

Facial Palsy Awareness Week 2023: Treat Me Right

Survey about the pathways of care for people with facial palsy and where misdiagnosis and late treatment occurs.

Survey dates: 10 – 21 February 2023

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Facial Palsy UK

Executive Summary

This report summarises the results of a survey carried out by Facial Palsy UK ahead of Facial Palsy Awareness week, which runs from 1-7 March 2023. This year's theme is 'Treat Me Right'. The survey was conducted to understand the care of people with facial palsy (or facial paralysis) via the NHS. The survey's key findings are as follows:

- Issues exist around early and correct diagnosis ensuring optimum treatment for the best chance of a full recovery.
- GPs and Emergency Departments are still not providing adequate eye care advice with less than half of those surveyed receiving eye drops, tape or information about eye care.
- There are also problems with GPs not knowing where to refer to despite patients having residual, life-changing symptoms.
- The tendency to syphon referrals by default to Ear, Nose & Throat (ENT) should be examined, as an improved care pathway could save the NHS money and reduce distress caused to those patients referred to non-specialist teams. Many treatment options become more costly the longer a patient is left.
- Clarity is needed as to whether facial palsy should be an option on insurance forms.

A full summary of the findings and recommendations is at the end of the report.

What is facial palsy?

The term facial palsy (also known as facial paralysis) 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

Responses were gathered through an online survey from people who have or have had facial palsy, are aged 18 and over, and are eligible for NHS health care. We also collected responses from parents/carers of children (under 18s) with facial palsy eligible for NHS health care. There were 264 respondents between 10 – 21 February 2023, the timeline being agreed by the Board of Trustees. Due to rounding, some percentages may not add up exactly to 100%.

About Facial Palsy UK

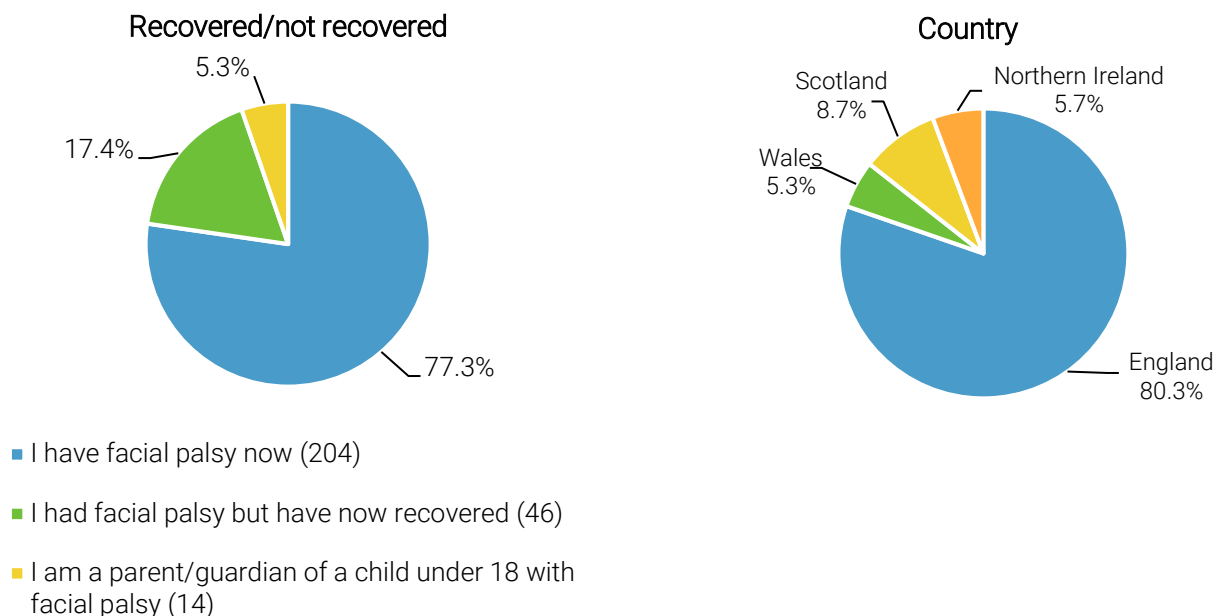
Facial Palsy UK is a charity registered in England & Wales (1148115) and Scotland (SC045086). Our mission is for every person in the UK affected by facial palsy to be given access to the best information, treatment and support available. Website: www.facialpalsy.org.uk.

Contents

Executive Summary.....	1
What is facial palsy?.....	2
About the survey	2
About Facial Palsy UK.....	2
Who completed the survey?.....	4
Timeline	5
Age	5
About the facial paralysis	6
Who do patients go to for initial help with facial palsy?	7
Diagnosis.....	8
Did the NHS need to rule out a suspected Stroke?.....	8
Were you or your child admitted to hospital? i.e. stayed in a hospital bed.....	9
Initial diagnosis.....	9
Length of time to reach initial diagnosis	10
Treatment.....	11
Misdiagnosis/changed diagnosis.....	13
Was the diagnosis (cause of facial palsy) later changed by a healthcare professional?.....	13
What was the diagnosis changed to?.....	13
Who changed the diagnosis?.....	14
How soon was the diagnosis corrected?	14
Was different medication/treatment given as a result of the change in diagnosis?	15
2018-2023 Sample	17
What was the diagnosis changed to? (2018-2023).....	17
Onward referrals.....	19
When diagnosed, did the GP or hospital clinic immediately refer to a specialist?	19
Requesting further follow-up treatment/care for facial palsy	19
Initial communications with the GP/Doctor	20
Obtaining a referral to secondary care.....	21
GP appointments	21
Length of time to see a specialist.....	21
Referrals	23
Onward referrals.....	25
NHS waste: Wasted Appointments	25
Treatments, Therapies & Surgeries	28
Travel Insurance.....	30
Full summary	31

Who completed the survey?

We asked people if they have facial palsy now or have had facial palsy but since recovered. We also asked if the respondent was a parent/carer of a minor with facial palsy, and general demographics. All respondents stated they live in the UK and are eligible for treatment via the NHS.



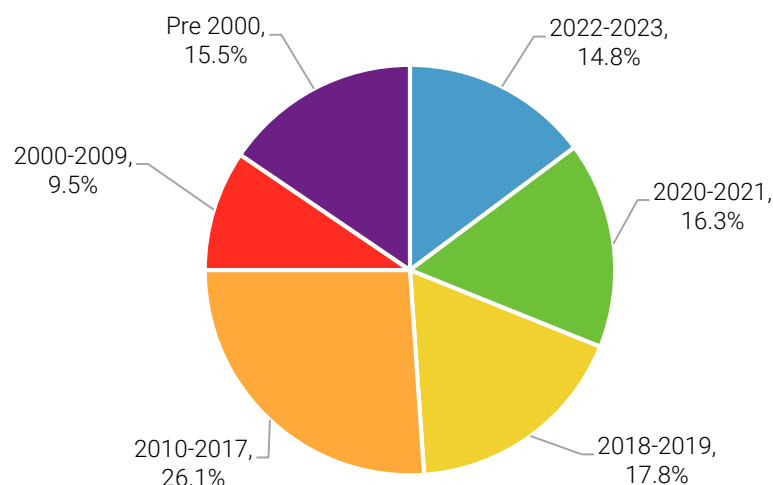
Age of person with facial palsy at time of diagnosis		
Age bracket	Percent	Number
Diagnosed at birth or a few days after	8.3%	22
0-5	3.8%	10
6-11	1.9%	5
12-17	3.0%	8
18-24	5.7%	15
25-34	18.9%	50
35-44	16.3%	43
45-54	18.2%	48
55-64	17.4%	46
65-74	6.4%	17
75+	0%	0
Total respondents		264

Respondents were asked how they would like us to designate their sex at birth or self-identified gender in our analysis with options for male (sex at birth), female (sex at birth) and identified gender with a freeform write-in box. 228 respondents were female, 35 were male, 1 identified as female and 1 person preferred not to answer.

Ethnic groups of respondents identified were White (93.9%), Mixed/Multiple ethnic groups (1.5%), Asian/Asian British (1.9%), Other (British Pakistani 0.4% and Latinoamerican (0.4%). 1.9% preferred not to answer.

Timeline

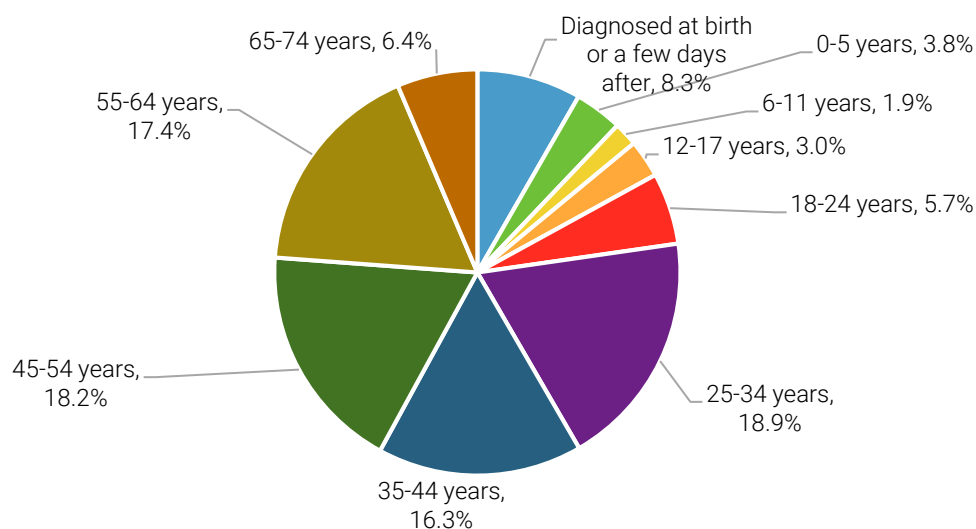
When did the facial palsy first occur?



Of those we surveyed, almost one third (31.1%) developed facial palsy between the start of the pandemic (2020) and now.

Age

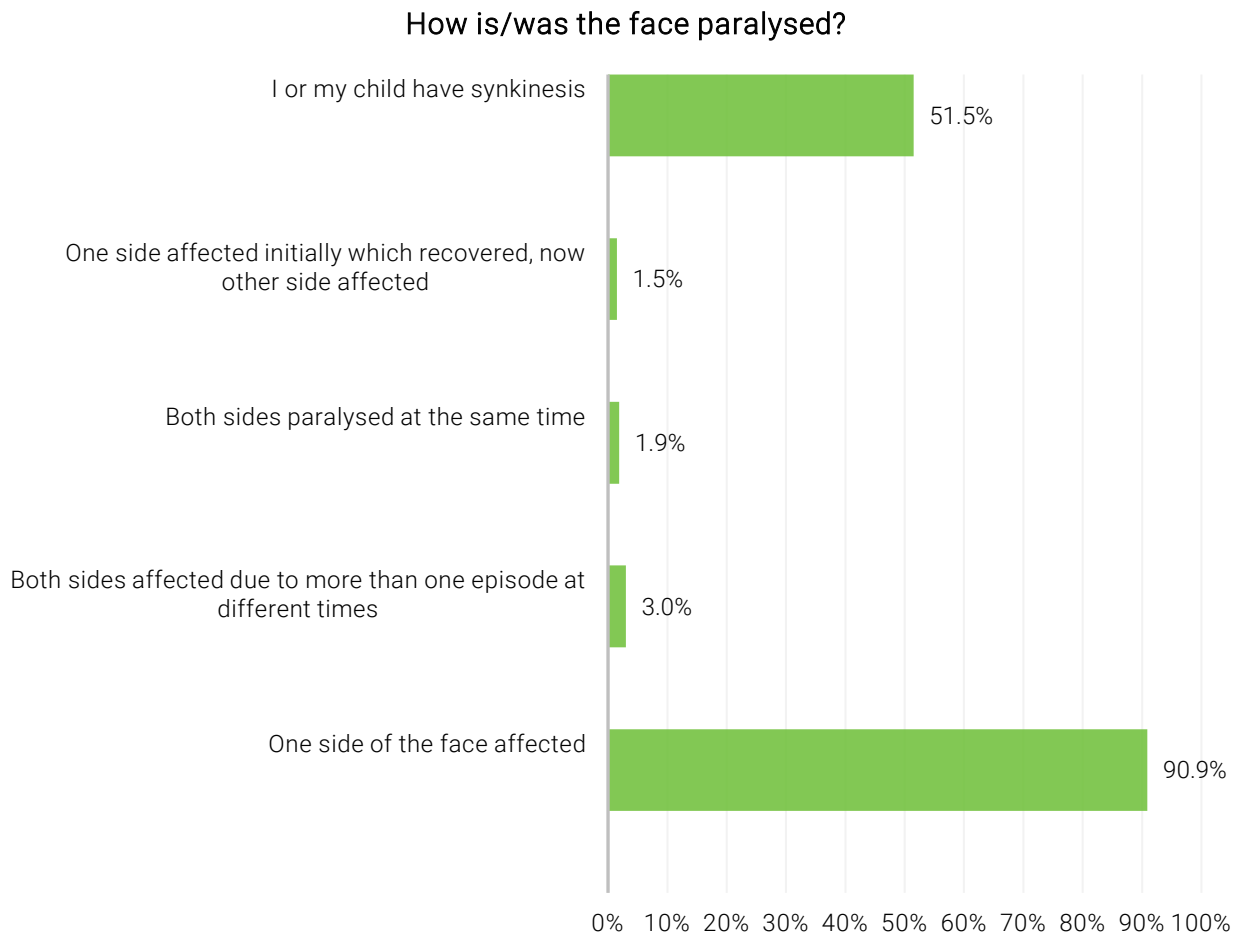
What age was the person when they were first diagnosed with facial palsy?



The majority of the respondents (70.8%) were in the 25-64 years age bracket.

About the facial paralysis

We wanted to understand how respondents' faces were affected.



The majority of respondents had one side of their face affected (90.1%) and over half (51.5%) were living with synkinesis.

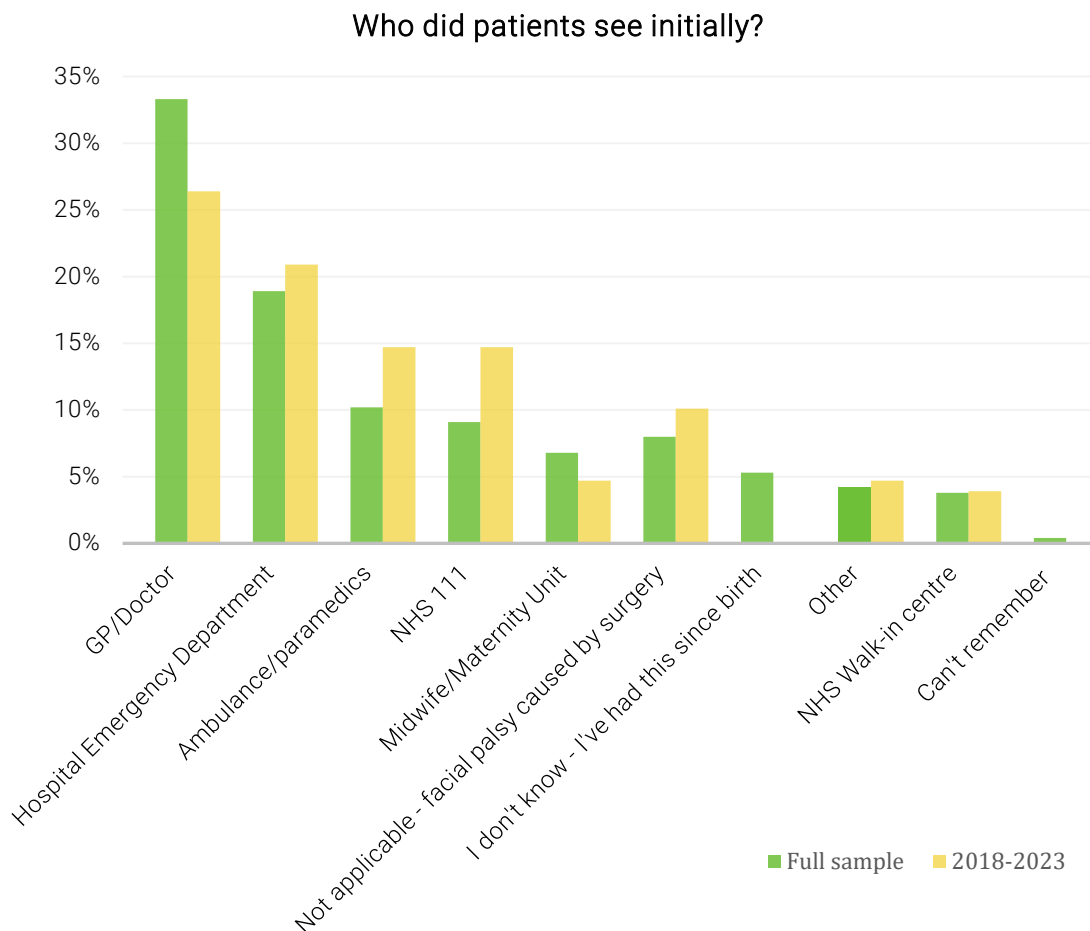
People living with synkinesis may have the following symptoms:

- Eye closes when smiling
- Cheek lifts when closing eyes
- Muscle tightness
- Facial twitching
- Eye waters on eating
- Facial pain
- Auditory synkinesis/noise
- Hearing distortion
- Asymmetrical smile
- Distress due to unwanted movement such as apparent winking (closing eye) on eating
- Functional difficulties such as food trapped in the cheek
- Difficulty speaking/being understood

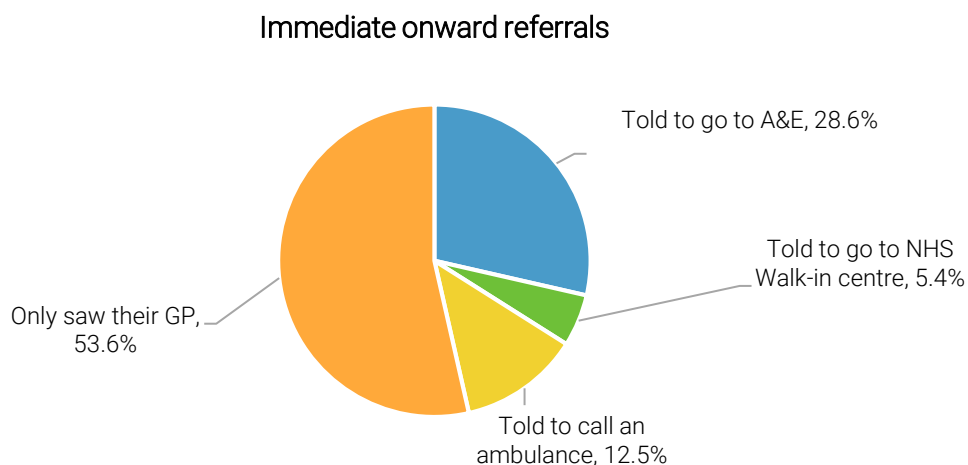
Please note the list above is not exhaustive.

Who do patients go to for initial help with facial palsy?

We asked who was the first person or team that the respondent sought help from when the facial paralysis was first noticed. We extracted data for years 2018-2023 to compare any differences.



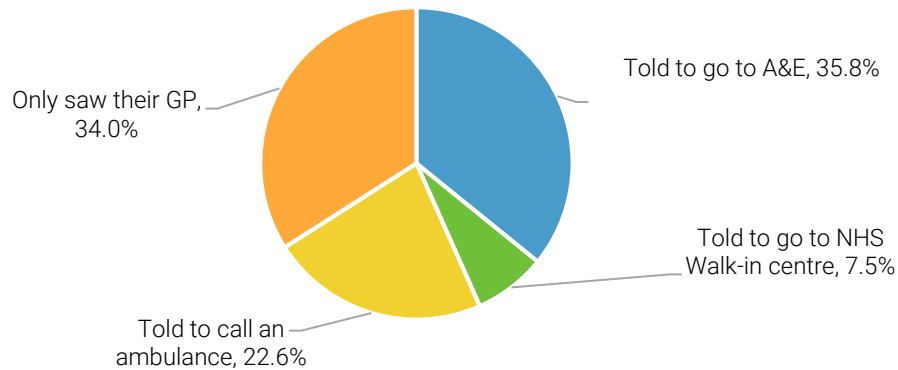
Out of 264 respondents, 112 (42.4%) initially contacted their GP (33.3%) or NHS 111 (9.1%). We asked these respondents if they were immediately referred elsewhere.



Of the 112 respondents, 60 (53.6%) were managed solely by their GP at this acute stage whereas 52 (46.5%) were immediately referred onwards to NHS emergency services. Of those who first contacted NHS 111, 45.8% were told to call an ambulance, 29.2% were told to go to A&E and 16.7% referred to their NHS walk-in centre. Just 8.3% contacting NHS 111 were seen by a GP.

Comparing the situation for those diagnosed between 2018 through until February 2023, there was a marked difference in how patients were managed. A caveat is that some people more newly diagnosed may remember more clearly how their diagnostic journey was managed. The responses may also have been affected by difficulties in seeing a GP during the COVID-19 pandemic.

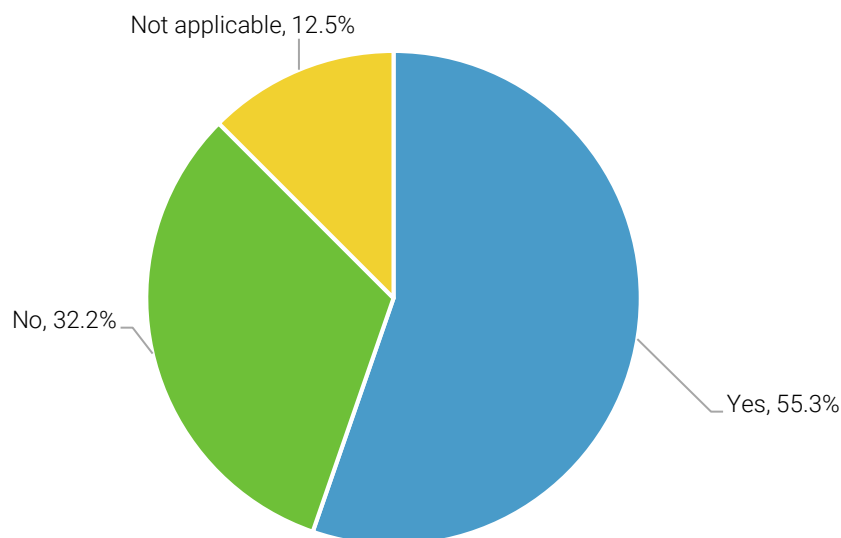
Immediate onward referrals 2018-2023



Diagnosis

We explored the steps taken by the NHS to arrive at a diagnosis and also whether this involved a stay in hospital. Of the 264 respondents, more than half were screened to see if the cause was stroke.

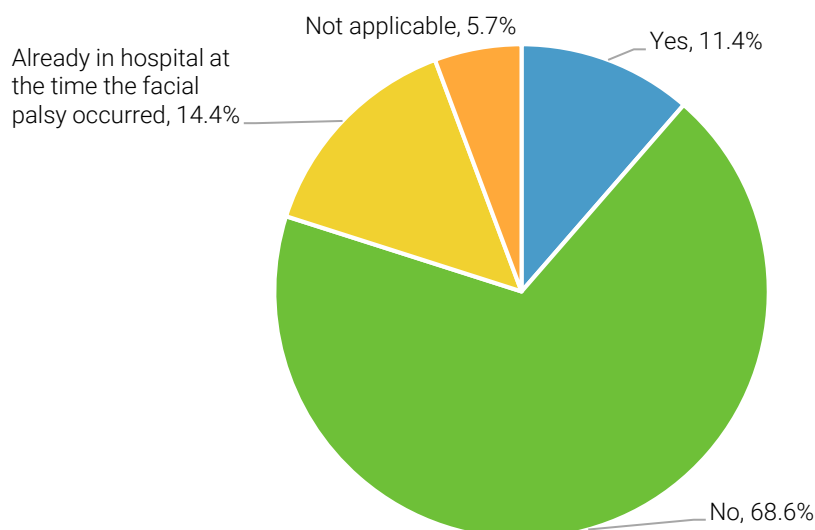
Did the NHS need to rule out a suspected stroke?



Of the 129 respondents who developed facial palsy between 2018 and 2023, 71.3% were screened for stroke. Again, this may be because people can remember better the tests that were carried out.

Were you or your child admitted to hospital? i.e. stayed in a hospital bed.

Of the 264 respondents, one tenth stayed in a hospital bed and 14.4% were already in hospital when the facial palsy occurred.



In comparison with 2018-2023, similarly around a tenth (10.1%) were admitted into hospital and 14.0% were already in hospital at the time the facial palsy occurred.

During the initial stages of diagnosis, of the 264 respondents, 34% were given an MRI scan and 14.8% a CT scan. These figures are similar to 2018-2023 with 35.7% receiving an MRI scan and 15.5% receiving a CT scan.

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	64.8%	171
Surgical injury	6.1%	16
Ramsay Hunt syndrome	5.3%	14
Tumour during adulthood	5.3%	14
Birth trauma	4.9%	13
Cause unknown	4.2%	11
Congenital facial palsy	3.8%	10
Stroke	1.9%	5
Guillain-Barré syndrome	0.8%	2
Head injury	0.8%	2
Tumour at birth	0.8%	2
Tumour during childhood	0.8%	2
Moebius syndrome	0.4%	1
Giant cell arteritis	0.4%	1
Total respondents		264

Length of time to reach initial diagnosis

As medications for conditions such as Bell's palsy and Ramsay Hunt syndrome should optimally be given as soon as possible (within 72 hours), we wanted to understand how long it took for patients to be diagnosed. We compared the whole sample to just those diagnosed in 2018-2023 as shown in the table below. Much work has been done by Facial Palsy UK since early 2018 to raise awareness about Ramsay Hunt syndrome and the differing symptoms, as well as treatment required, compared to Bell's palsy.

The recommended treatment for Bell's palsy is steroids within 72 hours, and for Ramsay Hunt syndrome is steroids and antivirals within 72 hours¹.

How long did it take your healthcare provider to reach an initial diagnosis?	Whole sample		2018-2023	
	Percent	Responses	Percent	Responses
Less than 12 hours	62.5%	165	71.3%	92
13-24 hours	8.7%	23	5.4%	7
Two days	4.5%	12	3.9%	5
Three days	3.0%	8	2.3%	3
Four days	0.8%	2	1.6%	2
Five days	0.4%	1	0.8%	1
Six days	1.1%	3	0.8%	1
Seven days	0.8%	2	0.8%	1
Longer than seven days	8.0%	21	6.2%	8
Other	10.2%	27	7.0%	9
Total respondents		264		129

More about those diagnosed within 72 hours

78.7% of those surveyed (208 respondents) were given an initial diagnosis within 72 hours. This figure has slightly improved for 2018-2023 (82.9%).

Considering the 208 people who were diagnosed within 72 hours, over half (119 respondents) of those were screened for stroke with 47 people (39.5%) having an MRI scan and 23 (19.3%) a CT scan. Comparing to the 78 respondents screened for stroke between 2018-2023, 30 (38.5%) were given an MRI scan and 17 (21.8%) were given a CT scan.

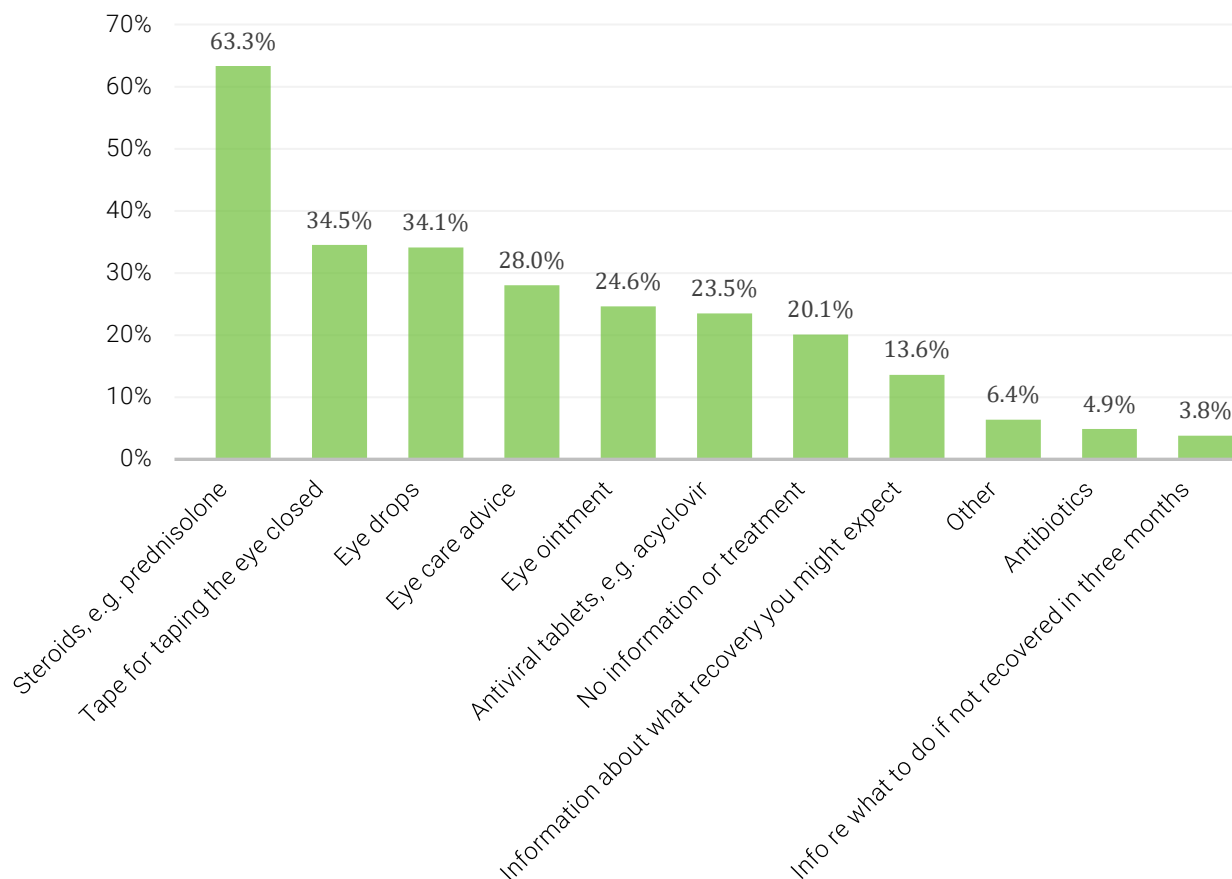
Of the whole sample screened for stroke, 107 respondents (89.9%) were diagnosed with Bell's palsy, 7 (5.9%) with Ramsay Hunt syndrome, 1 (0.8%) with birth trauma, 1 (0.8%) with a tumour, 1 (0.8%) with Giant cell arteritis and 2 (1.7%) with a stroke. 64 respondents given an initial diagnosis of either Bell's palsy or Ramsay Hunt syndrome were given an MRI or CT scan.

¹ <https://pubmed.ncbi.nlm.nih.gov/27746846/>

Treatment

We wanted to understand what treatment was prescribed or advice given within 72 hours of respondents seeing a health care provider.

Treatments/advice given within 72 hours



17 respondents ticked the 'Other' box with examples of treatment including receiving painkillers, medication/surgery for associated conditions, electrical stimulation, speech and language therapy and physiotherapy. One person was told to follow videos on facial yoga. From the results above it is clear that only approximately one third of patients were given any advice relating to eye care. A fifth of patients were given no information or treatment within the first 72 hours.

Sample of comments from survey respondents

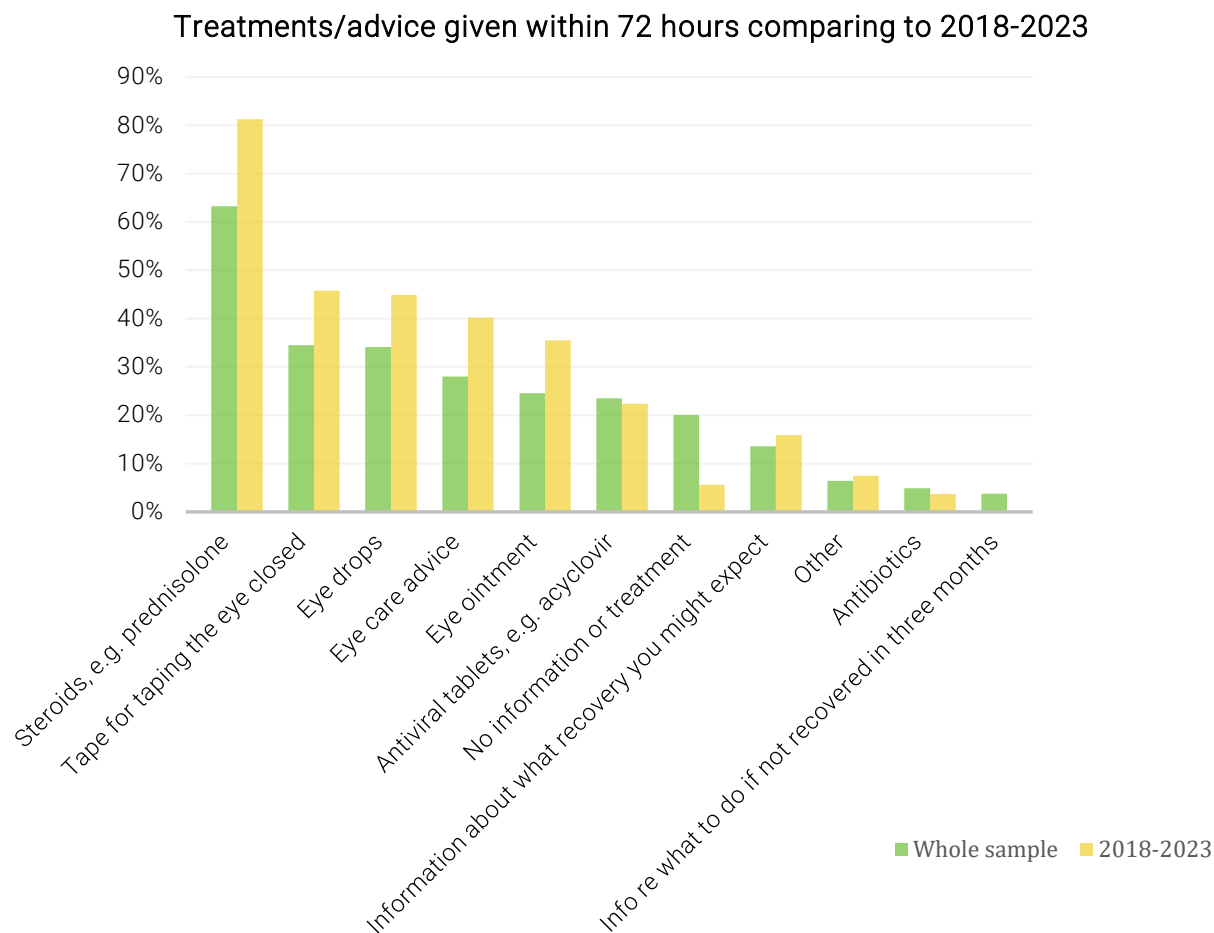
"Looked online and realised I needed eye drops and to tape my eye so bought myself."

"The advice given was a print-out regarding Bell's palsy."

"I was asked to take part in research so was given undisclosed meds. Steroids and anti-inflammatory being the active drugs. I unfortunately got the placebo for both."

"Initial diagnosis took place in A&E whilst I was in early labour. I was prescribed steroids but given no other information on the condition, prognosis or other possible side effects on eye health or synkinesis. After I had given birth a little over 24 hours later, I contacted my osteopath (privately) who gave me much more information and recommended I contact my GP. My GP was incredible and gave me all of the information covered above but the initial diagnosis did not cover this and nor did they indicate I should contact my GP as soon as possible to get the appropriate follow up care."

We then compared the whole sample to people diagnosed since 2018, shown in the chart below.



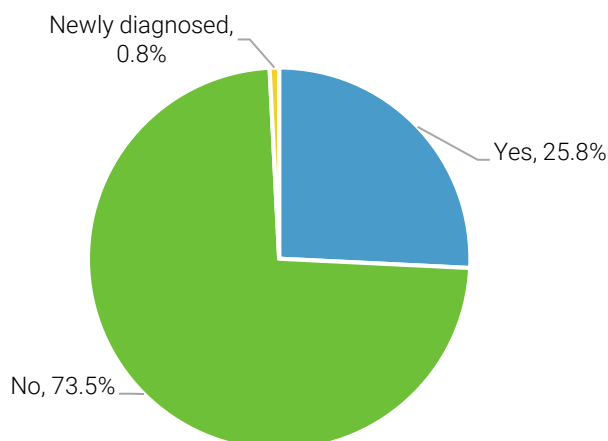
There has been an increase in the numbers receiving steroids within 72 hours as well as improved information regarding eye care. For anyone being prescribed steroids (which would suggest facial nerve involvement rather than a stroke), it is expected that information on eye care is imperative because the eye would normally be affected. However, less than half of the people treated within 72 hours were given eye care advice suggesting a lack of awareness among health professionals.

Of 86 respondents diagnosed with Bell's palsy between 2018-2023, 93.1% were diagnosed within three days and 91.9% were prescribed steroids within the 72-hour window. For those later diagnosed with Ramsay Hunt syndrome (18 respondents), only two people received a correct diagnosis within the 72-hour window and ten were later given antivirals with three previously having been given them, possibly as a precautionary measure.

Misdiagnosis/changed diagnosis

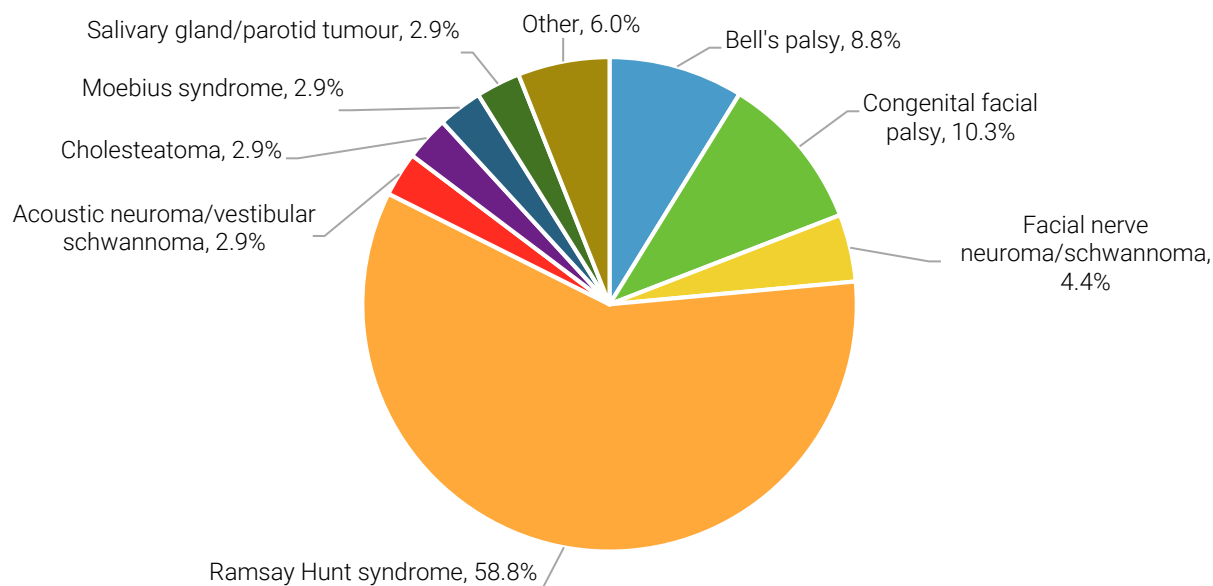
We wanted to understand more about where misdiagnosis occurs. This may sometimes be the result of other symptoms appearing later or it may be where symptoms have been missed.

Was the diagnosis (cause of facial palsy) later changed by a healthcare professional?



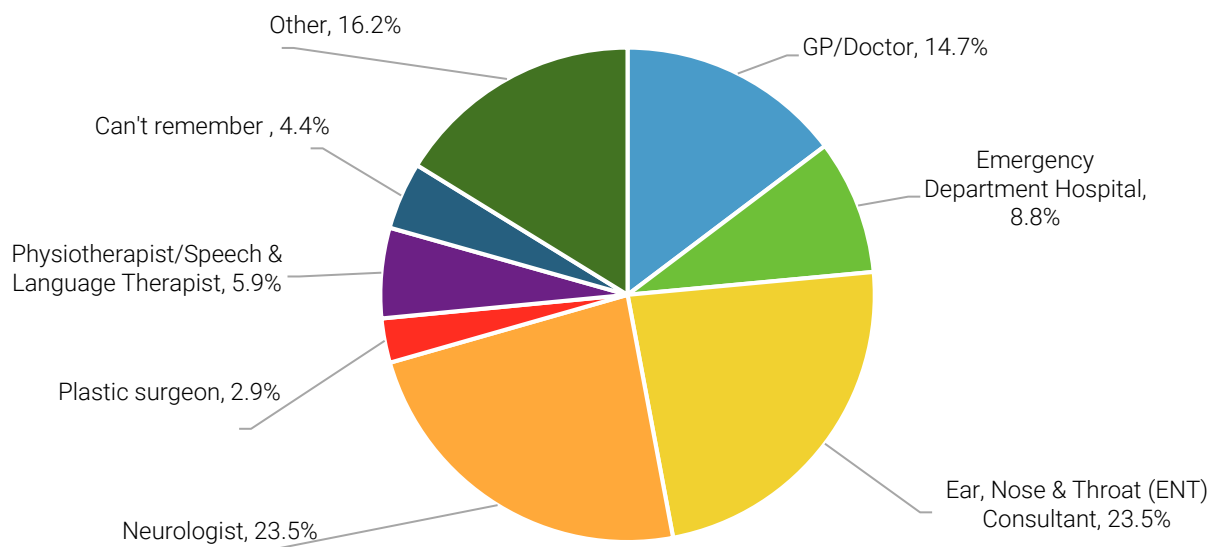
When surveyed, 68 respondents (25.8%) said their diagnosis was later changed by a healthcare professional. When comparing to the 2018-2023 sample, figures were similar with 75.2% not having their diagnosis changed, 23.3% having their diagnosis changed and 1.6% only recently diagnosed.

What was the diagnosis changed to?



The other category included cavernoma, virus of the main brainstem and where someone was diagnosed with general muscle tightness. One person said although they had an initial diagnosis they were later designated as cause unknown. Of the 40 respondents whose diagnosis was changed to Ramsay Hunt syndrome, 36 (90.0%) had previously been diagnosed with Bell's palsy.

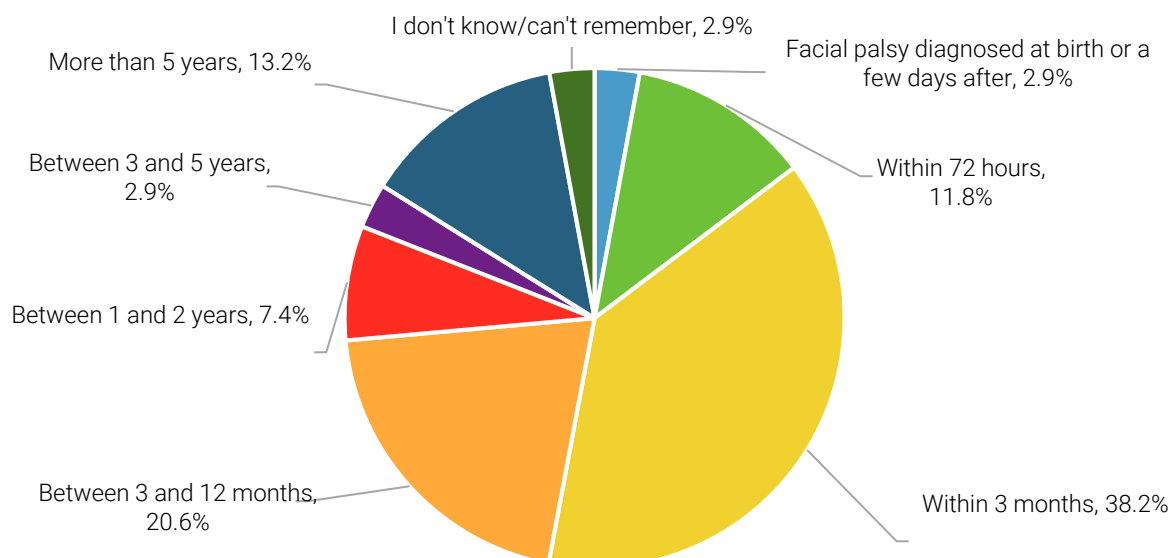
Who changed the diagnosis?



For nearly half of the 68 respondents misdiagnosed in the full sample, the diagnosis was changed later by either an Ear, Nose & Throat (ENT) Consultant (23.5%) or a Neurologist (23.5%).

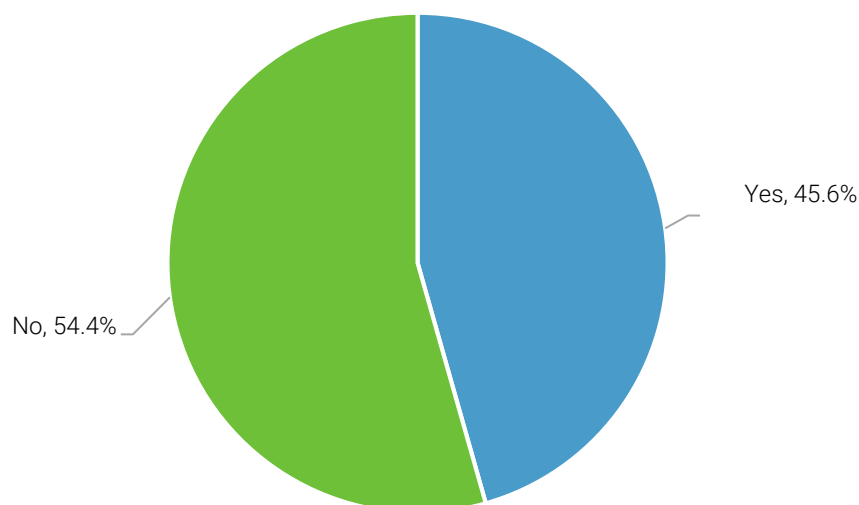
Healthcare professionals/clinics under the 'Other' category who changed the diagnosis included a glaucoma clinic, Maxillofacial consultant, Neonatal surgeon, Neurosurgeon, Oncologist and Paediatrician.

How soon was the diagnosis corrected?

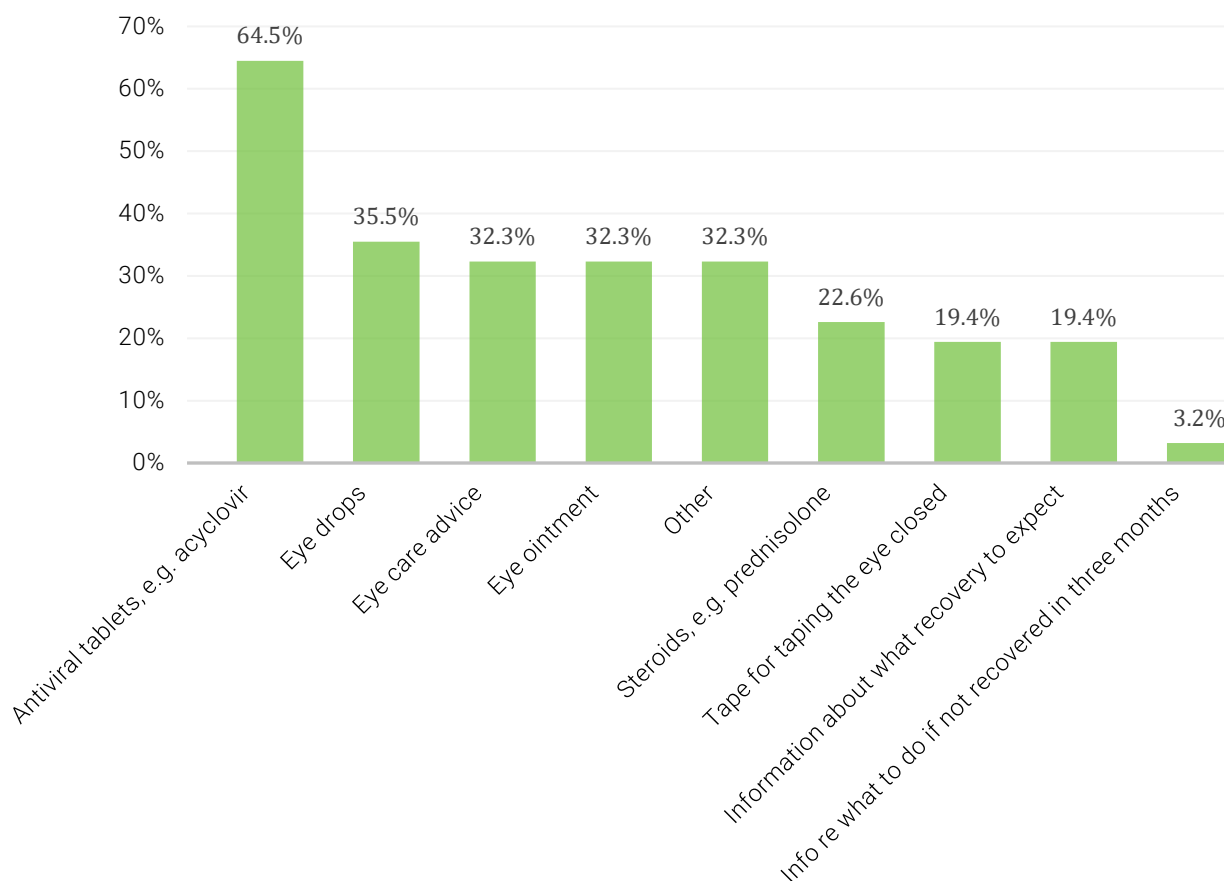


Of the 68 people misdiagnosed, 30 respondents (44.1%) waited more than three months for a correct diagnosis. Excluding those where the facial palsy was present at birth or a few days after, just 11.8% had their diagnosis changed within 72 hours and 26 respondents (38.2%) had their diagnosis corrected within three months but outside the 72-hour window. It is worth noting that it can be difficult to diagnose Ramsay Hunt syndrome if other symptoms develop later.

Was different medication/treatment given as a result of the change in diagnosis?



Treatments/advice given after the diagnosis was changed



64.5% of those misdiagnosed were later prescribed antiviral medication as a result of the change in diagnosis. Looking at who had their diagnosis changed to Ramsay Hunt syndrome (40 respondents), only 12 received antivirals in the recommended 72-hour window. A total of 18 respondents were given antivirals as a result of the diagnosis being changed.

A sample of comments from respondents who were later diagnosed with Ramsay Hunt syndrome

"Although I was diagnosed with Bell's Palsy in ER I soon realised myself that my symptoms matched RHS (thanks to Facial Palsy UK's site). 2 GPs at my surgery refused to accept 'Dr Google' (their words) and said my ear pain was a coincidence. Only sending a link to your site persuaded them, by which time it was about 10 days and I had to beg for antivirals. I feel sure my recovery would have been better if a correct diagnosis and treatment had been given sooner."

"My first appointment was only with a nurse during covid and was diagnosed with Bell's palsy. I got to the stage where I felt so ill and decided to contact GP again about 5 days later and then I was asked to send in photos of the inside of my mouth. The GP sent photos to an ENT consultant and agreed with GP it was Ramsay Hunt syndrome. Medication was prescribed and referred to eye hospital. I just think if all this was done the first day I attended the surgery and was seen by a qualified doctor I would have had an earlier diagnosis, prescribed medication early and would have had a better recovery. I was disappointed with the slow experience I received by my GP."

"It was difficult for the hospital staff to diagnose Ramsay Hunt Syndrome as it was not until I arrived home the next day that I found I could not put my hearing aid in the palsy side. Spots were found inside the ear. I was asked by my GP to send a photo of the ear and she then diagnosed Ramsey Hunt Syndrome. As this was within the crucial 72-hour window I was immediately prescribed the correct medication."

"I wish I was diagnosed with RHS sooner as I could have got the right treatment in time, however I do understand I only had at the time one blister in my ear and not even I thought it was related. It was only because a week or 2 after palsy started my whole body was in so much pain I had to go to A&E and they diagnosed the shingles so my whole diagnosis got changed from BP to RHS."

"GP said he thought it was Bell's Palsy but sent me to A&E to check it out. They diagnosed Bell's Palsy. My condition deteriorated, and I was in considerable pain. Out of hours doctor diagnosed Ramsay Hunt and said to get GP the next morning. GP came and refused to believe that diagnosis and insisted I had Bell's Palsy. A few days later I was really bad, my husband contacted GP and said if he didn't come and treat me for Ramsay Hunt he was taking me back to A&E. He did treat me then but came too late to make any great difference."

A sample of comments from respondents who were later diagnosed with other causes

"As I was being treated for Stroke I didn't get the vital treatment I should have had within 72hrs. I wasn't given Steroids & Antivirals until the 6th day! I still have Bell's Palsy 5yrs & 4months later & it's highly likely it will be permanent."

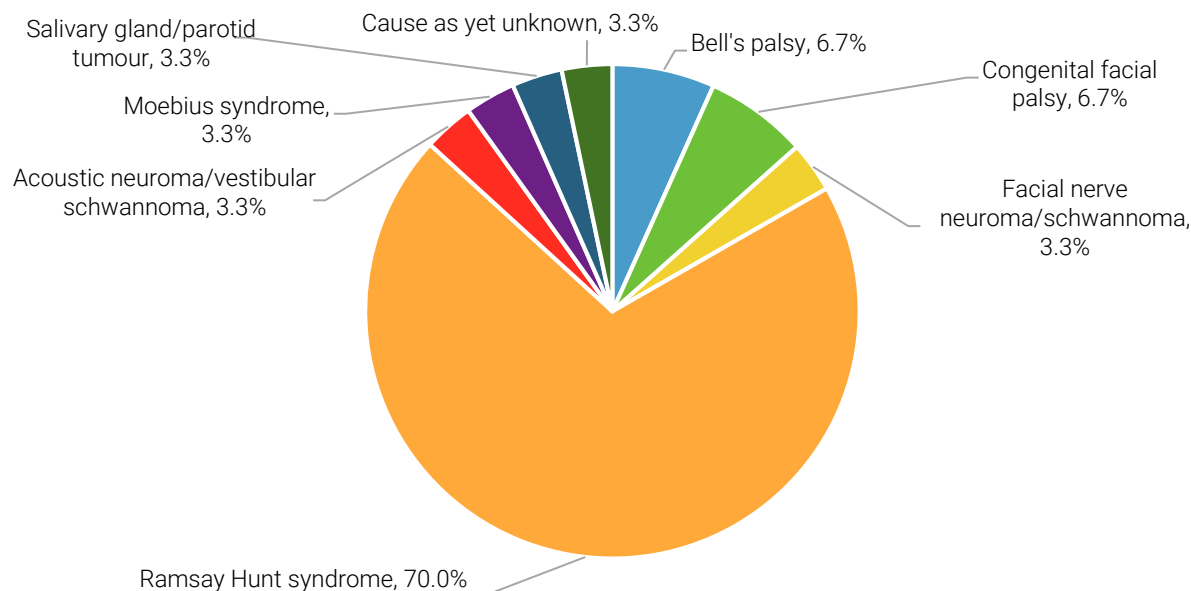
"The out of hours doctor referred me to A&E, they looked at possible stroke but when CT scan was clear, no further diagnosis was given. I then was unable to get a GP appointment until 4 days later. My son suggested Bell's and I told the GP."

"I think I didn't get checked properly. I got discharged after 6 months and told to live with it, it got worse after about 18 months, again just told to live with it, then around 3 years later I started getting pain and problems swallowing, again got fobbed off so I paid to go private for my own CT and MRI scans and that found my stage 4 cancer so pretty annoyed but they still won't admit I was misdiagnosed."

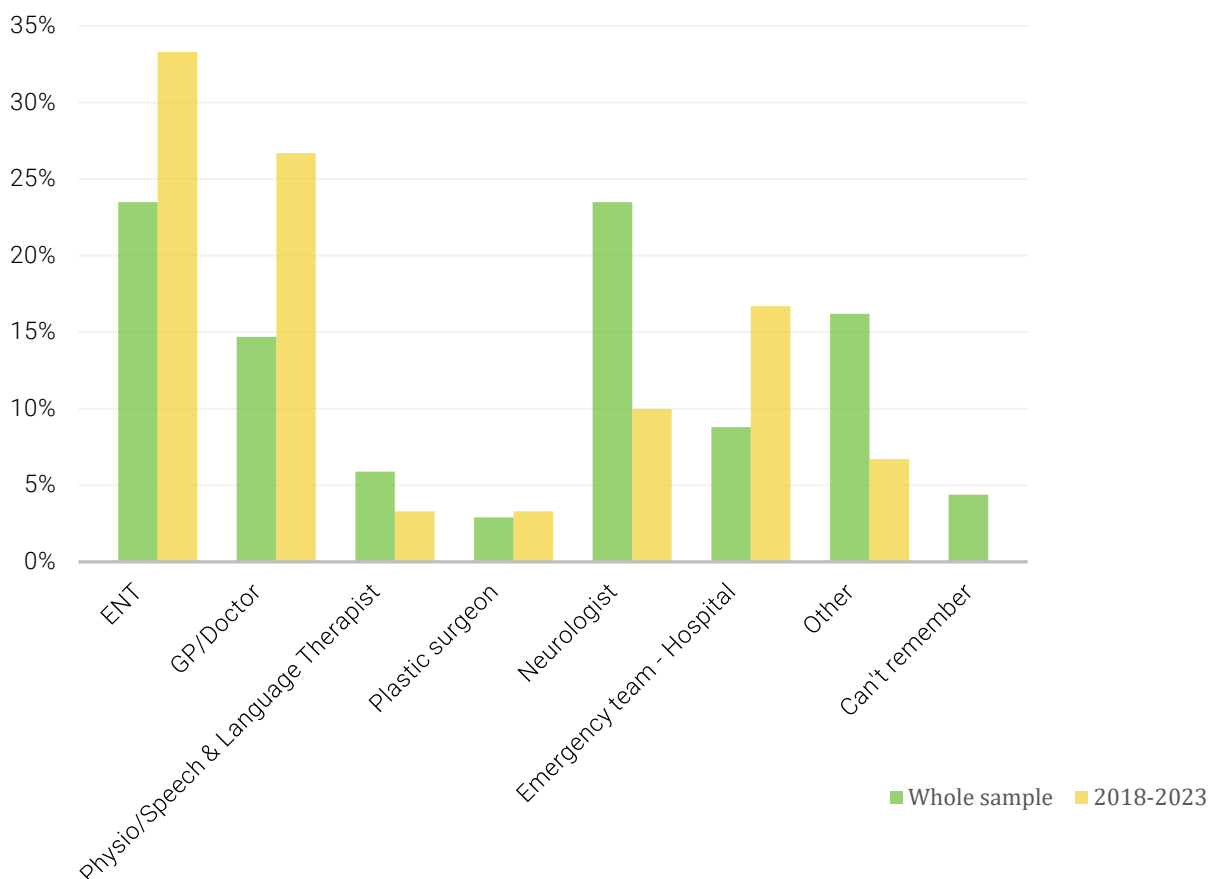
2018-2023 Sample

When comparing to the 2018-2023 sample (below) where 30 people had a changed diagnosis, there was a big jump in the numbers having their diagnosis changed to Ramsay Hunt syndrome (70% compared to 58.8%). This suggests awareness of the condition may be growing.

What was the diagnosis changed to? (2018-2023)



Who changed the diagnosis? Comparing to 2018-2023



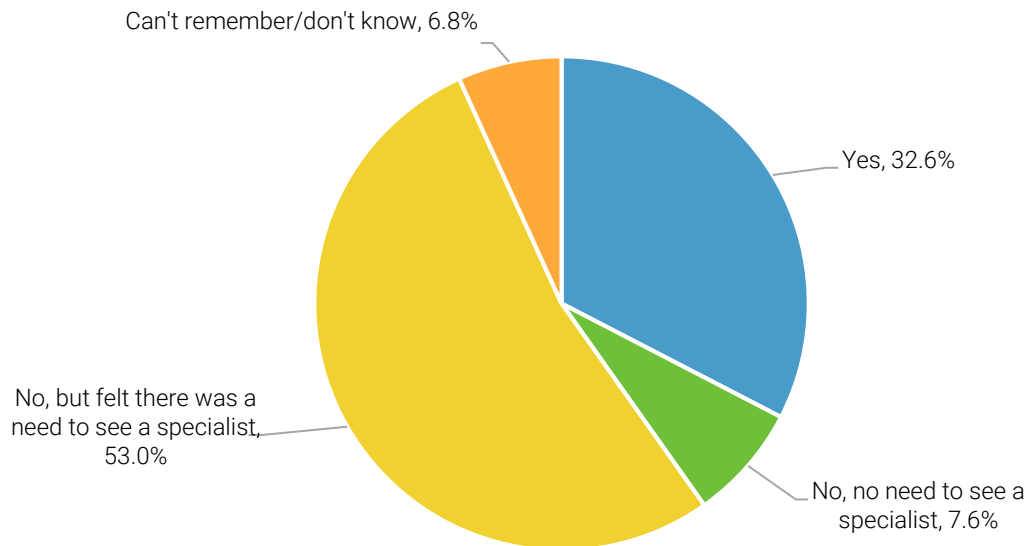
Between 2018-2023 there was an increased number of Ear, Nose and Throat (ENT) consultants, GP/Doctors and Emergency teams at the hospital involved in changing the diagnosis compared to the sample as a whole. Some people may have been less likely to see other specialists at this point which would skew the sample, but it's important to remember that fewer people were seen by their GP/Doctor as the first point of contact over the past five years.

Across the whole sample, 11.8% received the correct diagnosis within 72 hours, this increased to 16.7% for those who developed facial palsy between 2018 and 2023. Of the 30 who developed facial palsy between 2018 and 2023 whose diagnosis was changed, 17 (56.7%) were then prescribed different medication. The largest change was the introduction of antivirals for 12 people (70.6%).

Onward referrals

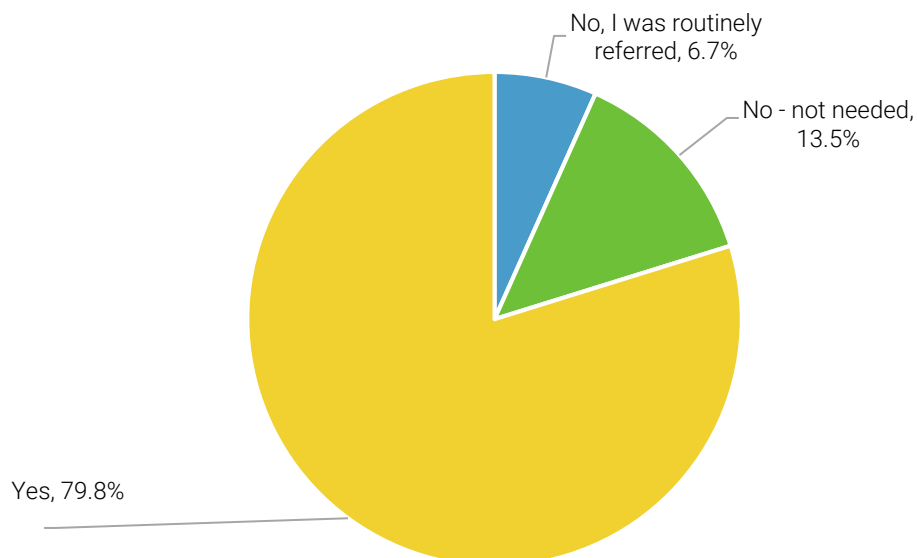
Please note that in many cases it is not necessary to refer a patient to a specialist for further help immediately. Some patients are followed up though and some aren't, and we wanted to understand the fuller picture and also what respondents' expectations were.

When diagnosed, did the GP or hospital clinic immediately refer to a specialist?



Requesting further follow-up treatment/care for facial palsy

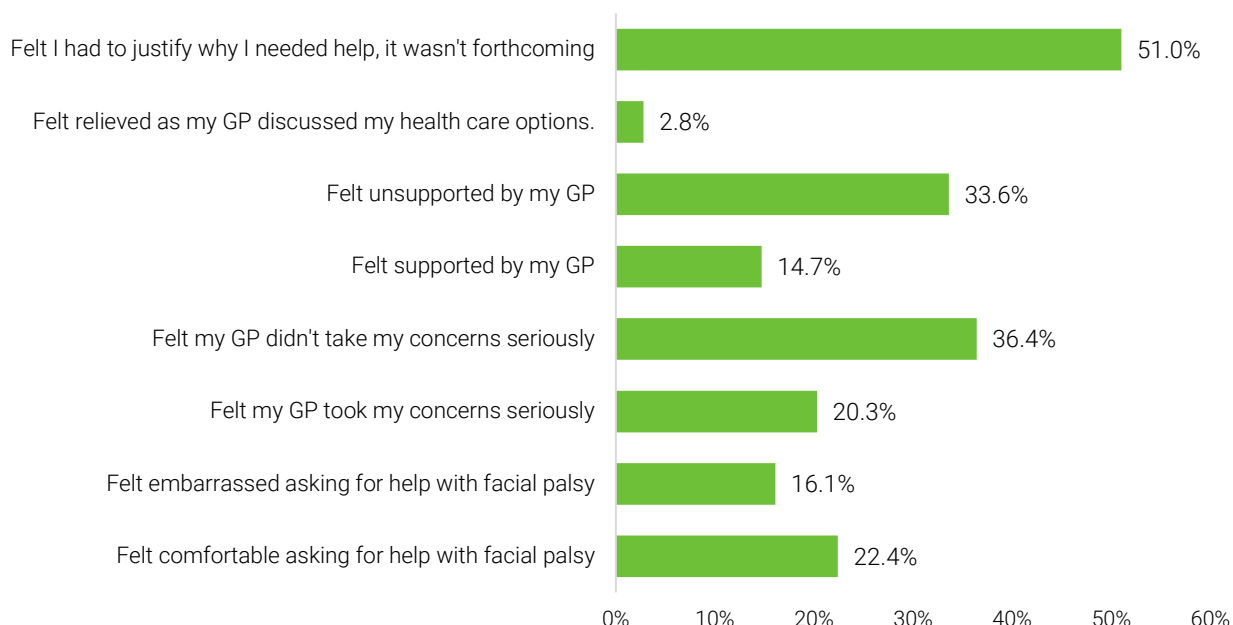
Of the 264 respondents, 178 people weren't immediately referred to a specialist. We asked this segment whether they had to request further follow-up care.



142 respondents (79.8%) needed to request a referral to a specialist.

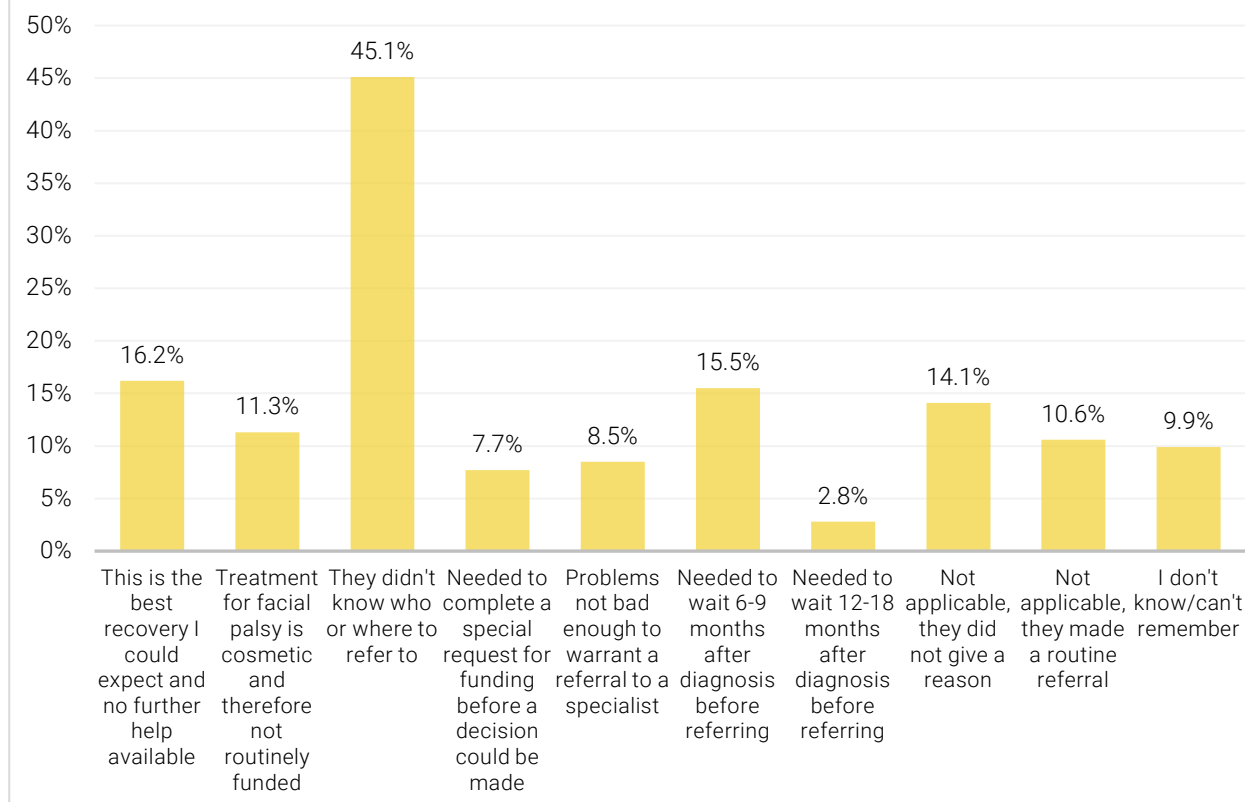
Initial communications with the GP/Doctor

How did people feel when approaching their GP?



Of the 142 respondents who requested follow-up health care, the biggest problem faced by over half (51.0%) was feeling that they had to justify to their GP why they needed help. More than a third (33.6%) felt unsupported by their GP and that their GP did not take their concerns seriously (36.4%).

Reasons given by GPs for not referring patients



Almost a half (64 respondents, 45.1%) found that their GP did not know who or where to refer patients to. Similarly, 26 respondents were told they needed to wait either 6-9 (15.5%) or 12-18 (2.8%) months before they could be referred; 11 respondents were not referred immediately due to funding constraints (7.7%); and 23 were refused a referral and told they could not expect any further recovery (16.2%). 11 respondents (7.7%) 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.

Obtaining a referral to secondary care

Out of 142 respondents who were not given a routine referral:

- 44.4% were only given a referral after doing their own research and giving their GP the name of a specialist.
- 23.2% were referred only after several requests for help.
- 3.5% were only given a referral after changing their GP and 2.1% were referred after a successful request for funding.
- 7.0% are still waiting for a referral to a specialist and 3.5% had their funding request declined.

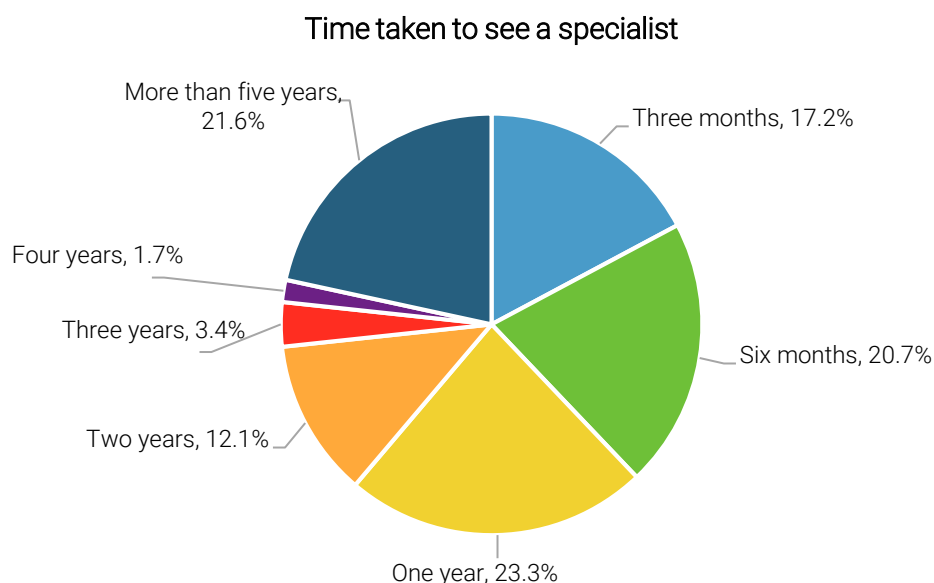
GP appointments

Of those who needed to speak to their GP about a referral to a specialist:

- 24.8% only needed one appointment.
- 21.9% needed two appointments.
- 20.0% needed three appointments.
- 33.3% needed more than three appointments with their GP before a referral was made.

Length of time to see a specialist

Out of 116 respondents who requested a referral, we wanted to find out how long it took to see a specialist from when respondents were initially diagnosed.



A sample of comments from respondents about accessing specialist health care

"GP said you have lived with it all your life why mess now. No emotional support."

"My GP told me to "get over myself" and "stop being so obsessed with my face". After 4 months of no recovered movement. After this I had to pay for private help and eventually after 5 years and a lot of credit cards I got referral to an NHS doctor."

"I had to find all my info through facial palsy support groups or online every doctor told me I would recover just to give it time... even though I was clearly developing synkinesis and in terrible pain."

"I think that the care pathway for Bell's palsy needs to be updated, to include the facial palsy units. My GP did not know about them."

"It's just seems to be that it's not deemed an actual medical problem, and it's just cosmetic. They also don't take into consideration the mental health impact having facial palsy has. Particularly if you've lived with it since birth. My mental health has certainly suffered because of my FP."

"GP was clueless and made me think I was being a dramatic mother and repeatedly told me it was cosmetic and that his recurring eye infections had nothing to do with the palsy."

"I went private as my GP didn't know enough and just said "most people recover after 3 months" when my budget ran out I went back to NHS and got referred but waited 6-9 months for appointment. When I went for the appointment they had referred me to the wrong consultant, so I had to wait another 3 months before I saw anyone."

"I sought help privately. there is no specialist facial therapy in Wales, though they are trying to set this up (with a plastic surgeon in Morriston). They would not refer me to England."

"How alone I was and how incredibly disinterested both the GP and physio were. Neither bothered to even look up Bell's Palsy. It was because I was a nurse that I began to learn about things myself."

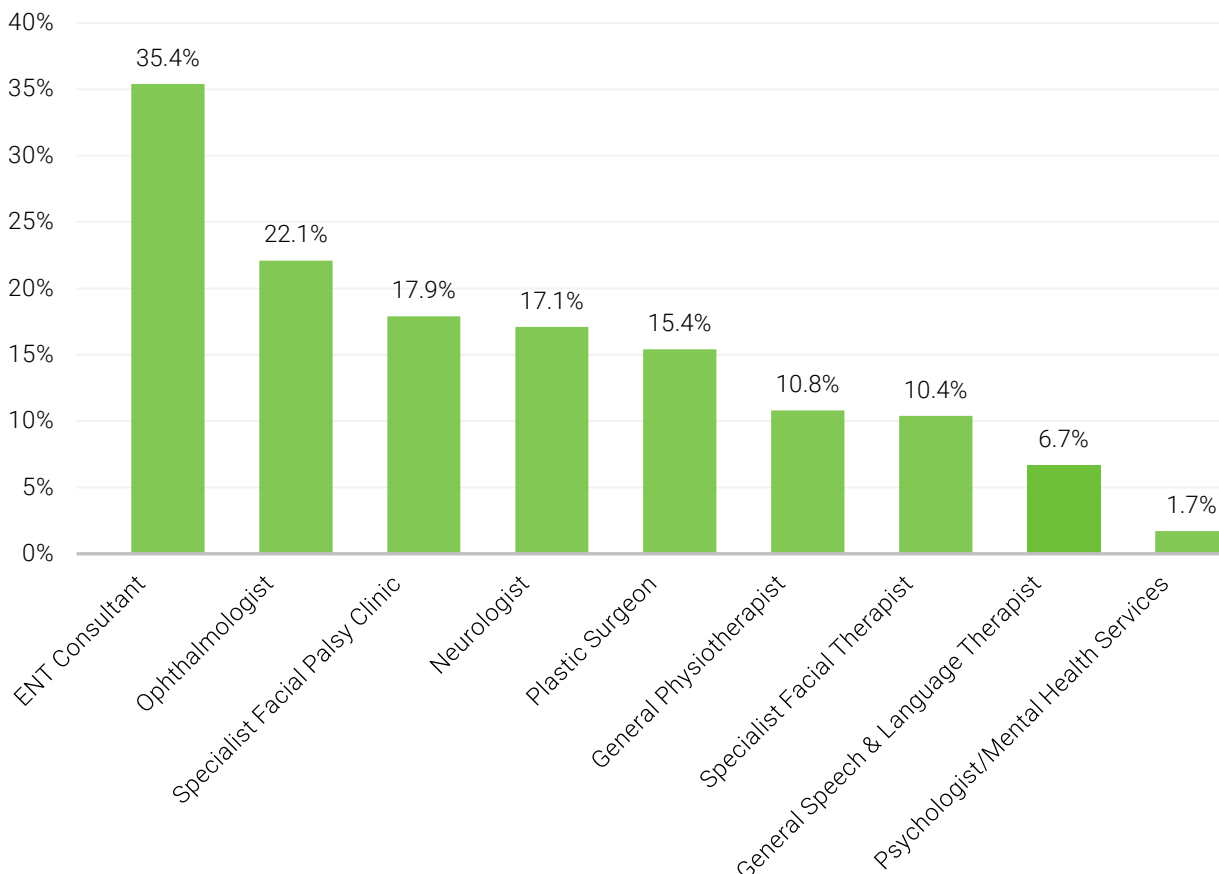
We asked respondents to briefly describe what issues they were asking for help with in relation to their facial palsy. The word cloud summarises these responses:



Referrals

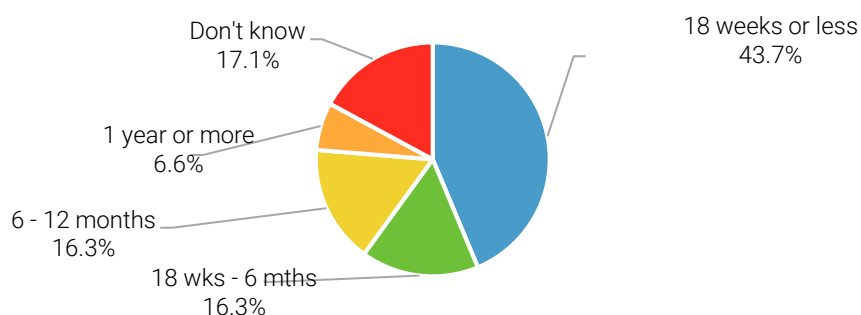
The majority of patients referred to secondary care see an ENT Consultant, Ophthalmologist, Specialist Facial Palsy Clinic or Neurologist. In the free text boxes, a very small number of respondents mentioned being referred to Maxillofacial consultants, paediatricians and neurosurgeons.

Which clinics were patients referred to initially?



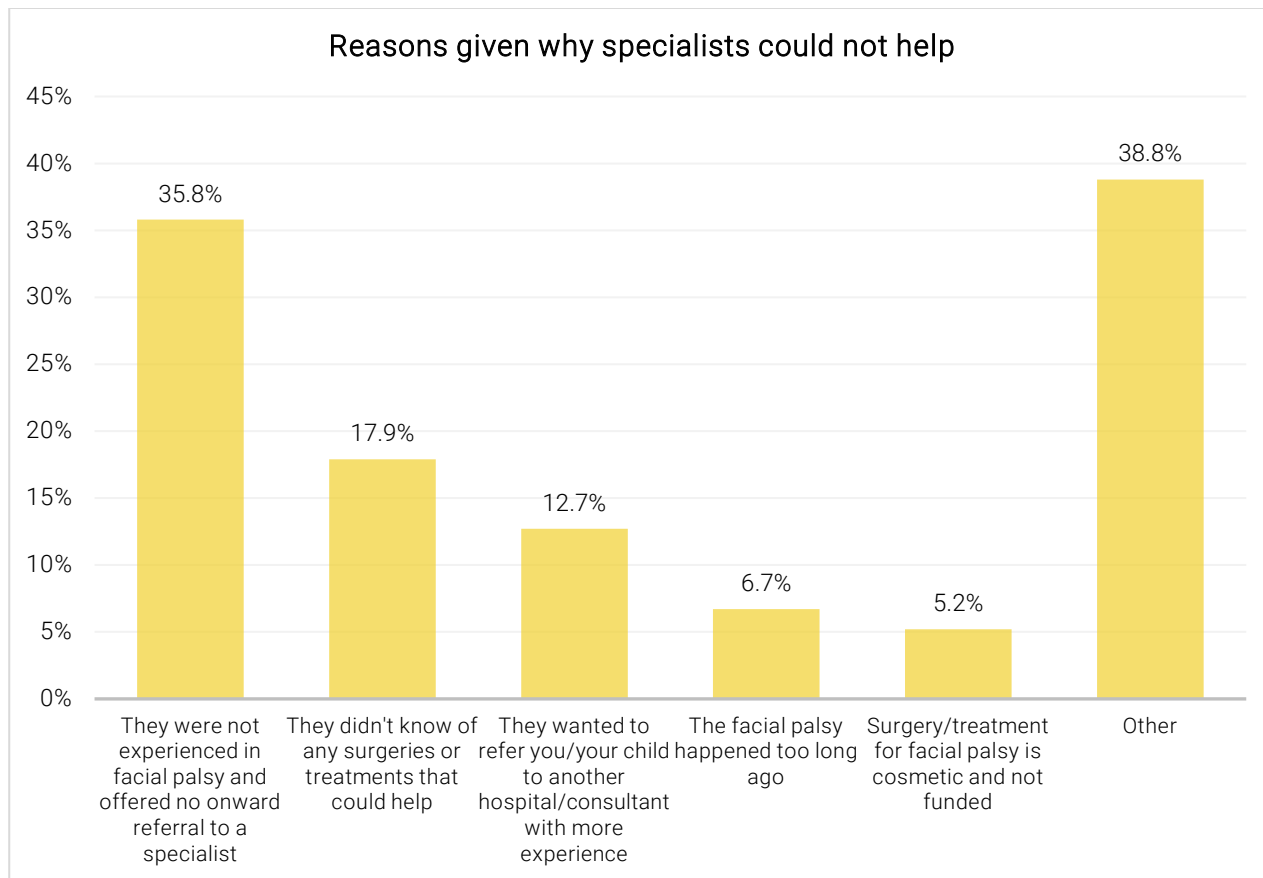
Just 43.7% experienced a wait time of 18 weeks or less. The maximum waiting time for non-urgent consultant-led treatment in the NHS is supposed to be 18 weeks from the day the appointment was booked through the NHS e-Referral Service². 39.2% had to wait longer than 18 weeks and 17.1% could not remember how long they waited for their appointment.

Length of time waiting for the appointment



² <https://www.nhs.uk/nhs-services/hospitals/guide-to-nhs-waiting-times-in-england/>

A total of 134 out of 240 respondents stated that the expert they initially were referred to was unable to help them with their facial palsy. The reasons for this are shown in the chart below. Only 106 respondents (44.2%) felt that the specialist they were initially referred to could help them.



Sample of comments from those who selected 'Other'.

"Helped with eye treatment but not facial palsy generally."

"I was given totally incorrect advice and told to exercise my damaged side."

"One of the initial consultants made my situation worse, my eye did not close after Botox was administered too close to my tear duct and it did not close for eighteen months. I was also told after a certain number of psychological support appointments I'd had all I could have and yet I was really struggling to accept my facial palsy and to come to terms with things like going out in public, not being able to eat easily, brush my teeth, kiss my husband and my son, smile, talk, hear, think, my head felt like it was being crushed in a vice for years!"

"The first referral wasn't to the right specialist for my face. Speech therapy was denied."

"It was an ophthalmology appointment and they only dealt with the eye. I have had to get private help for the facial palsy as the earliest appointment for that was in 8 months."

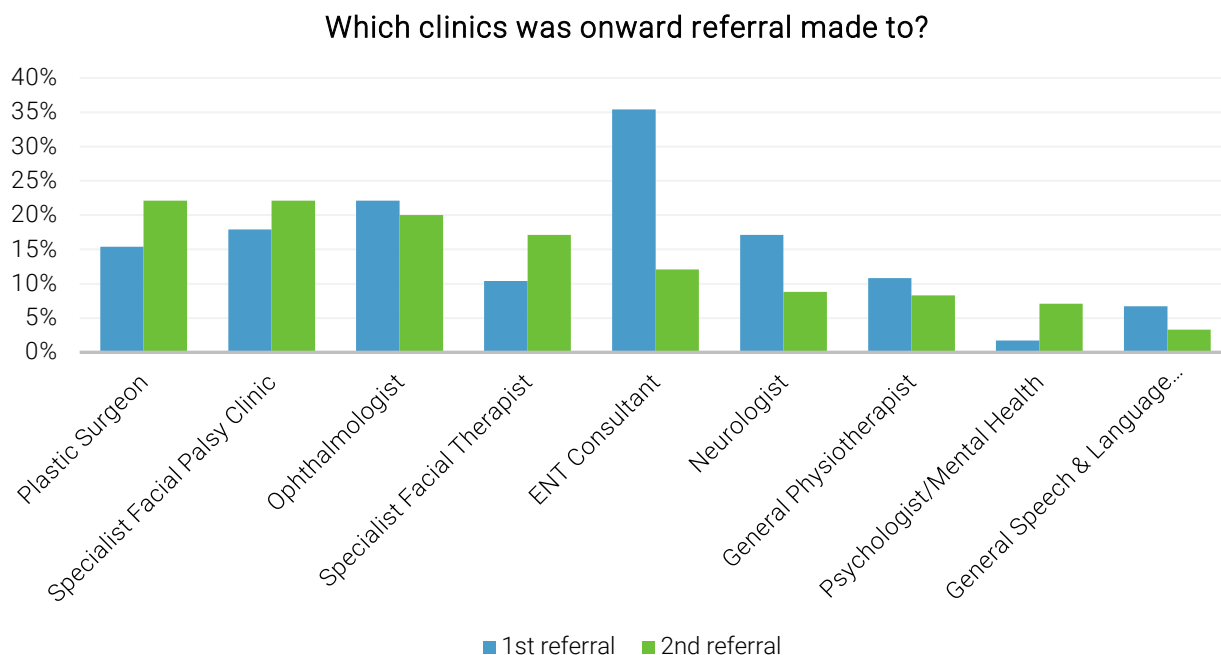
"They said ENT don't deal with Bell's palsy anymore."

"Said it would recover in its own time."

"They would only give me Botox on my non affected side for symmetry but I needed Botox in my affected side for the pain."

Onward referrals

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

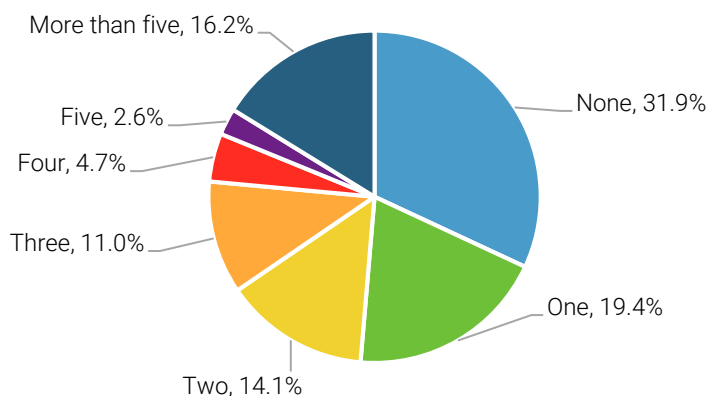


The chart above shows where initial referrals were made to compared to where second referrals were made to. Fewer 'second' referrals were made to ENT and neurology, but more were made to plastic surgeons, specialist facial palsy clinics and specialist facial therapists. The number of general physiotherapy appointments reduced slightly 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. There are a few ENT consultants who specialise in facial palsy but anecdotal feedback received by Facial Palsy UK suggests that many are unaware of the treatments available to help people suffering with long-term complications of the condition.

NHS waste: Wasted Appointments

We asked the 191 respondents who needed onward referrals to different specialists 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.

Wasted Appointments



Helpful appointments were attended by 31.9% of respondents with around a fifth (19.4%) saying they had experienced one appointment that was of no benefit to them due to the health professional not being an expert in facial palsy. Approximately a third of the sample (32.4%) stated they had attended between two and five appointments that didn't benefit them. Some respondents (16.2%) stated they had attended more than five appointments that did not benefit them.

Feedback about NHS appointments:

"I was referred to a non-specialist facial palsy consultant. So, after waiting so long for help to be told they couldn't help was soul destroying."

"Neurologist didn't know much about it. I was in hospital and they didn't tape or help me with my eye. Ended up with severe abrasions to the cornea. Saw ophthalmologist and they did an emergency tarsorrhaphy, they said the condition of cornea was very bad. Had been three weeks since start of facial palsy yet no eye care."

"I feel ENT hold on to patients too long assessing for weeks of progress of the palsy (when clearly it would benefit earlier intervention by specialist) before referral to a specialist hospital."

"Only had treatment for initial concerns with lack of eye closure and potential hearing. No antivirals received. Bells did not recover but ENT / ophthalmology did good job with initial monitoring but no clear path for treatment when recovery did not happen. Mentioned physio but not clear of how to arrange it and would take years to get appointment. I live in Oxfordshire but found out nearly a year later by accident there was a specialist clinic at John Radcliffe but no one aware of its existence! Now that I was able to get referral I feel in much better hands but prior to that felt like medical professionals were very aware of treatment for acute Bell's palsy but nothing beyond that. I saw ENT 3 times - the first 2 were very constructive, however on 3rd visit, at which point I had real issues - my face was severely swollen (which I now know was the extreme tightness of muscles) and significant balance issues and had no idea what to do next, but I was told I was fine and would be discharged from their care."

"The appointments left me feeling helpless as there was just no way forward it was don't worry you will be fine in a few months...but I really wasn't."

"I wish I could see a specialist and that any appointments I've attended would actually do something as opposed to listen to my woes."

"The paediatrician was very good but again not enough knowledge about facial palsy first time in his 20 + career treating it."

"It took 5 years before my first referral admitted I wasn't their speciality. During that time the fact I had seen someone about it was weaponised against me by GPs as 'you've had an appointment what more do you want' 'you'd better think about getting over it and seeing it as who you are' 'at least you didn't have a stroke'".

"GP and local hospital teams were unaware of specialist FP clinic (only 30 miles) from home in neighbouring trust. I only found out through Facial Palsy UK & went back to my GP to be referred for treatment for synkinesis....if I had an appropriate referral sooner, I wonder whether the outcome would have been better and long term treatment avoided."

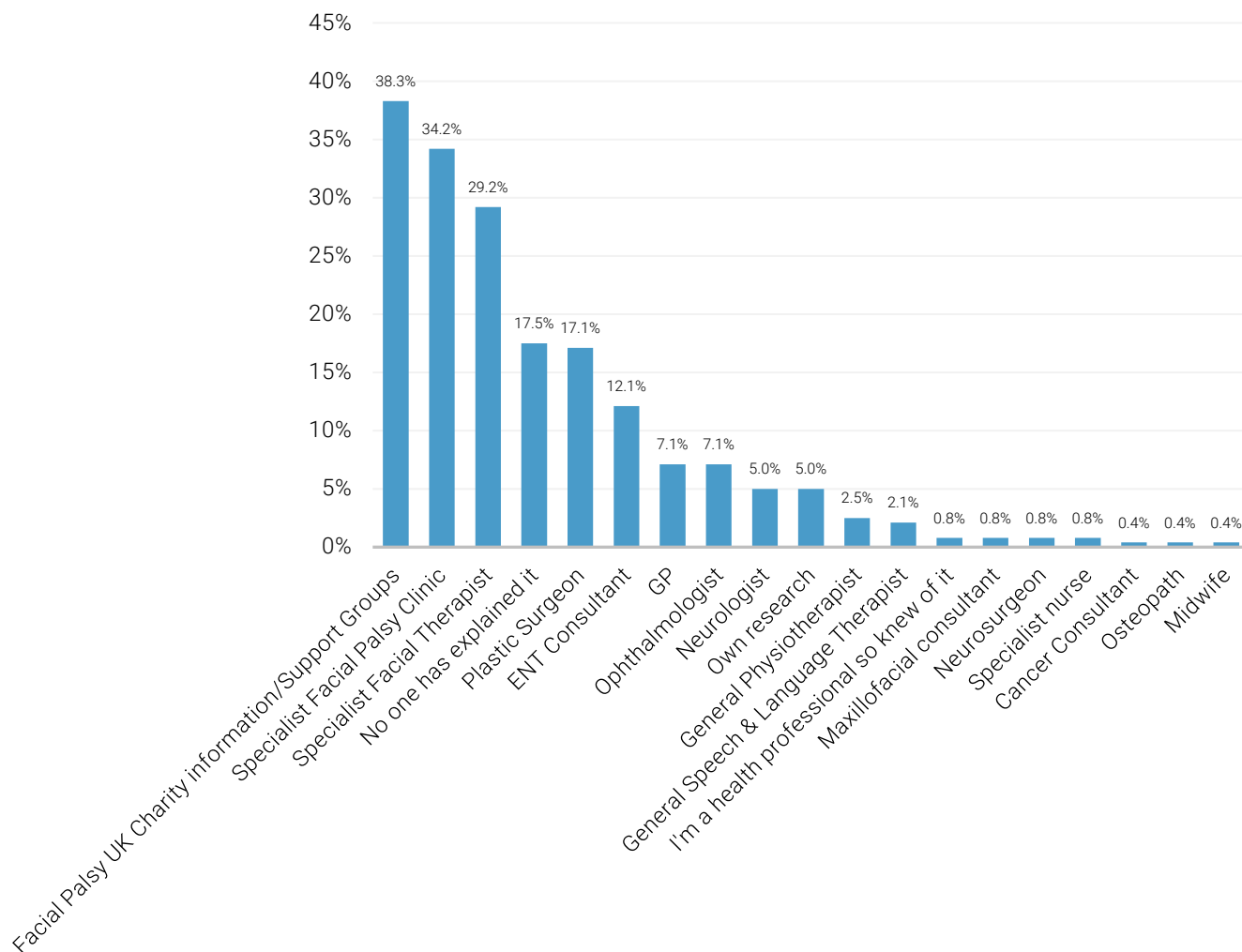
"Just felt no one really knew anything about it."

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.

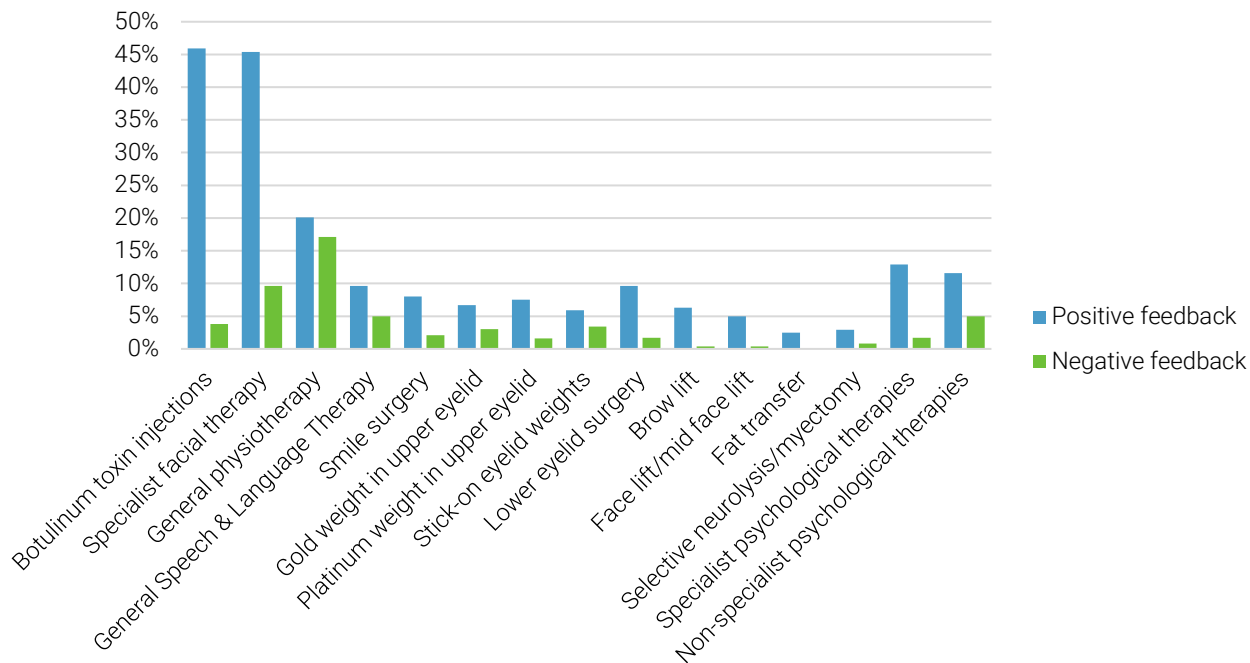
Who explained facial palsy fully and in a way you can understand?



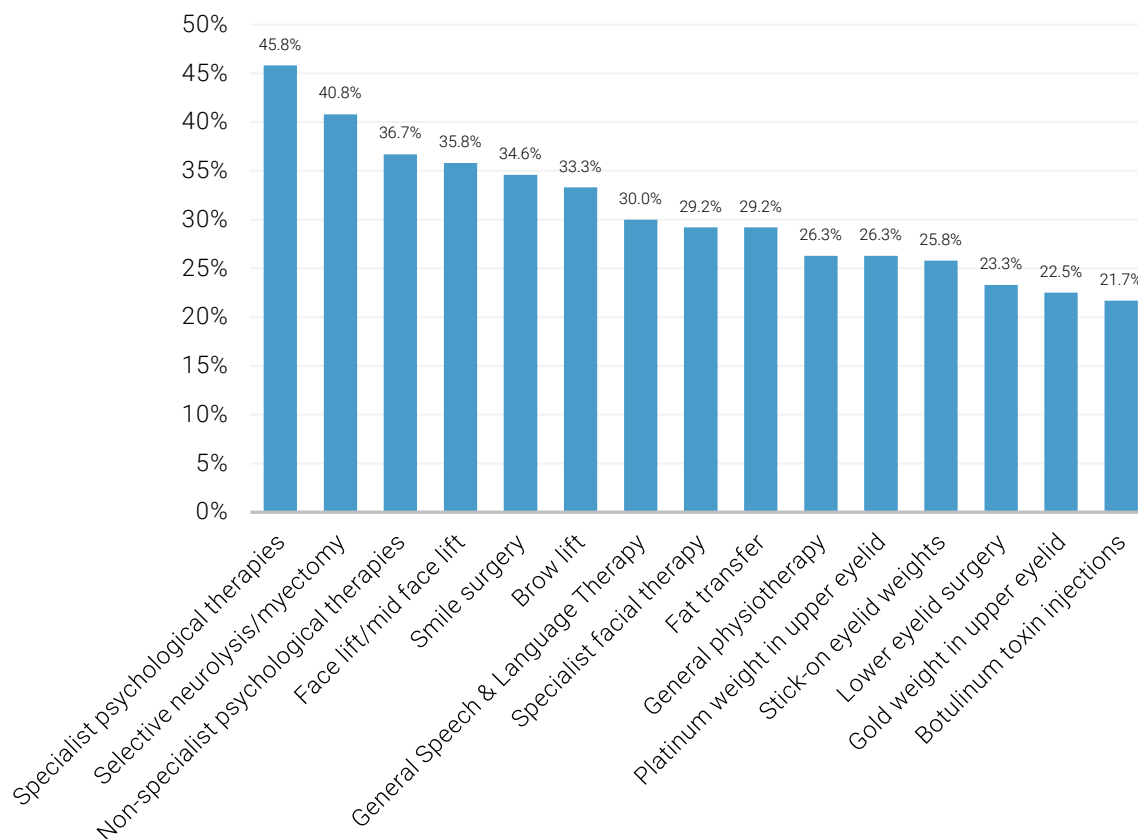
As many patients are filtered through ENT first, improvements could be made in terms of the information they are given at this touchpoint.

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. The graph below details comparison of positive and negative feedback by 240 respondents regarding follow-up care. Total figures are based on a percentage of who tried each health care option.



If people had not experienced the surgeries, treatments or therapies above they could select either 'not suitable for me', 'not applicable' or 'not offered but would like to discuss/access'. The graph below shows the percentage of those wanting to discuss/access different options.



Travel Insurance

Having received a small number of enquiries about difficulties getting facial palsy recognised by travel insurers, we added a few questions on this topic to find out more about people's experiences.

We ruled out people with Bell's palsy for these questions as Bell's palsy is listed as a condition for insurance purposes leaving 117 respondents of whom 58 (49.6%) had tried to purchase travel insurance since the diagnosis of facial palsy. Of these only 20 (34.5%) declared the facial palsy on travel insurance forms. Reasons given included:

- Didn't think it was necessary
- Declared as other condition causing the facial palsy, e.g. tumour, syndrome, etc.
- Concern insurers would not cover for nerves, muscles, face, etc.
- Follow-up healthcare not offered so if NHS don't see it as an ongoing medical condition then travel insurers shouldn't either.
- The facial palsy is not going to change.
- Recovered enough to function.

Just four people had had problems declaring facial palsy on travel insurance forms and eight people said they declared they had Bell's palsy due to a lack of other options.

Comments about insurance

"Although asymptomatic, declaring all seems to have made a significant price jump."

"Do find it irritating that you can only select Bell's palsy!!!"

"I entered as dry eye problem instead as facial palsy not an option."

"Trouble with life insurance policy, had to provide my MRI report and they refused to cover me for stroke."

Full summary

Diagnosis

Key points:

- 33.3% initially sought help from their GP and 22.7% by an Accident and Emergency Clinic (18.9%) or NHS Walk-in centre (3.8%).
- Approximately one quarter of respondents (25.8%) were initially misdiagnosed or had their diagnosis changed at a later date. The most commonly misdiagnosed cause of facial palsy was Ramsay Hunt syndrome, this was frequently misdiagnosed as Bell's palsy.
- Between 2018-2023 there was an increased number of Ear, Nose and Throat (ENT) consultants, GP/Doctors and Emergency teams at the hospital involved in changing the diagnosis compared to the sample as a whole.

Actions:

- 1) Put tools in place for GPs and Hospitals to better identify the differential diagnoses.
- 2) Awareness campaign.
- 3) Devise an educational module for GPs to access as Continuing Professional Development.
- 4) Target ENT (Ear, Nose and Throat departments) to raise awareness and ask them to do some education within A&E departments.

Treatment

Key points:

- A total of 36 respondents (13.6%) were initially diagnosed with Bell's palsy and had their diagnosis later changed to Ramsay Hunt syndrome. This changes the treatment plan due to the introduction of antiviral medication which is again time-sensitive and like steroids is optimally taken within 72-hours.

Actions:

- 1) Raise awareness with GPs and A&E clinics re when to add antivirals, e.g. a patient presenting with Bell's palsy in severe pain. The cost of antivirals is cheap and cost effective.

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. 142 respondents needed to request follow-up health care. More than a third felt that their GP did not take their concerns seriously and more than a half (51%) felt they had to justify why they needed help.
- 45.1% 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.
- Over half (62.1%) of the 116 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 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 wastes NHS money.

Actions:

- 1) 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) 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.
- 5) Second flowchart for other causes of facial palsy.
- 6) 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.
- 7) Create an algorithm for GPs and Emergency Departments to improve the pathways for this patient group.

Referrals

Key points:

- Of 240 respondents, more than one third (85) were initially referred to ENT.
- Only 106 respondents (44.2%) felt that the specialist they were initially referred to could help them. Only 17 people (12.7%) were referred to another consultant with more experience at this point.
- Of 191 respondents who needed onward referrals to different specialists, just 61 (31.9%) felt they had been immediately referred to an expert and that there had been no wasted appointments seeing someone who could not help them. 37 participants (19.4%) felt they had attended at least one appointment which was of no benefit due to the health professional not being an expert. 93 (48.7%) felt they had attended two or more appointments that were of no benefit with 31 (16.2%) of those stating they had had more than five appointments that were not beneficial.

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. 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/>.

Treatments, Therapies & Surgeries

Key points:

- The Facial Palsy UK charity was credited as the most important source of information with 38.3% of respondents stating that the charity explained facial palsy fully and in a way that they could understand. This question was also asked in our [2019 survey](#) with 19.8% of participants crediting the charity as explaining facial palsy fully and in a way they could understand. This is a 93.4% increase over four years and is a good indicator of how the charity is meeting the demands of those we support. This could be due to an improvement in our website or a deterioration in information by the NHS services driving people to search for information themselves.
- It is also clear from feedback that better information is provided by expert health professionals in facial palsy, e.g. specialist facial palsy clinics (34.2%) and specialist facial therapists (29.2%). ENT Consultants who are the first referral touchpoint for many patients scored low with just 12.1% explaining the condition to patients in a way that was helpful.
- Considering the healthcare options for those with facial palsy, feedback shows that Botulinum toxin injections and specialist facial therapy had the biggest difference between people finding them helpful compared to unhelpful.
- For those who could not access specific treatments, therapies or surgeries, specialist psychological therapy was most sought after (45.8%) and non-specialist psychological help (36.7%). There was also a significant interest in selective neurolysis/myectomy surgery for synkinesis (40.8%) which is a relatively new surgery.
- Treatment and advice around eye care within the first 72 hours was inadequate for more than half of those diagnosed.

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.
- 3) More awareness is needed about the importance of eye care.

Travel insurance

- Of those with a diagnosis of facial palsy rather than Bell's palsy, 58 people had tried to purchase travel insurance since their diagnosis. Of those only 20 (34.5%) declared the facial palsy on travel insurance forms for a variety of reasons. Only four people had problems declaring travel insurance on forms and eight people said they declared they had Bell's palsy due to a lack of other options.

Actions:

- 1) Reach out to an insurance expert to find out whether facial palsy should be declared, particularly if there is incomplete eye closure. Questions need asking re whether eye issues would be covered if not declared or declared incorrectly as Bell's palsy. E.g. what would happen if some lost their sight in the affected eye due to an accident travelling, that might have been a different outcome if able to blink?

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-selected. 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.