling via their GP helpful (41.5%).

Respondents also told us about other ways they were getting support such as via Facebook groups, HealthUnlocked forum, friends, families and other charities (usually specific to their cause of facial palsy). It's clear that while some types of support suit some people, there isn't a 'one size fits all'.

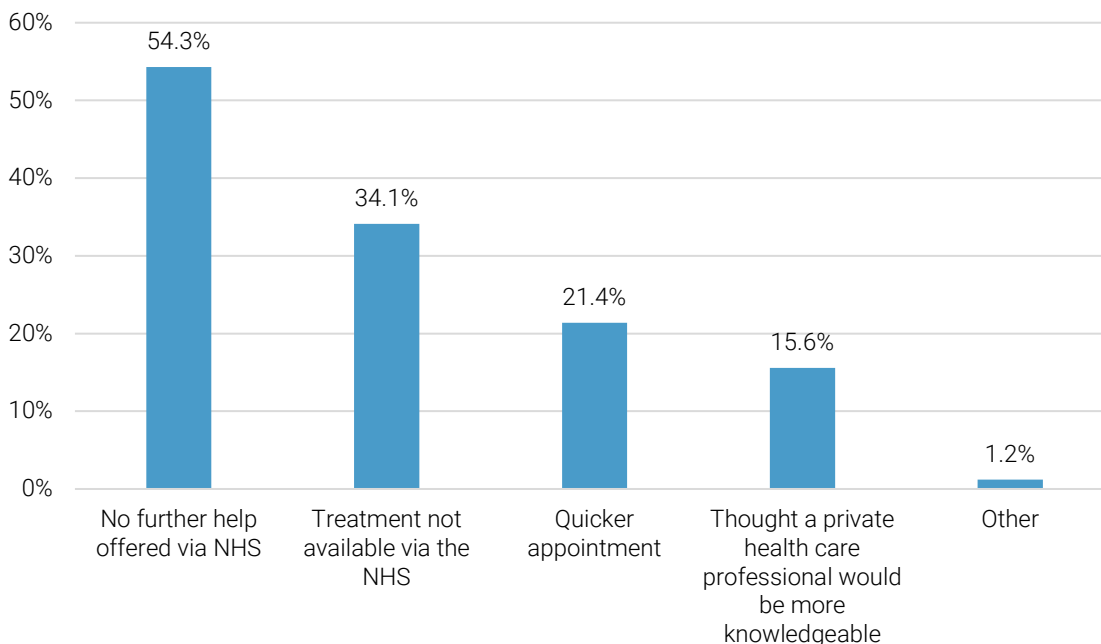
"I tried to tell my GP I was suffering from anxiety and feeling low. But no referral. I could only get reassurance online." Survey respondent.

"I have had no support from any health professional. I live in Wales and there is no physiotherapy available for Bell's or counselling. I had no support at all." Survey respondent.

"The facial palsy group was the only time I ever met anyone else with the same condition. It was a six hour round trip but worth it." Survey respondent.

## Finding help outside the NHS

Some respondents (169) also sought help privately, away from the NHS. We wanted to understand their reasons for doing so.



As per the table above:

- Over half (54.3%) of those who sought help privately did so because no further help was offered via the NHS.
- Included in the 'Other' category were respondents whose employer paid for health care and where a second opinion was sought privately.

The most commonly accessed private health care options were:

- Acupuncture – 100 respondents accessed, 56.0% found it helpful, 42.0% said it made no difference and 2.0% said it made things worse.
- Electrical stimulation therapy – 49 respondents accessed, 26.5% found it helpful, 47.0% said it made no difference and 26.5% said it made things worse.
- Specialist facial therapy – 43 respondents accessed, 72.1% found it helpful, 27.9% said it made no difference and nobody said it made things worse.
- General physiotherapy – 38 respondents accessed, 55.3% found it helpful, 42.1% said it made no difference and 2.6% said it made things worse.
- Botulinum toxin injections – 26 respondents accessed, 88.5% found them helpful, 11.5% said they made no difference and nobody said they made things worse.

In addition to the above, a very small number of respondents tried different surgeries, therapies, homeopathy and chiropractors.



## Key Focus for Facial Palsy UK

Finally we asked the 421 respondents to rank in order of importance the following statements to help guide our strategy as a charity:

1. Health professionals should be more aware of the impact of facial palsy (score 1010)
2. People with facial palsy should be able to routinely access treatments, surgeries and therapies that could help (score 1010)
3. The general public should be more aware of the impact of facial palsy (score 506)

## Summary

### Diagnosis

Key points:

- 91.6% of survey respondents were diagnosed between the ages of 18-64 – all working age with 65.9% of respondents 25-54 year olds.
- 41.8% were initially diagnosed by their GP and 36.4% by an Accident and Emergency Clinic or NHS Walk-in centre.
- Approximately one in five respondents (19%) were initially misdiagnosed. The most commonly misdiagnosed cause of facial palsy was Ramsay Hunt syndrome, this was frequently misdiagnosed as Bell's palsy.
- Respondents had 24 different causes of facial palsy with some still undiagnosed, the most common cause was Bell's palsy affecting 59.9% of the sample.

Actions:

- 1) Create a flow-chart for diagnosis for GPs and other generalist clinicians on Facial Palsy UK's new Health Professionals' website.
- 2) Awareness campaign.
- 3) Devise an educational module for GPs to access as Continuing Professional Development.

### Physical issues

Key points:

- There are 21 different physical issues associated with facial palsy.
- The physical issues affect four out of the five senses in the human body.
- A physical issue in one part of the face can impact in other ways, e.g. difficulty talking and muscle tightness/tension is tiring, a frequently watering or dry eye will affect vision.
- 14 physical issues have affected over half of the respondents.

Actions:

- 1) Highlight the ongoing physical issues of facial palsy from any cause.
- 2) Promote the need for more research into interventions that are most beneficial.
- 3) Advocate for patients who are struggling to access treatments that can help.

## Psychological impact

### Key points:

- The main three psychological issues that affected more than 70% of those surveyed were self-consciousness, low self-esteem and grief.
- Low self-esteem was the psychological issue most likely to improve with time with just over half still reporting ongoing issues in this area compared to three quarters affected initially.
- Self-consciousness was an ongoing problem for 82.9%.
- More than 50% of respondents suffer with anxiety and depression. This supports the need for patients being sent to specialist facial palsy MDTs (multidisciplinary teams) with psychologist support.

### Actions:

- 1) Use the media to highlight the psychosocial impact of facial palsy.
- 2) Advocate for patients who are struggling to access appropriate treatments.
- 3) Research into how physical treatments such as Botox and facial therapy improve psychological wellbeing.

## Living with facial palsy

### Key points:

- Facial therapists state that facial palsy is a communicative disability and this is reflected in the social difficulties reported. Non-verbal expression is important in everyday life and many people would have relied on using spontaneous non-verbal cues before they had facial palsy.
- Feelings about being in photographs changed dramatically, 71.5% said they liked being in photos before having facial palsy compared to 6.3% now.
- Approximately half of those surveyed no longer enjoy social events such as weddings, this may possibly be compounded by the expectation of being photographed.
- When asked what could improve their quality of life, 84.1% said routine access to health care, 83.8% said more psychological support for people with facial palsy and 81.0% said more awareness of facial palsy among the general public to improve attitudes and understanding.

### Actions:

- 1) Contact Facial Palsy UK's local MP and reach out to Secretary of State for Health and Social Care to explore how we can improve pathways of care. Submit petition to House of Commons to encourage greater awareness of the impact of facial palsy in the UK.
- 2) Create awareness videos featuring people with facial palsy talking about how their life has changed.
- 3) Art projects to raise awareness of the impact of facial palsy on everyday lives.

## Follow-up health care

### Key points:

- It is not reasonable to expect someone with Bell's palsy to be immediately referred to a specialist unless there are doubts over diagnosis, because approximately 71% of people diagnosed will make a full recovery. For those who don't make a good recovery, they often have to request follow-up care via their GP. 211 respondents needed to request follow-up health care. More than a third said their GP did not take their concerns seriously.

- 41.7% of the respondents who requested a referral found that their GP couldn't do so because they didn't know who or where to refer to. This was the top reason for non-referral. Changing things at the GP level would potentially have a big impact on reducing the number of appointments being made with a non-specialist in FP, as they are the ones who can dictate where that first referral is made.
- Other reasons for non-referral were due to GPs' lack of knowledge about facial palsy and the help available as well as funding pressures.
- Over half (58%) of the respondents referred to a specialist waited a year or more for the appointment. For those not destined to fully recover from an acquired facial palsy, many of the treatment options available to restore function in the patient's native facial muscles start to become less effective/ineffective at this time (depending on patient age, etc.). This means that, not only is the patient's long-term outcome impacted upon, the cost of any subsequent treatments (e.g. facial reanimation surgery) becomes significantly more expensive. Delays in seeing a facial palsy specialist cost the NHS money.

## Actions:

- 1) Recent Freedom of Information requests suggest that there is a postcode lottery in the UK regarding funding of facial palsy treatments. However, this survey has highlighted the bigger problem of GPs not knowing where to refer patients. A list of specialists will be made available on our Health Professionals' website for GPs to access.
- 2) Other educational content will be made available and adverts placed in GP publications when the website is launched.
- 3) Create a download with a picture of a face which shows all the physical and psychological symptoms of facial palsy. People can tick the issues relevant to them and give to their GP rather than having to educate the GP about facial palsy.
- 4) Invite GPs to support groups as part of continuing professional development\*.
- 5) Create a flowchart for the Facial Palsy UK patient website showing what they should expect in terms of follow-up care for Bell's palsy and Ramsay Hunt syndrome. This should reference NICE guidelines stating they need a referral within three months where there is incomplete recovery.
- 6) Second flowchart for other causes of facial palsy
- 7) Write an article for the British Journal of General Practice on Facial Palsy about the management of facial palsy at a primary care level, principally focusing on when, why and where to refer patients for secondary care.

\*<https://www.rcgp.org.uk/training-exams/practice/revalidation/mythbusters-appraisal-and-revalidation/continuing-professional-development.aspx>

## Referrals

### Key points:

- 58.7% of the 354 respondents who accessed follow-up care were seen by either ENT or neurology.
- 354 respondents were initially referred to a specialist but 200 (56.5%) said they were unable to help them. Only 25 people were referred to another consultant with more experience at this point.
- Out of 354 respondents who accessed follow-up health care, 54.5% said they'd attended at least one appointment with either a consultant, surgeon or therapist that was of no benefit to them because the health professional was not an expert in facial palsy. There was an average of 2.5 wasted appointments for all respondents. For recent Bell's palsy cases (2012-2018) there was an average of 2.8 wasted appointments.

Actions:

- 1) It is vitally important to establish how referral routes for facial palsy can be improved to ensure people are seen by the appropriate clinician first time. This must be a priority. Currently, well established referral criteria and pathways do not exist in the NHS. Getting the patient to the right place first time will reduce NHS costs (i.e. by avoiding inappropriate referrals) as well as maximising patients' quality of life. ENT and Neurology are two specialties which play an important role in arranging necessary investigations and ruling out more sinister causes of facial palsy. Because these investigations are not currently standardised, patients will clearly benefit from being referred to a centre which specialises in facial palsy. However, on contacting the Getting It Right First Time (GIRFT) review team (<https://gettingitrightfirsttime.co.uk/>), they confirmed that neither ENT nor Neurology have included facial palsy in their data packs. Also, if early intervention avoids the need for more complex procedures in the future, this will offer an additional cost saving to the NHS. Furthermore, early access to the correct allied health professionals at this stage (e.g. facial therapists and psychologists) can help to ensure more rapid return to work. We must look at 'best practice' sites and promote NHS pathways to improve care of patients with facial palsy. <https://www.england.nhs.uk/rightcare/what-is-nhs-rightcare/>.
- 2) Contact GIRFT with our findings and establish how to improve the quality of NHS care for this patient group by reducing unwarranted variations. Promote a rationalised approach to investigations for Bell's palsy and Ramsay Hunt syndrome.

## Treatments, Therapies & Surgeries

Key points:

- Feedback from survey respondents clearly shows they receive better information from experts in facial palsy, e.g. specialist facial palsy clinics.
- 22.9% of respondents who accessed secondary care said that no one had explained their condition to them in a way they could understand.
- Feedback shows that surgeries and facial therapy can be very helpful for people with facial palsy. However, just 41.8% had been seen by a specialist facial therapist.
- Peer support via Facial Palsy UK support groups, and psychotherapies as part of a Facial Palsy Specialist Multidisciplinary team were most beneficial, most likely because those involved in giving support are more familiar with the impact of facial palsy.
- Many people are having to try and find help privately. 40.1% of our total respondents had sought help privately.

Actions:

- 1) More research is needed to show the benefit of joined-up health care plans for people with facial palsy. Health care professionals need to understand the overall impact of this condition and that they need to treat people holistically.
- 2) More work needs to be done in challenging those who believe facial palsy is a cosmetic rather than medical condition.

## Survey limitations

Participants were recruited through Facial Palsy UK social media channels and newsletters, and were limited to those who had access online, so were self-selection. The survey is not nationally representative and so may not be representative of the general population. Responses reflect the contribution made by Facial Palsy UK to the health and wellbeing of these participants.