



# Results of Facial Palsy UK's Ramsay Hunt syndrome survey (UK responses)

Survey dates: 20 June 2017 – 2 February 2018

## What is Ramsay Hunt syndrome?

Ramsay Hunt syndrome (RHS) is the name given to describe the symptoms of a shingles infection which causes a facial palsy, usually on just one side of the face. The facial nerve or 7th cranial nerve supplies the muscles used to control different areas of the face. As a result of the shingles virus, the facial nerve becomes inflamed and irritated. Shingles is caused by the same virus that causes chickenpox (varicella zoster virus, or VZV).

## About the survey

This survey is intended to find out more about the effects of Ramsay Hunt syndrome. Please note, we may abbreviate Ramsay Hunt syndrome to RHS. This was a worldwide survey to collect as much data as possible. Responses were gathered by online survey. This report extracts only statistics relevant to the UK. We have reported the non-UK results in a separate report. As this condition is commonly misdiagnosed we asked people and their representatives to complete the survey who had either been diagnosed immediately with RHS, later diagnosed or believed they have had RHS to take part. For questions specific to medical care we filtered out those who hadn't been officially diagnosed and will report on those who did not receive an official diagnosis at the end of the survey. There were 206 respondents from the UK.

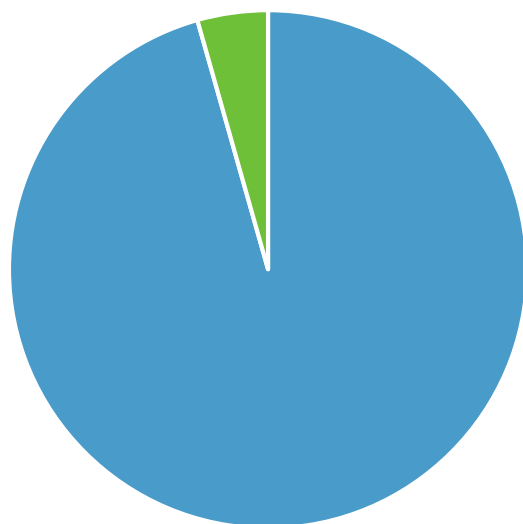
## About Facial Palsy UK

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.

# Contents

|   |    |
|---|----|
| What is Ramsay Hunt syndrome? .....                               | 1  |
| About the survey .....  | 1  |
| About Facial Palsy UK .....                                       | 1  |
| Contents.....   | 2  |
| Who completed the survey?.....                                    | 3  |
| What was the diagnosis?.....                                      | 4  |
| Data sample – where people had an official diagnosis of RHS ..... | 5  |
| Multiple episodes of RHS .....                                    | 7  |
| The Ramsay Hunt syndrome journey.....                             | 8  |
| About the diagnosis & treatment .....                             | 9  |
| Medication – antivirals .....                                     | 10 |
| Medication - steroids.....  | 11 |
| Eye care .....  | 11 |
| Follow-up care .....  | 12 |
| Follow-up care with a GP.....                                     | 14 |
| Private Healthcare/Complimentary therapies.....                   | 15 |
| What health issues were experienced? .....                        | 16 |
| Treatments & therapies .....                                      | 18 |
| Dental care .....   | 19 |
| Long-term symptoms .....  | 20 |
| Employment.....   | 22 |
| Students.....   | 25 |
| No official diagnosis of RHS .....                                | 25 |
| Medication .....  | 27 |
| Health issues .....   | 28 |
| Summary .....   | 30 |
| Diagnosis.....  | 30 |
| Health issues .....   | 31 |
| Treatments and therapies.....                                     | 32 |
| Patient referrals.....  | 33 |
| Other key points and actions .....                                | 33 |

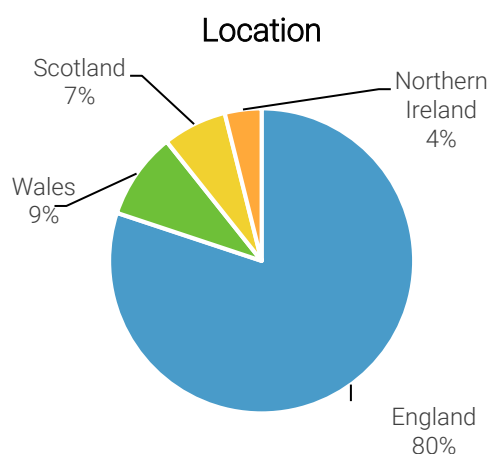
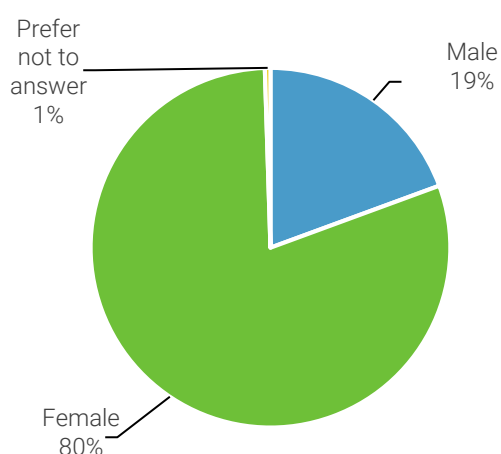
## Who completed the survey?



- Person who has had facial paralysis or has it now
- Person responsible for someone who has facial paralysis or has had it in the past

| AGE OF PERSON WITH FACIAL PALSY |       |        |
|---------------------------------|-------|--------|
| Age bracket                     | %     | Number |
| 0-13                            | 1.5%  | 3      |
| 14-17                           | 1.5%  | 3      |
| 18-24                           | 2.4%  | 5      |
| 25-34                           | 10.2% | 21     |
| 35-54                           | 46.6% | 96     |
| 55-74                           | 32.5% | 67     |
| 75+                             | 5.3%  | 11     |

| Responses from                             | Percent | Responses  |
|--|---------|------------|
| Adult with facial palsy                    | 95.63%  | 197        |
| Parent of child with facial palsy          | 2.43%   | 5          |
| Child of parent with facial palsy          | 0.97%   | 2          |
| Partner/spouse of person with facial palsy | 0.97%   | 2          |
| <b>Total respondents</b>                   |         | <b>206</b> |



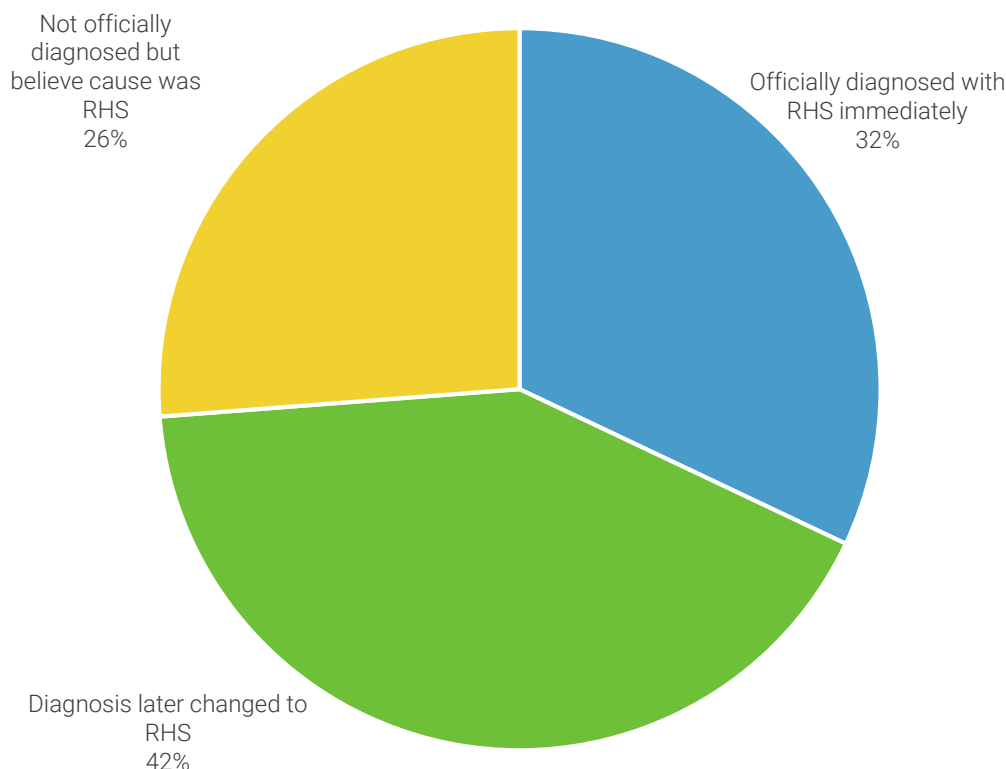
People were asked how they would like their gender to be designated in our statistics.

# What was the diagnosis?

Initial diagnosis given by the health care professional when the facial paralysis first occurred

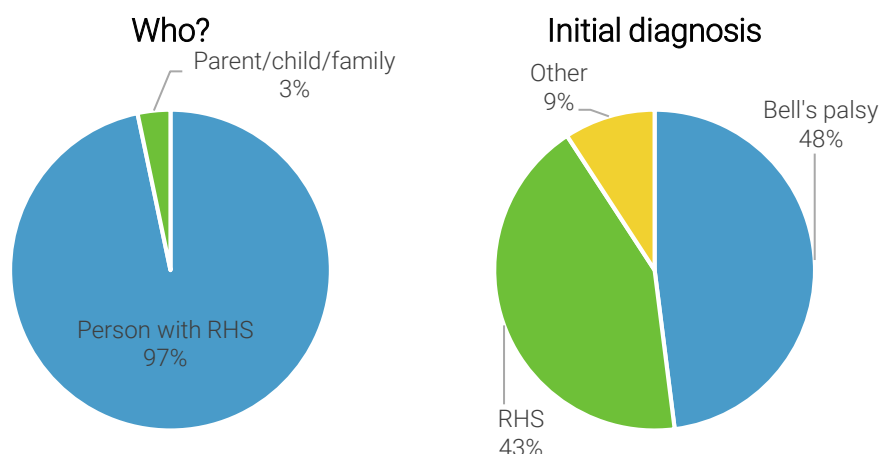
| Diagnosis   | Percent | Responses  |
|---|---------|------------|
| Bell's palsy  | 56.31%  | 116        |
| Ramsay Hunt syndrome  | 32.04%  | 65         |
| General facial nerve paralysis (no further detail given of cause) | 4.37%   | 10         |
| Shingles  | 1.94%   | 4          |
| Ear infection   | 1.46%   | 3          |
| Lyme disease  | 0.97%   | 2          |
| Stroke  | 0.49%   | 1          |
| Allergic reaction   | 0.49%   | 1          |
| Benign paroxysmal positional vertigo (BPPV)                       | 0.49%   | 1          |
| Stress  | 0.49%   | 1          |
| Trigeminal neuralgia  | 0.49%   | 1          |
| Tooth abscess   | 0.49%   | 1          |
| <b>Total respondents</b>  |         | <b>206</b> |

Facial Palsy UK believes that Ramsay Hunt syndrome is frequently misdiagnosed. Patient feedback below suggests this is the case. 65 respondents out of 206 were diagnosed with RHS immediately, 87 people had their diagnosis changed at a later date to RHS. 54 people believe they have had RHS but have never been officially diagnosed.

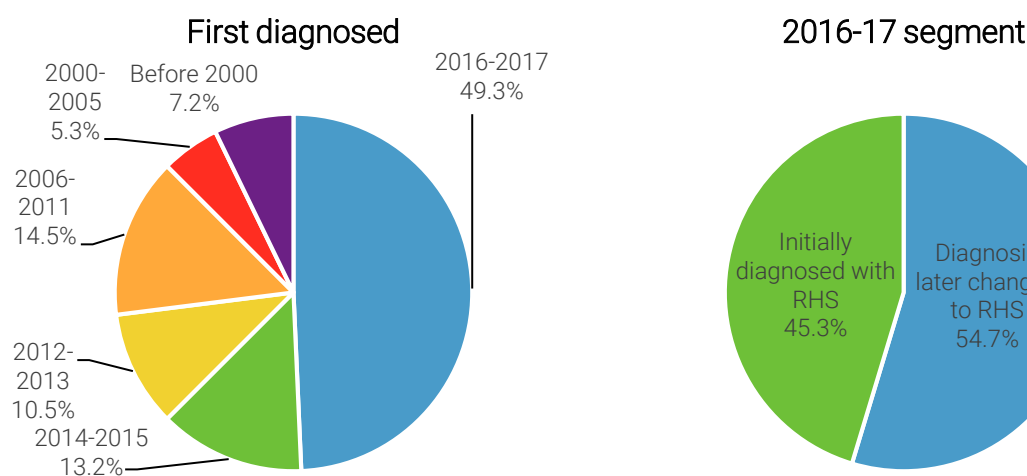


## Data sample – where people had an official diagnosis of RHS

The following statistics apply to the 152 UK participants of which 87 had their diagnosis changed at a later date to Ramsay Hunt syndrome by a health professional.

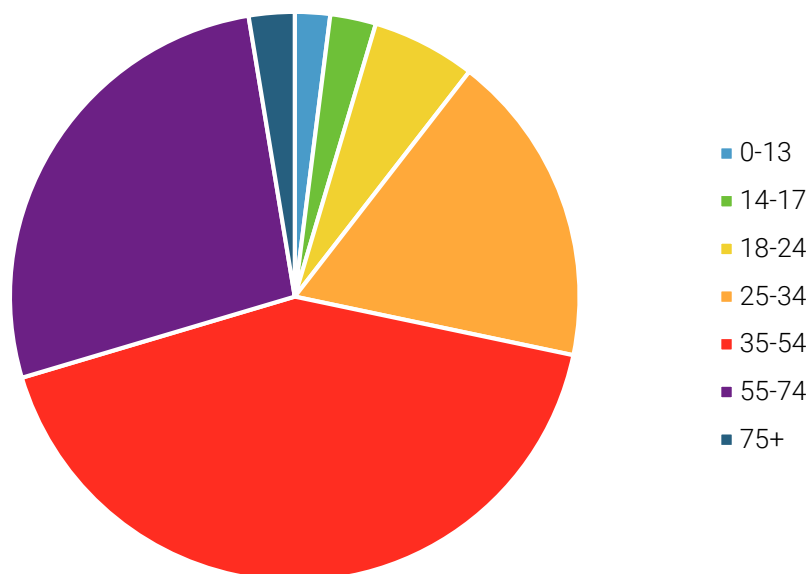


### When was the first episode of Ramsay Hunt syndrome?



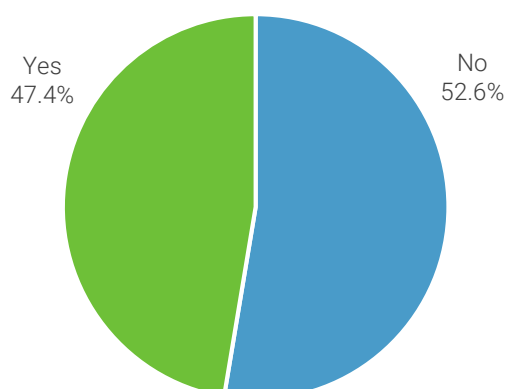
Thinking about those officially diagnosed with Ramsay Hunt syndrome, we analysed the segment of those diagnosed in 2016-17 to see if early diagnosis had improved. Out of the 152 patients who were diagnosed at any time, 65 people (42.8%) were initially diagnosed with Ramsay Hunt syndrome and 87 (57.2%) had their diagnosis changed to RHS at a later date. There was therefore a minimal 2.5% improvement for the 2016-17 sample compared to the sample of all 152 officially diagnosed with RHS. This suggests that early diagnosis has not greatly improved for those more recently affected.

## Age of person when first diagnosed with Ramsay Hunt syndrome



| Responses         | Percent | Responses |
|-------------------|---------|-----------|
| 0-13              | 2.0%    | 3         |
| 14-17             | 2.6%    | 4         |
| 18-24             | 5.9%    | 9         |
| 25-34             | 17.8%   | 27        |
| 35-54             | 42.1%   | 64        |
| 55-74             | 27.0%   | 41        |
| 75+               | 2.6%    | 4         |
| Total respondents |         | 152       |

### Other health problems?



When asked about other health problems, over half of the sample (52.6%) reported no other health problems prior to being diagnosed with Ramsay Hunt syndrome.

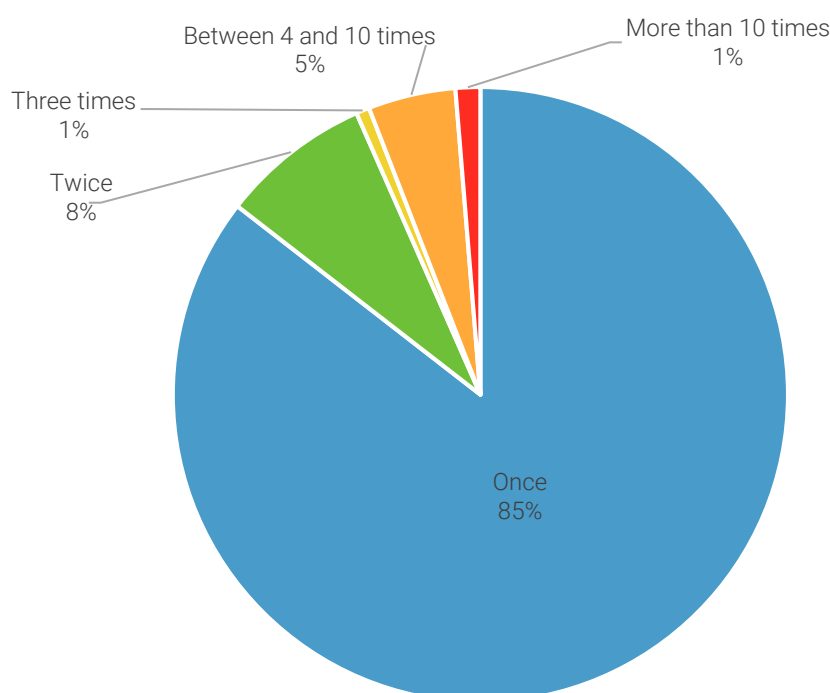
7.2% of the sample had a history of shingles or had shingles elsewhere on the body at the time of diagnosis.

4.6% were previously suffering with depression, anxiety or stress.

2% were pregnant or had recently given birth.

1.3% had cancer. The remainder of health problems reported covered many different conditions.

## Number of times people have had Ramsay Hunt syndrome



85.5% (130 people) had Ramsay Hunt syndrome once. 14.5% (22 people) have had the condition more than once with 6% (nine people) having had the condition more than 4 times.

## Multiple episodes of RHS

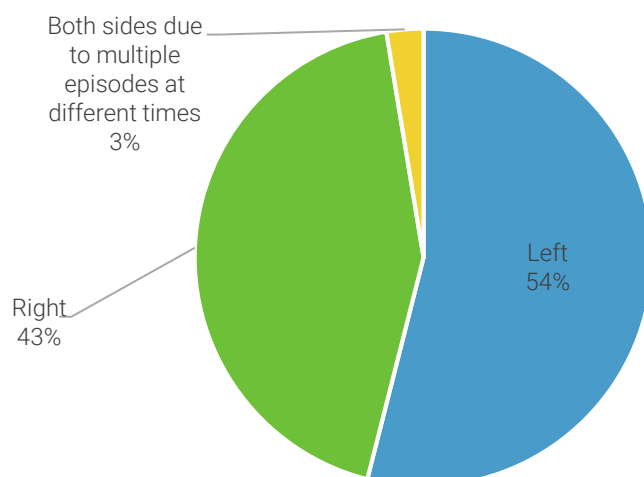
22 people who have had RHS more than once were asked if they had been offered long term antivirals to prevent a further attack of Ramsay Hunt syndrome.

| Location (total responses) | Percentage offered long term antivirals as prevention strategy | Offered to  |
|----------------------------|--|---|
| England (15)               | 9%   | Two people (one had RHS twice and one between 4 and 10 times) |
| Wales (3)                  | 9%   | Two people (one had RHS twice and one between 4 and 10 times) |
| Northern Ireland (3)       | 4.5%   | Based on one person who had RHS three times                   |
| Scotland (1)               | 0%   |   |
|                            | <b>22.5%</b>   | <b>Offered preventative drugs</b>                             |

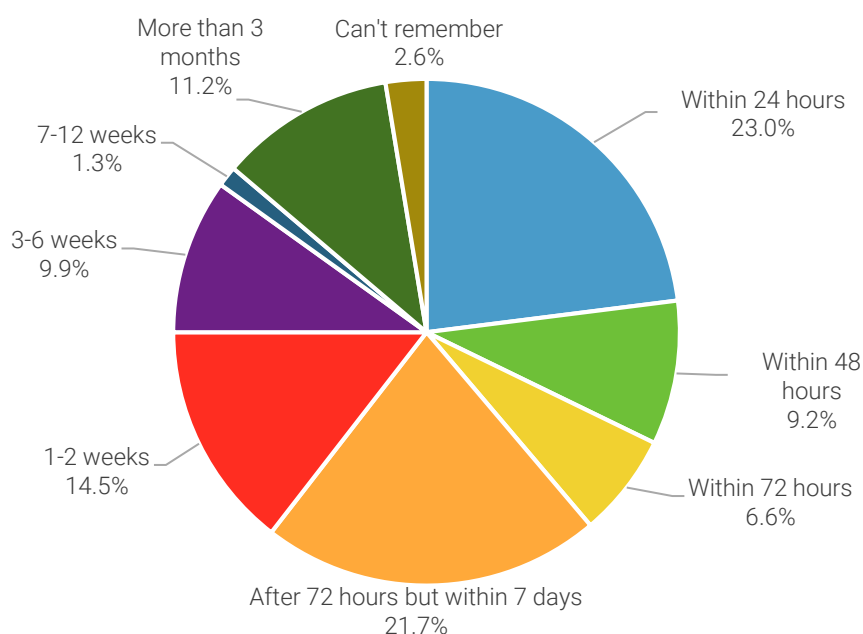
Out of the nine people who have had the condition four times or more, three have been prescribed antivirals to either carry in the event of another attack, or have been prescribed long-term antivirals.

# The Ramsay Hunt syndrome journey

Which side of the face was paralysed?



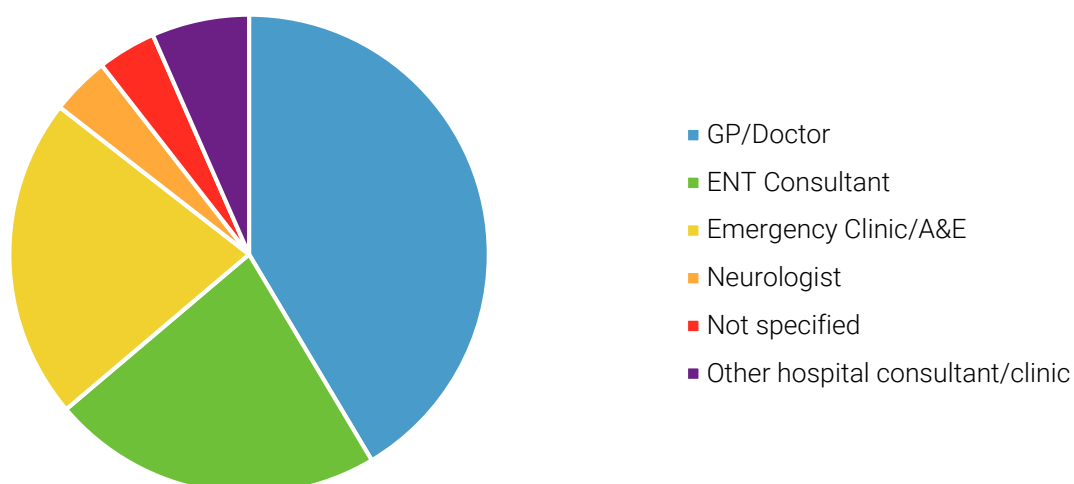
How soon was a diagnosis of Ramsay Hunt syndrome made by a health professional after the facial paralysis began?



| Responses                        | Percent | Responses  | Comment  |
|----------------------------------|---------|------------|--|
| Within 24 hours                  | 23.0%   | 35         | 38.8% officially diagnosed within the 72 hour window |
| Within 48 hours                  | 9.2%    | 14         |  |
| Within 72 hours                  | 6.6%    | 10         |  |
| After 72 hours but within 7 days | 21.7%   | 33         |  |
| 1-2 weeks                        | 14.5%   | 22         |  |
| 3-6 weeks                        | 9.9%    | 15         |  |
| 7-12 weeks                       | 1.3%    | 2          |  |
| More than 3 months               | 11.2%   | 17         |  |
| Can't remember                   | 2.6%    | 4          |  |
| <b>Total respondents</b>         |         | <b>152</b> |  |



## Which health professionals were involved in making the official diagnosis?

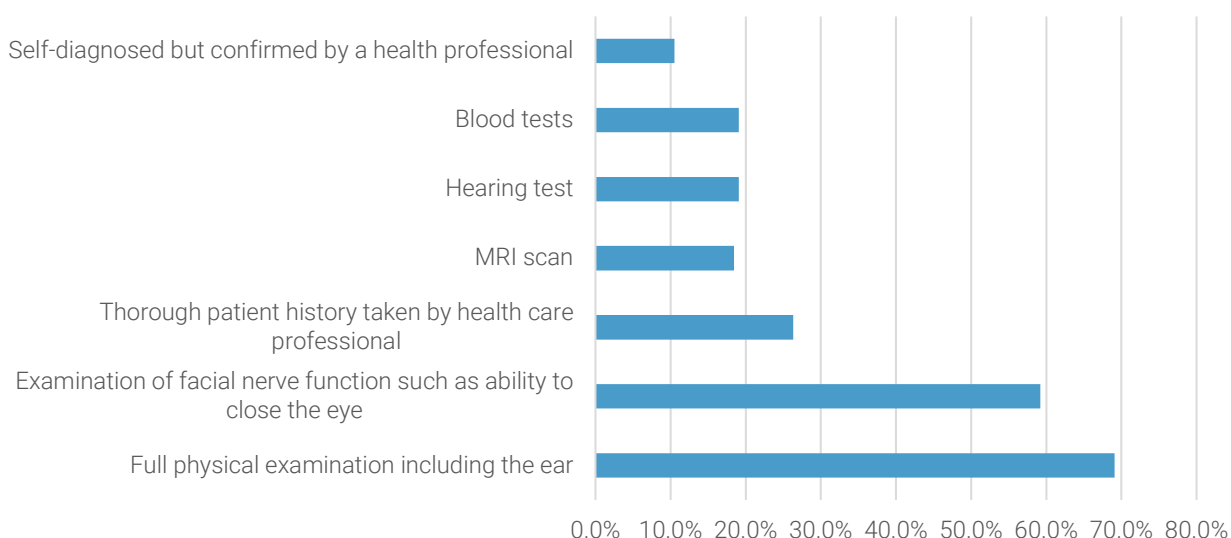


| Responses                           | Percent | Responses  |
|-------------------------------------|---------|------------|
| GP/Doctor                           | 41.45%  | 63         |
| Ear, Nose & Throat (ENT) consultant | 22.37%  | 34         |
| Emergency clinic/A&E                | 21.71%  | 33         |
| Neurologist                         | 3.95%   | 6          |
| Not specified                       | 3.95%   | 6          |
| Other hospital consultant/clinic    | 6.58%   | 10         |
| <b>Total respondents</b>            |         | <b>152</b> |

Of 152 people officially diagnosed with Ramsay Hunt syndrome, 96 (63.2%) were diagnosed by GP/Doctor and Emergency clinics/A&E.

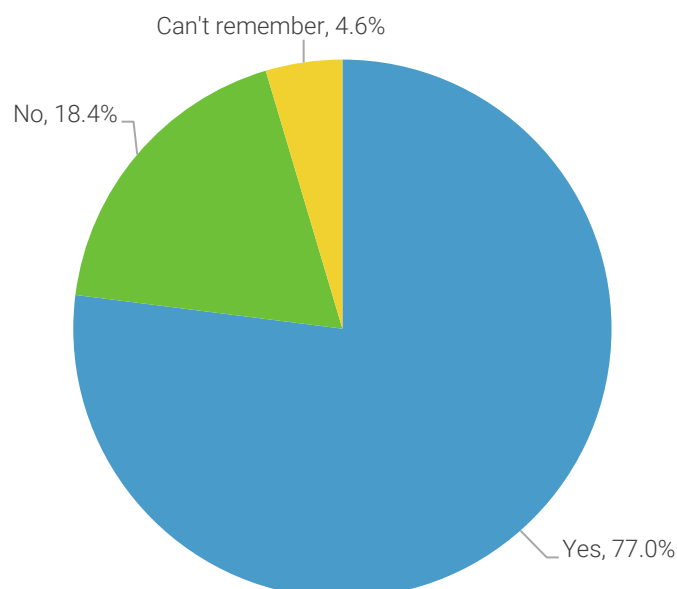
## About the diagnosis & treatment

### How was the diagnosis made?



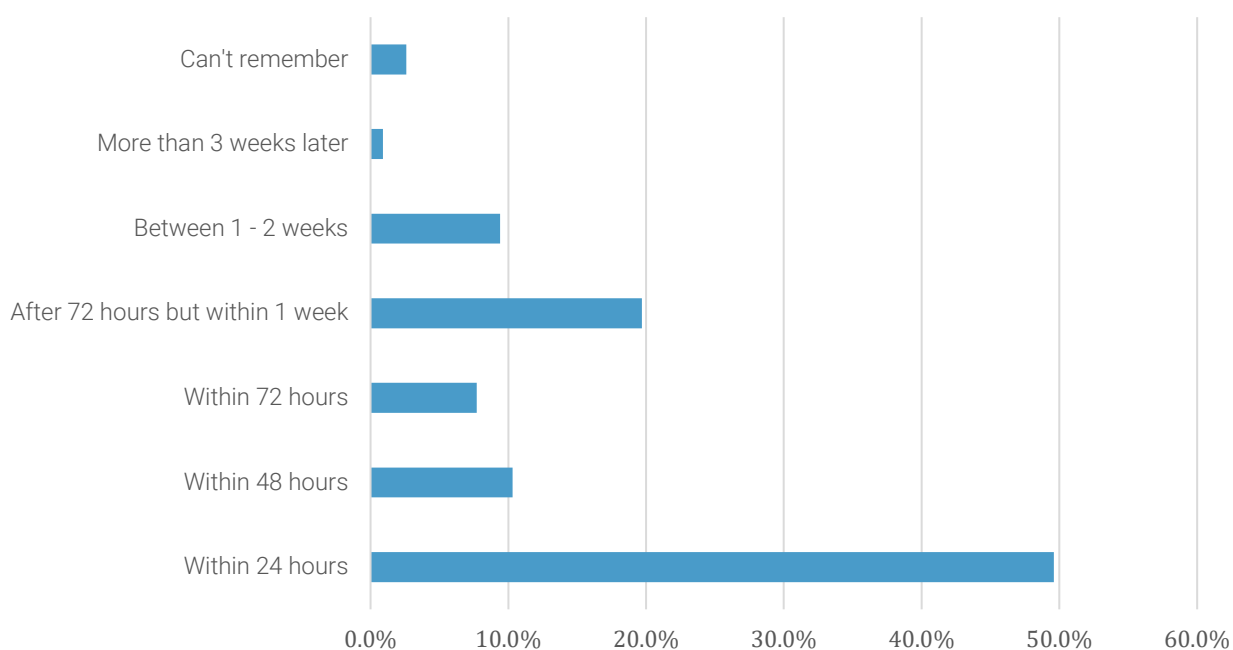
## Medication – antivirals

Were antivirals prescribed?



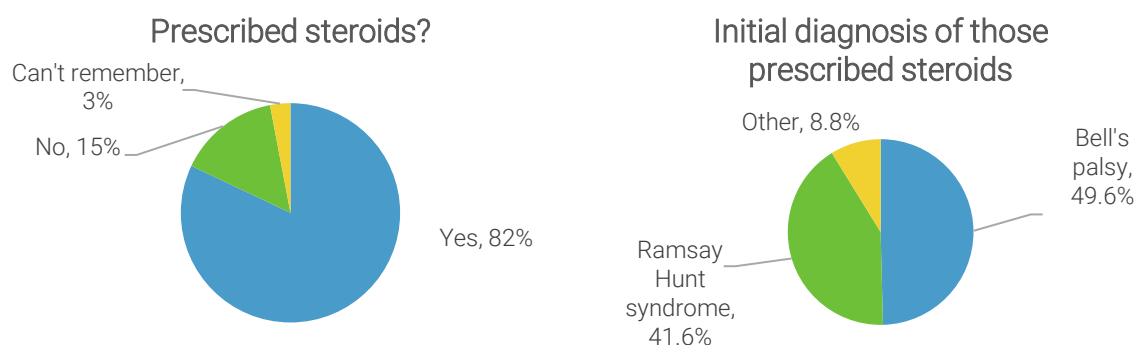
77% of people (117 out of 152) with a confirmed diagnosis of Ramsay Hunt syndrome were prescribed antivirals.

On seeing a health professional, how quickly were antivirals prescribed?

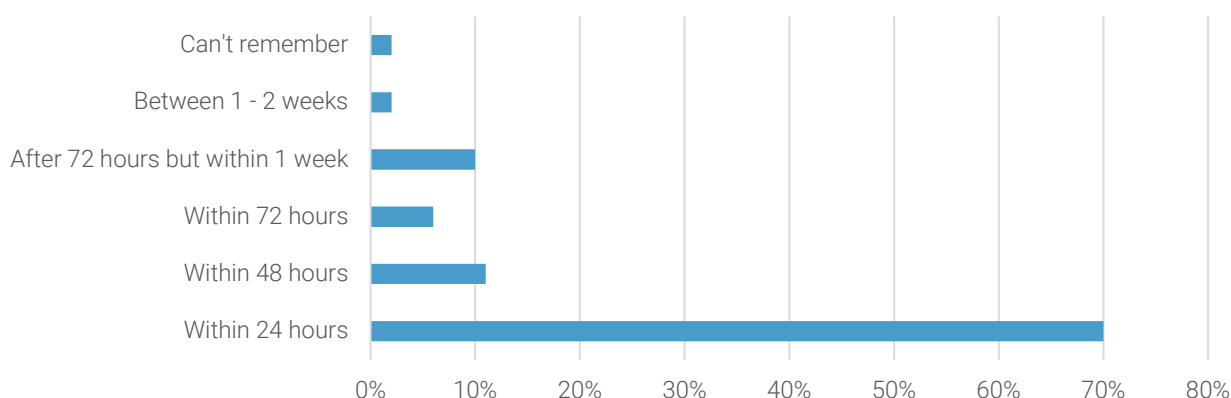


67.5% of those prescribed antivirals who had a confirmed diagnosis of RHS were prescribed them within the 72 hour window and less than half (49.57%) received antivirals within 24 hours. 79 people out of 152 (52%) officially diagnosed received antivirals within 72 hours.

## Medication - steroids



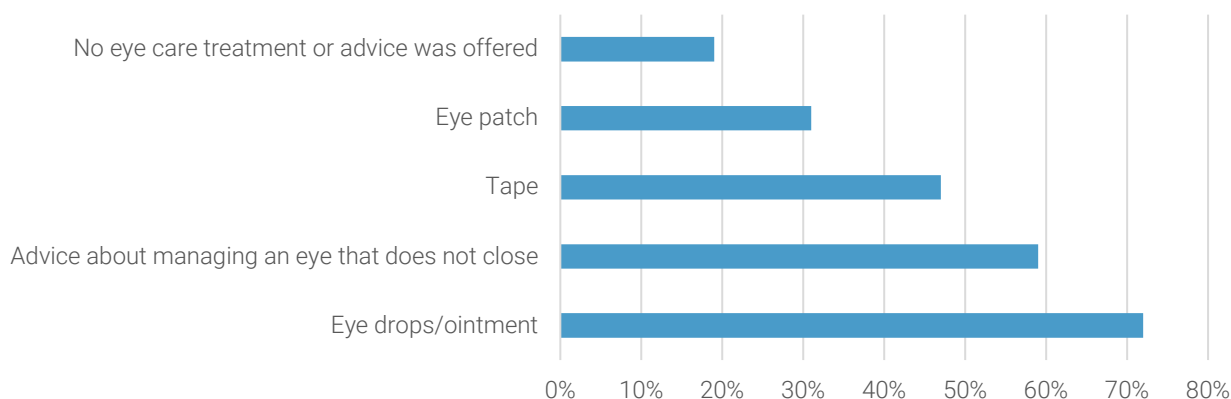
On seeing a health professional, how quickly were steroids prescribed?



87% of those prescribed steroids who had a confirmed diagnosis of RHS were prescribed them within the 72 hour window. 110 people out of 152 (72%) officially diagnosed received steroids within 72 hours.

## Eye care

In relation to eye care, we asked what was offered at the point of diagnosis.



No eye care advice was offered to 19% of those officially diagnosed with Ramsay Hunt syndrome. 59% were offered general advice about managing an eye that does not close. Eye drops/ointment were offered to 72%. We expect fewer people to be offered tape or an eye patch, as these tend to be provided when the diagnosis is made in the hospital setting.

## Follow-up care

We asked those with an official diagnosis of Ramsay Hunt syndrome, were you followed up after the initial episode of facial paralysis?

Just 63% of respondents who had been officially diagnosed with Ramsay Hunt syndrome were routinely followed up by their GP or at a hospital clinic.

| Responses   | Percent | Number     |
|---|---------|------------|
| No - I had to request a follow-up appointment from my GP/doctor           | 26%     | 39         |
| No - I have not seen my GP/doctor or hospital for a follow-up appointment | 11%     | 17         |
| Yes - an appointment was routinely offered by my GP/doctor                | 18%     | 27         |
| Yes - I was given a follow-up appointment to attend the hospital          | 45%     | 69         |
| <b>Total respondents</b>  |         | <b>152</b> |

We then asked a series of questions aimed only at the 69 people who had been given a follow-up appointment to attend the hospital.

Which hospital clinic was referral made to?

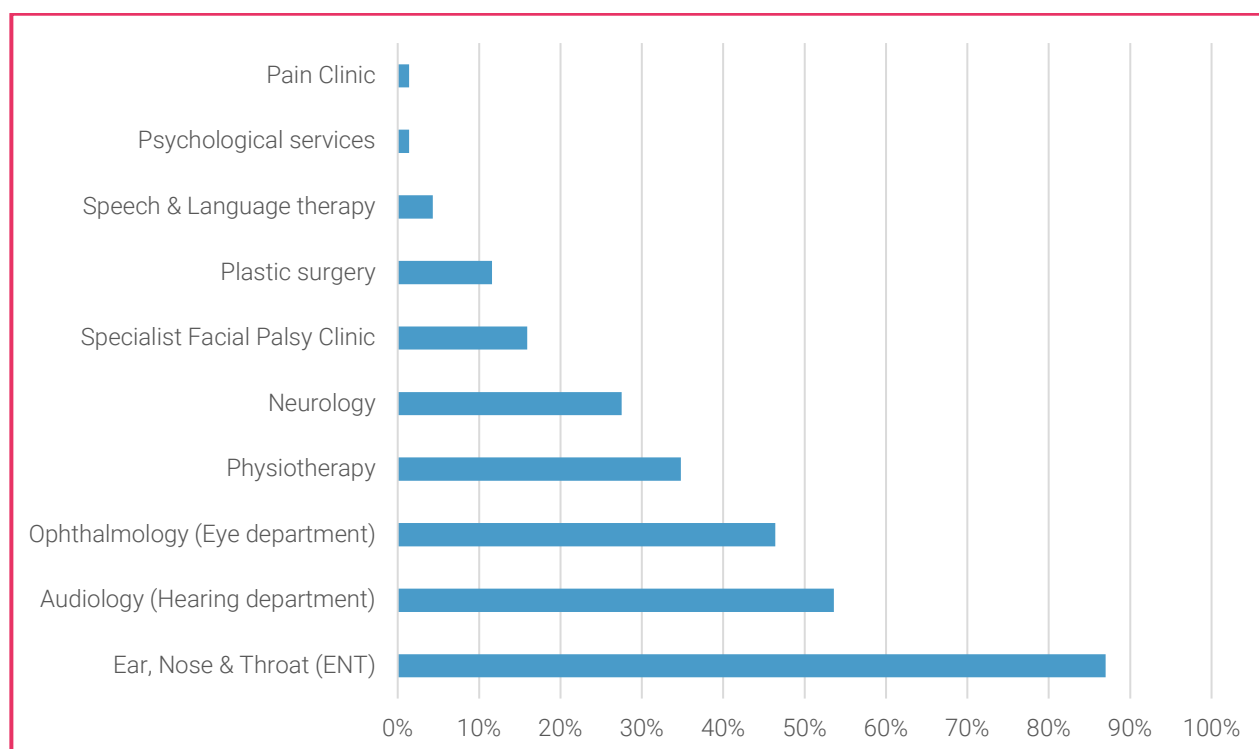


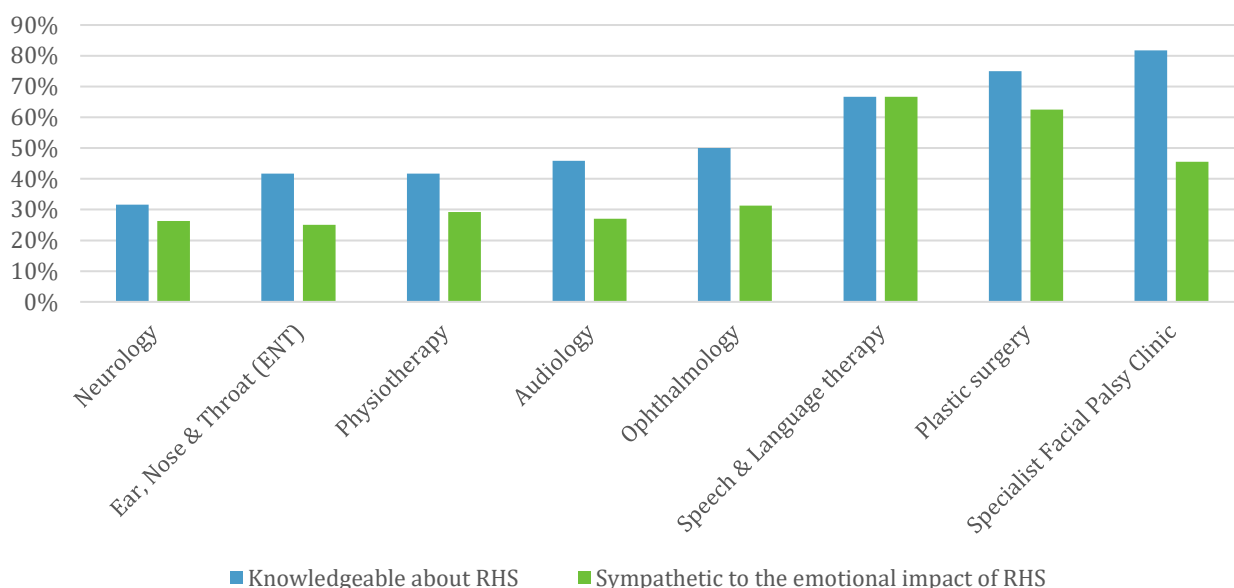
Table below shows the number of respondents who were referred to a clinic and within what timeframe.

| Clinic type<br>69/152 people<br>received a routine<br>hospital referral | Within 3<br>months | Within 6<br>months | Within 12<br>months | More than<br>12 months | Can't<br>remember | Total<br>responses |
|---|--------------------|--------------------|---------------------|------------------------|-------------------|--------------------|
| Ear, Nose & Throat  | 57                 | 2                  | 1                   |                        |                   | 60                 |
| Audiology   | 27                 | 7                  | 1                   | 2                      |                   | 37                 |
| Ophthalmology   | 23                 | 2                  | 3                   | 4                      |                   | 32                 |
| Physiotherapy   | 11                 | 3                  | 7                   | 3                      |                   | 24                 |
| Neurology   | 11                 | 4                  | 1                   | 2                      | 1                 | 19                 |
| Specialist Facial<br>Palsy Clinic                                       | 3                  | 1                  | 2                   | 5                      |                   | 11                 |
| Plastic surgery   | 2                  | 2                  | 2                   | 2                      |                   | 8                  |
| Speech &<br>Language therapy  | 1                  | 2                  |                     |                        |                   | 3                  |
| Psychological<br>services   |                    | 1                  |                     |                        |                   | 1                  |
| Pain Clinic   | 1                  |                    |                     |                        |                   | 1                  |

*"The main issue I had when I became diagnosed was accessing the appropriate services. There was a lack of service provision in NHS Lothian. I moved home to access healthcare services in another area."*

Other clinics attended were the Hospital of Tropical Diseases in London (1), general children's clinic (1) and maxillofacial (3).

The chart below shows the % of people who agreed with statements that the health care provider was 1) Knowledgeable about RHS and 2) Sympathetic to the emotional impact of RHS.



*"One doctor in Neurology told me to grow my hair/fringe so that it wouldn't notice!!!"*

## Follow-up care with a GP

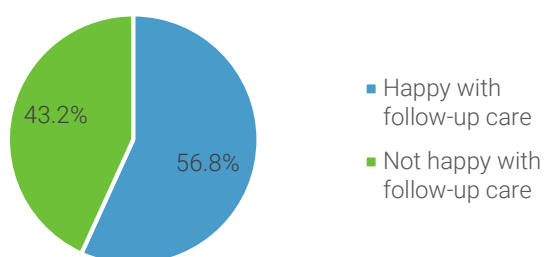
45 out of the 69 people (65.2%) who received a routine follow-up with the hospital also approached their GP/doctor for additional follow-up care.

The following statistics refer to 111 people followed up by their GP:

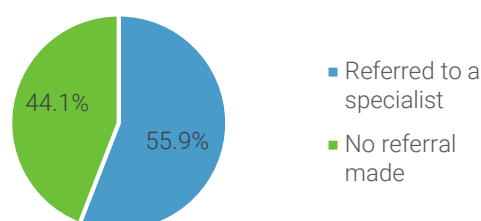
- 45 people who had already been routinely reviewed by a hospital clinic
- 27 people who were routinely followed up by their GP
- 39 people who requested follow-up with their GP

| Statement  | Agree with this statement | Neither agree nor disagree | Disagree with this statement | Not applicable |
|--|---------------------------|----------------------------|------------------------------|----------------|
| The doctor was happy to refer to the local hospital                                | 56.8%                     | 14.4%                      | 19.8%                        | 9.0%           |
| The doctor was supportive in terms of needing time off work/school                 | 53.2%                     | 17.1%                      | 8.1%                         | 21.6%          |
| The doctor checked eye closure and explained how to care for the eye               | 49.5%                     | 15.3%                      | 30.6%                        | 4.5%           |
| The doctor was sympathetic to the emotional impact of RHS                          | 39.6%                     | 20.7%                      | 36.0%                        | 3.6%           |
| Knowledgeable about RHS  | 30.6%                     | 21.6%                      | 45.0%                        | 2.7%           |
| The doctor checked for any ear/hearing problems                                    | 30.6%                     | 13.5%                      | 51.4%                        | 4.5%           |
| The doctor checked inside the mouth  | 29.7%                     | 8.1%                       | 55.9%                        | 6.3%           |
| The doctor was happy to refer to a specialist facial palsy clinic outside the area | 21.6%                     | 17.1%                      | 45.0%                        | 16.2%          |

Patient feedback about GP



Referrals by GP for additional follow-up care



*"My GP did not diagnose RHS and ignored my complaint of severe ear pain and told me the sickness (vertigo) was 'bad luck'. Even after I was referred to an ENT specialist and properly diagnosed, my GP still refused to acknowledge RHS and kept saying I had Bell's palsy."*

*"Lots of treatment out there I could have had, but was given a copy of Bell's palsy exercises off the computer, that was it. After a few years I asked to see a consultant but they were reluctant. Finally got to see the right person but it took 4 years."*

*"I asked for facial paralysis treatment. I was told NHS has no money for that."*

43.2% of people were unhappy with the support given by their GP in relation to their symptoms.

## Additional referrals made to a specialist by the GP

62 of 111 people (55.9%) were referred for further follow-up care.

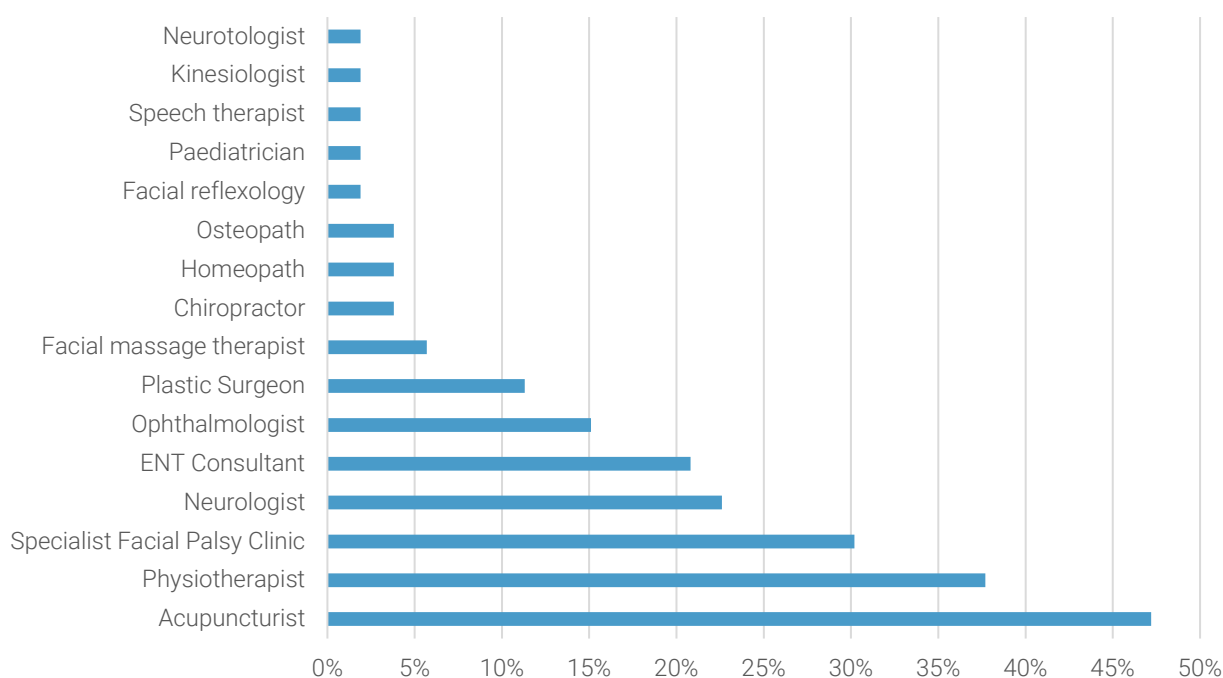
| Clinic type                    | Within 3 months | Within 6 months | Within 12 months | More than 12 months | Can't remember | Total responses |
|--------------------------------|-----------------|-----------------|------------------|---------------------|----------------|-----------------|
| Ear, Nose & Throat (ENT)       | 28              | 4               | 1                | 2                   | 2              | 37              |
| Ophthalmology (Eye department) | 18              | 6               | 3                | 1                   | 1              | 29              |
| Specialist Facial Palsy Clinic | 3               | 6               | 4                | 9                   | 0              | 22              |
| Neurology                      | 9               | 6               | 1                | 3                   | 1              | 20              |
| Physiotherapy                  | 10              | 5               | 0                | 5                   | 0              | 20              |
| Audiology (Hearing department) | 12              | 3               | 1                | 1                   | 2              | 19              |
| Plastic surgery                | 1               | 2               | 0                | 6                   | 1              | 10              |
| Psychological services         | 0               | 1               | 2                | 2                   | 0              | 5               |
| Pain Clinic                    | 1               | 0               | 0                | 1                   | 1              | 3               |
| Speech & Language therapy      | 0               | 0               | 0                | 2                   | 0              | 2               |

We invited people who had struggled to get a referral to comment about their experiences. The top 3 reported issues were:

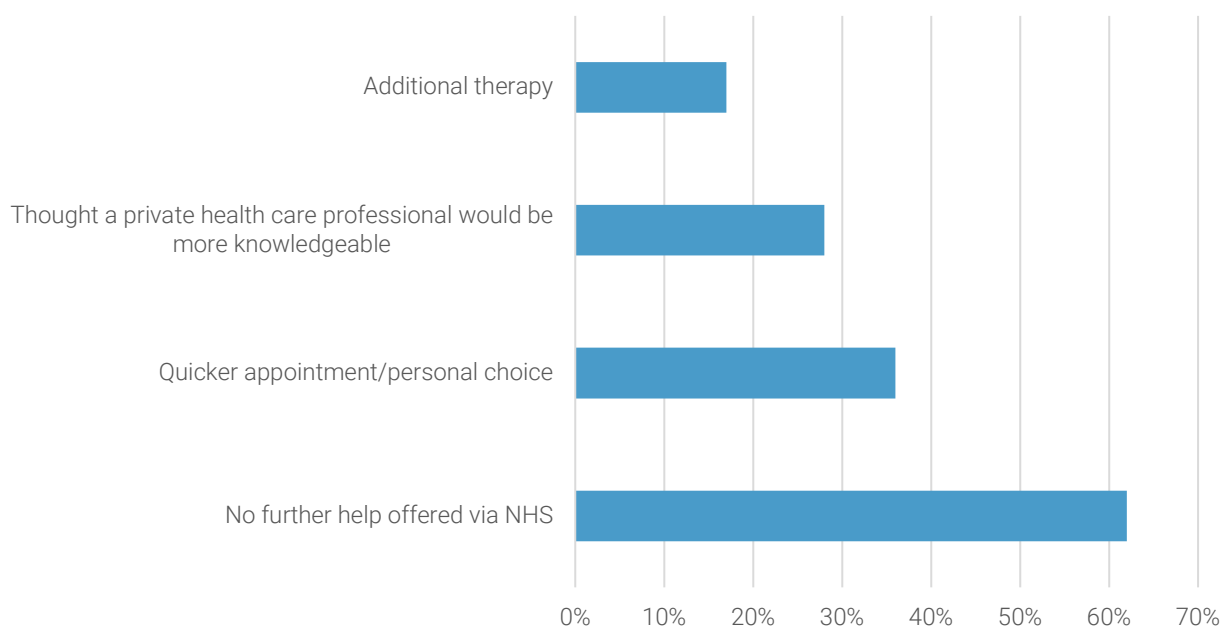
- 1) People had to do their own research to find a specialist.
- 2) GP did not know specialist care existed for people with facial palsy.
- 3) The GP was unhelpful in providing follow-up care, i.e. making a referral.

## Private Healthcare/Complimentary therapies

53 out of the 152 people (34.9%) sought help outside the NHS to treat the effects of RHS as per the chart below.



## The reasons 53 people sought private healthcare and/or complementary therapies



## What health issues were experienced?

Health issues experienced in connection with Ramsay Hunt syndrome by 152 participants with confirmed diagnosis

| Health issue   | Percent | Number |
|--|---------|--------|
| Facial paralysis (unable to make facial expressions) | 94.7%   | 144    |
| Eating & drinking problems                           | 89.5%   | 136    |
| Ear pain   | 84.2%   | 128    |
| Dry eye  | 81.6%   | 124    |
| Fatigue  | 79.6%   | 121    |
| Muscle tightness/tension/facial pain                 | 78.9%   | 120    |
| Self-consciousness                                   | 77.0%   | 117    |
| Numbness on the face                                 | 69.7%   | 106    |
| Speech problems                                      | 68.4%   | 104    |
| Low self-esteem                                      | 61.2%   | 93     |
| Tinnitus   | 59.9%   | 91     |
| Hearing problems                                     | 56.6%   | 86     |
| Anxiety  | 56.6%   | 86     |
| Vertigo  | 55.9%   | 85     |
| Vision problems                                      | 53.9%   | 82     |
| Uncontrolled facial movements/twitching              | 47.4%   | 72     |
| Depression   | 45.4%   | 69     |
| Neck pain  | 40.8%   | 62     |
| Pins and needles                                     | 32.9%   | 50     |
| Dental problems                                      | 28.9%   | 44     |

In further comments, four people also indicated they had felt suicidal.



## Ongoing health issues six months after diagnosis

Nine people had recovered by six months, 22 people had not had the condition for six months. Percentages are based on 121 people who had RHS at the six month stage.

| Health issue  | Percent | Number |
|---|---------|--------|
| Muscle tightness/tension/facial pain                        | 68.6%   | 83     |
| Self-consciousness  | 64.5%   | 78     |
| Fatigue   | 62.0%   | 75     |
| Facial paralysis (unable to make facial expressions)        | 61.2%   | 74     |
| Dry eye   | 58.7%   | 71     |
| Eating & drinking problems                                  | 52.1%   | 63     |
| Anxiety   | 47.9%   | 58     |
| Numbness on the face  | 45.5%   | 55     |
| Low self-esteem   | 45.5%   | 55     |
| Tinnitus  | 44.6%   | 54     |
| Uncontrolled facial movements/twitching                     | 43.0%   | 52     |
| Speech problems   | 38.8%   | 47     |
| Ear pain  | 36.4%   | 44     |
| Depression  | 36.4%   | 44     |
| Hearing problems  | 35.5%   | 43     |
| Vision problems   | 34.7%   | 42     |
| Vertigo   | 33.1%   | 40     |
| Dental problems   | 22.3%   | 27     |
| Neck pain   | 20.7%   | 25     |
| Pins and needles  | 17.4%   | 21     |
| Permanent corneal damage diagnosed by a health professional | 3.3%    | 4      |
| Ongoing soreness in lining of the mouth                     | 1.7%    | 2      |
| Suicidal  | 1.7%    | 2      |
| Had condition less than six months - not applicable         |         | 22     |
| Not applicable – fully recovered at six months              |         | 9      |

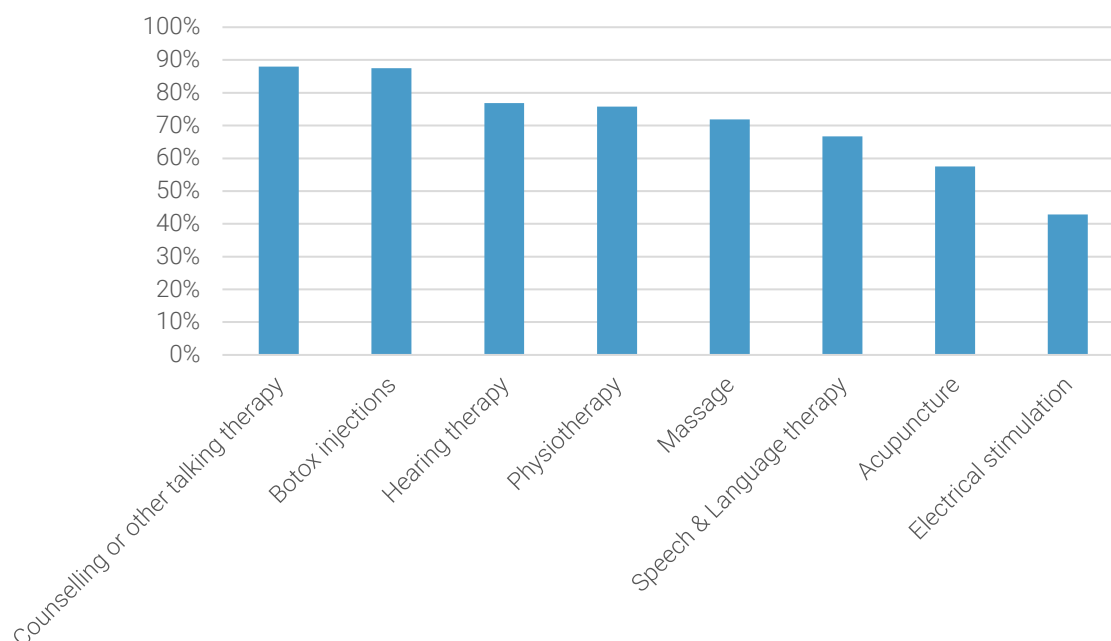
25 people (16.4%) had had shingles on another part of their body in the past.

## Treatments & therapies

We asked people to tell us about treatments and therapies they had tried and rank them according to helpfulness. The table below ranks the treatments in order of 'big improvement'.

| Treatment/<br>Therapy                   | Made a big<br>improvement | Helpful | Made no<br>difference | Made<br>things<br>worse | Haven't<br>tried | Who<br>tried | Responses |
|---|---------------------------|---------|-----------------------|-------------------------|------------------|--------------|-----------|
| Physiotherapy                           | 19                        | 28      | 14                    | 1                       | 90               | 62           | 152       |
| Botox injections                        | 11                        | 17      | 2                     | 2                       | 120              | 32           | 152       |
| Massage                                 | 11                        | 35      | 14                    | 4                       | 88               | 64           | 152       |
| Acupuncture                             | 8                         | 11      | 14                    | 0                       | 119              | 33           | 152       |
| Electrical<br>stimulation               | 4                         | 8       | 11                    | 5                       | 124              | 28           | 152       |
| Speech & Language<br>therapy            | 2                         | 6       | 4                     | 0                       | 140              | 12           | 152       |
| Counselling or other<br>talking therapy | 2                         | 20      | 1                     | 2                       | 127              | 25           | 152       |
| Hearing therapy                         | 0                         | 10      | 3                     | 0                       | 139              | 13           | 152       |

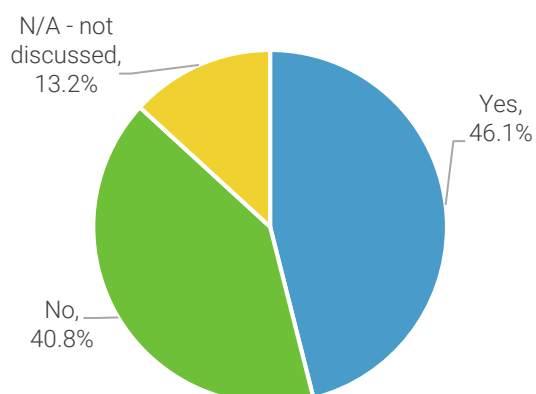
We have added the 'Made a big improvement' and 'Helpful' scores in the chart below to give a picture of how much positive feedback there was about the different treatments and therapies.



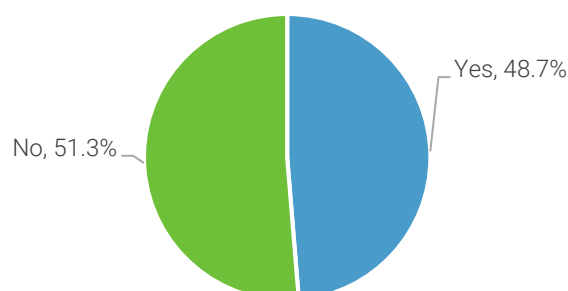
## Dental care

76 people visited a dentist while experiencing facial paralysis and we asked them the following questions:

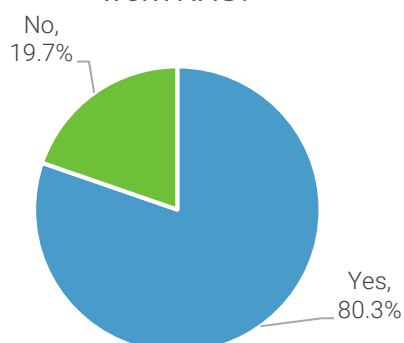
Had your dentist heard of Ramsay Hunt syndrome?



Did your dentist instruct you to pay more attention to dental hygiene on the affected side of the mouth while symptoms of facial paralysis last?



Were you happy with the support offered by your dentist in relation to your symptoms from RHS?



*"My dentist offered advice on how to keep my mouth healthy whilst my saliva gland is not functioning properly."*

*"My dentist was the one who told me that I had ulcers in my mouth as I attended an appointment."*

*"I wish my dentist had been aware of what RHS was."*

*"My dentist didn't seem too bothered when I mentioned about my condition."*

## Long-term symptoms

61.2% of those surveyed told us they were diagnosed with Ramsay Hunt syndrome more than 12 months ago. 90.3% of those said they are still experiencing health issues linked to the condition. We asked these 84 people what their 'Top 3' ongoing issues are. The table below shows how issues ranked, fatigue and dry eye issues jointly ranked 3<sup>rd</sup>. Muscle tightness/tension/facial pain and facial paralysis (inability to make facial expressions) were the top two issues.

| Health issue   | Overall Rank | Score |
|--|--------------|-------|
| Muscle tightness/tension/facial pain                 | 1.0          | 76    |
| Facial paralysis (unable to make facial expressions) | 2.0          | 73    |
| Fatigue  | 3.0          | 48    |
| Dry eye/vision problems                              | 3.0          | 48    |
| Vertigo  | 4.0          | 35    |
| Self-consciousness                                   | 5.0          | 31    |
| Tinnitus (hearing sounds from inside your body)      | 6.0          | 28    |
| Uncontrolled facial movements/twitching              | 7.0          | 25    |
| Depression/anxiety                                   | 8.0          | 23    |
| Ear pain   | 8.0          | 23    |
| Eating & drinking problems                           | 9.0          | 22    |
| Hearing problems                                     | 10.0         | 20    |
| Numbness on the face                                 | 11.0         | 15    |
| Speech problems                                      | 12.0         | 12    |
| Pins and needles                                     | 13.0         | 10    |
| Low self-esteem                                      | 14.0         | 8     |
| Neck pain  | 15.0         | 7     |

### General comments received by people who had had RHS more than 12 months

*"The entire experience of the brutality of this condition was terrifying and life-changing. Not being able to rely on health practitioner for support for the simple reason that they didn't know. The general ignorance about the condition is alarming. I am still suffering from anxiety. I am frightened. Life-changing experience and fear of losing my identity permanently. Continuous buzz and fog in my head."*

*"Vertigo or disequilibrium is constant! Unsure if connected but 'brain fog' is an ongoing problem. I am much less active since RHS as walking, even driving takes effort and concentration."*

*"Love to smile again to be able to eat a sandwich and to talk without feeling self-consciousness. I feel sad as if part of me has gone for ever."*

*"The pain, pins and needles in the left side of my face can last anything from a day to a week. I don't want to talk, eat, stand up or move when my face starts to hurt. It hurts even more when I talk or move my head, all I want to do is lay down and be on my own. It makes me moody and agitated around others and weepy. The paralysis of the face is difficult for me at times, most people think I've had a stroke. I hate having my photo taken as it makes my face look lop-sided and when I smile my face looks deformed, eating can be tricky but I have learnt to adapt with this, although my inner cheek on the left bears the signs of scaring from me biting my inner cheek when eating."*

*"Pain disrupts sleeping making me agitated and has affected my temper, the lack of taste on my tongue and weird sensations in it constantly irritates me. Any change in temperatures is painful and stress makes my face drop and I then dribble from the corner of my mouth. This had led to me withdrawing from social situations and leaves me feeling isolated on occasions. I do wish I was no longer living as the pain does wear me down."*

*"Speech problems are intermittent but when they happen I feel very awkward. Eating and drinking problems are very difficult socially and make me embarrassed. It has made me decline invitations to go out for a meal and when I do go out I have to choose soft, moist food to try to avoid accidents."*

*"My face has lost its symmetry. I don't have a smile but a snarl. There is muscle tension in my cheeks and my eye has a constant twitch. Botox injections bring some improvement but as it wears off its back to normal. There is still the biting of the cheeks and the tightness. I still experience stares from people and inquisitive questions from young children. It does make me feel low when I look at myself in the mirror."*

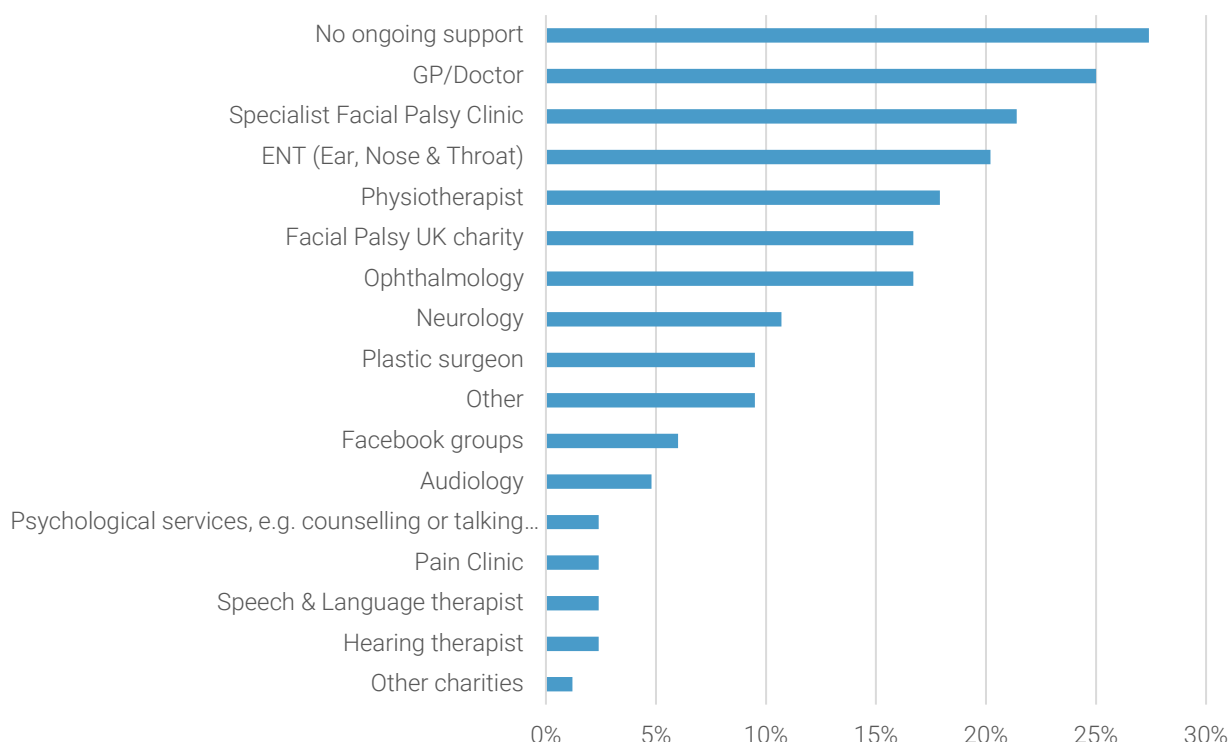
*"The fatigue dictates my life, as does the balance issues i.e. vertigo. I had to leave work and move to a smaller home on one floor. I walk slowly with the aid of a stick and overbalance often. The facial twitches, which increase with tiredness, are embarrassing and make me self-conscious and to restrict social interaction and has led to depression."*

*"I still feel as though I am speaking out of the side of my mouth especially with letters b, f, w. Embarrassed sometimes when eating - wiping my mouth, dabbing my eye that waters. My right eyelid that droops and feels like a dark hand stopping me looking up especially when I am tired."*

*"Hearing sounds is fractured and not clear. Facial muscle tightens when eating and speaking."*

### Support 12 months after diagnosis

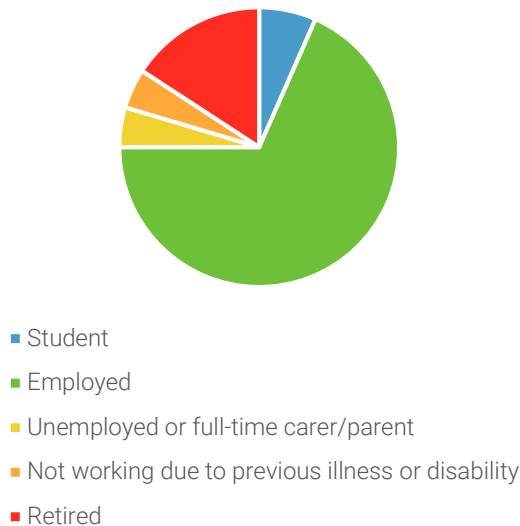
The 84 people who had had RHS for more than 12 months and still have ongoing symptoms were asked who is offering support. 27.4% are receiving no ongoing support.



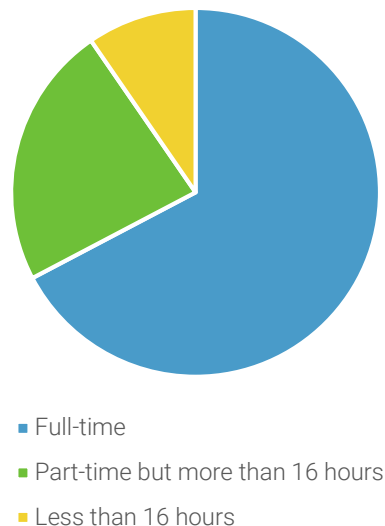
# Employment

We asked some questions about employment status to understand how this condition had impacted people's lives. 104 out of the 152 officially diagnosed with Ramsay Hunt syndrome were employed.

## Employment status



## Employed - hours worked

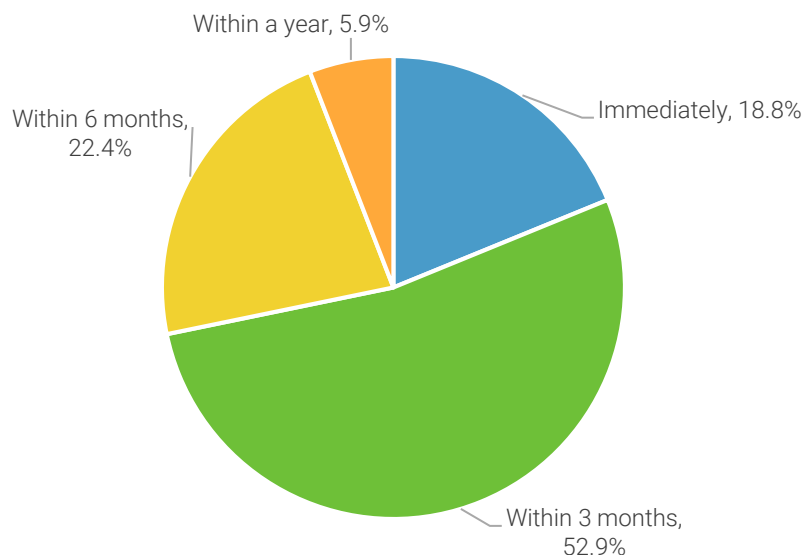


Some people shared with us the type of roles they were in at the time of diagnosis.

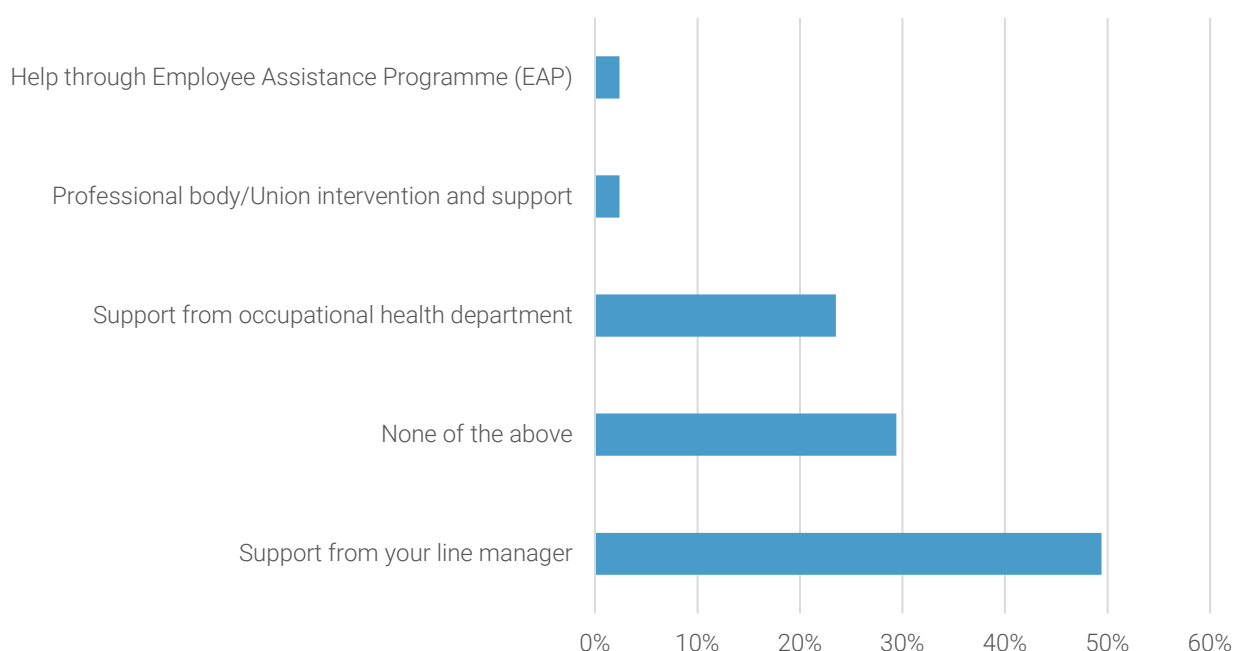
81.7% returned to the same job after developing the condition.

85 people returned to the same job after being diagnosed with Ramsay Hunt syndrome. The following questions about returning to work are based on this segment.

## How soon did people return to work?

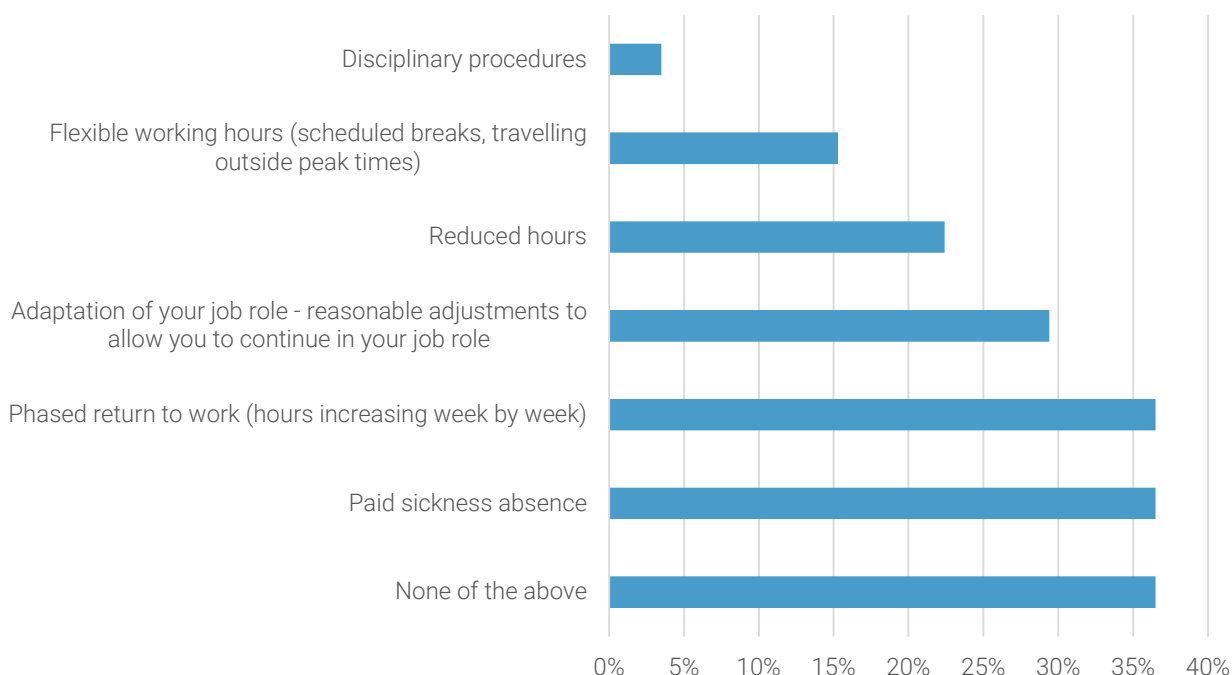


## What support did they receive on their return to work?

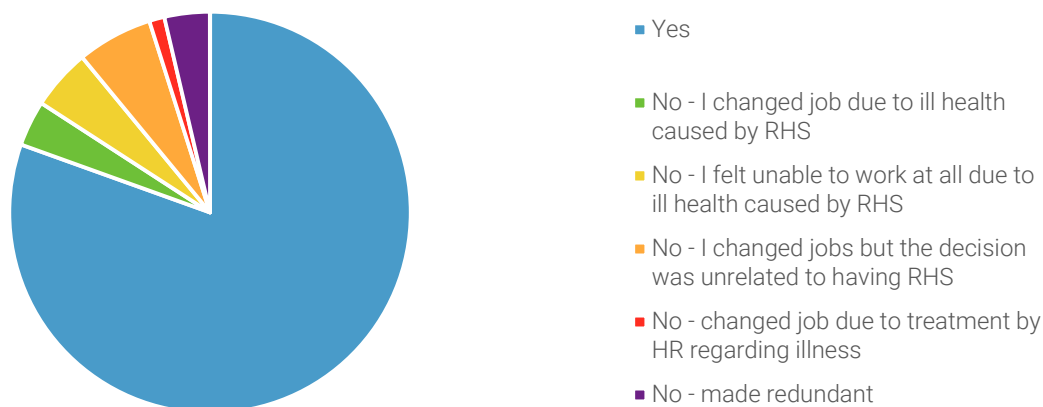


| Support offered                                  | Percent | Number |
|--|---------|--------|
| Support from colleagues                          | 54.10%  | 46     |
| Support from your line manager                   | 49.40%  | 42     |
| Support from occupational health department      | 23.50%  | 20     |
| Professional body/Union intervention and support | 2.40%   | 2      |
| Help through Employee Assistance Programme (EAP) | 2.40%   | 2      |
| None of the above                                | 29.40%  | 25     |

## Which of the following were discussed by their employer?



## Did people remain in the same job?



9.8% changed jobs or left employment as a direct impact of Ramsay Hunt syndrome.

*"No support from work was offered. However when I returned to work my diagnosis was Bell's palsy. It took six years for my diagnosis to be changed to Ramsay Hunt."*

*"I was made redundant because of reorganisation. But I was well aware that my presence as front of the office was not desirable. My face did not fit with the image of the company. I applied for several jobs, secured interviews on the strength of my CV, but was rejected after interview. It became a pattern."*

*"I closed my business due to RHS."*

*"Employer was superb."*



## Students

20 people were students or studying for a qualification when diagnosed with Ramsay Hunt syndrome. 85% said that their studies were disrupted.

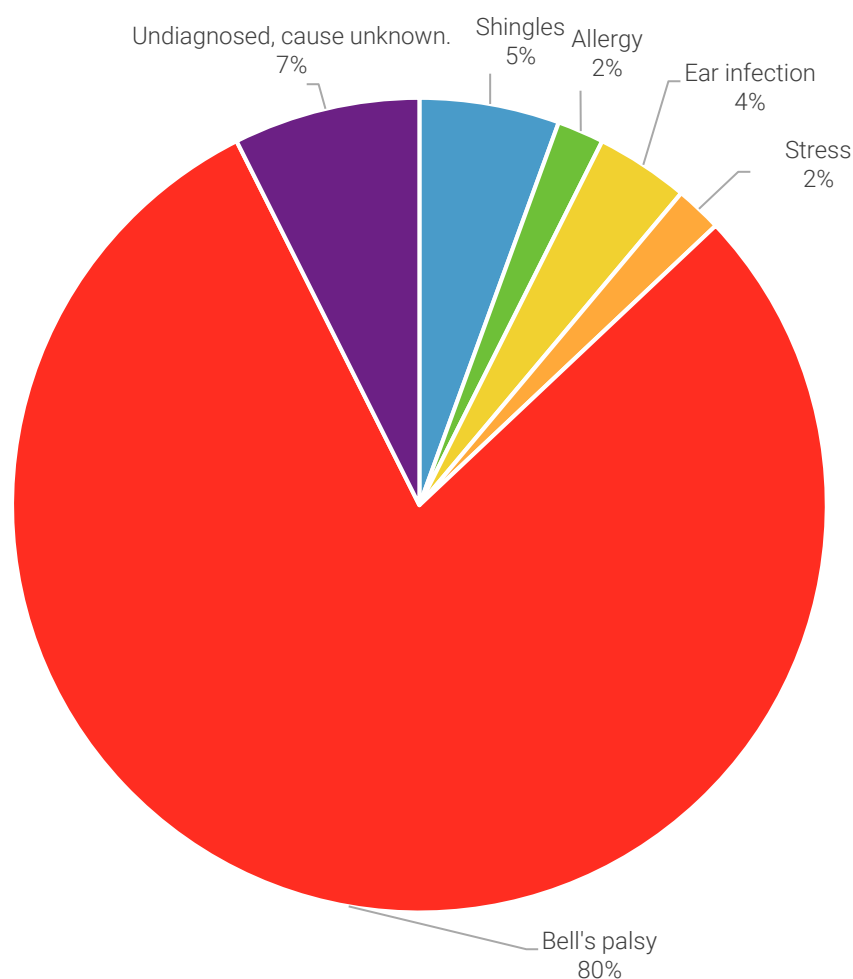
*"I couldn't face going to school, I was dizzy and my self-esteem plummeted. I was bullied and my grades suffered."*

*"Was studying for a Master's degree part-time as part of my graduate employment programme. After diagnosis felt too fatigued, too much pain and mental health suffered. Did not complete the degree as a result."*

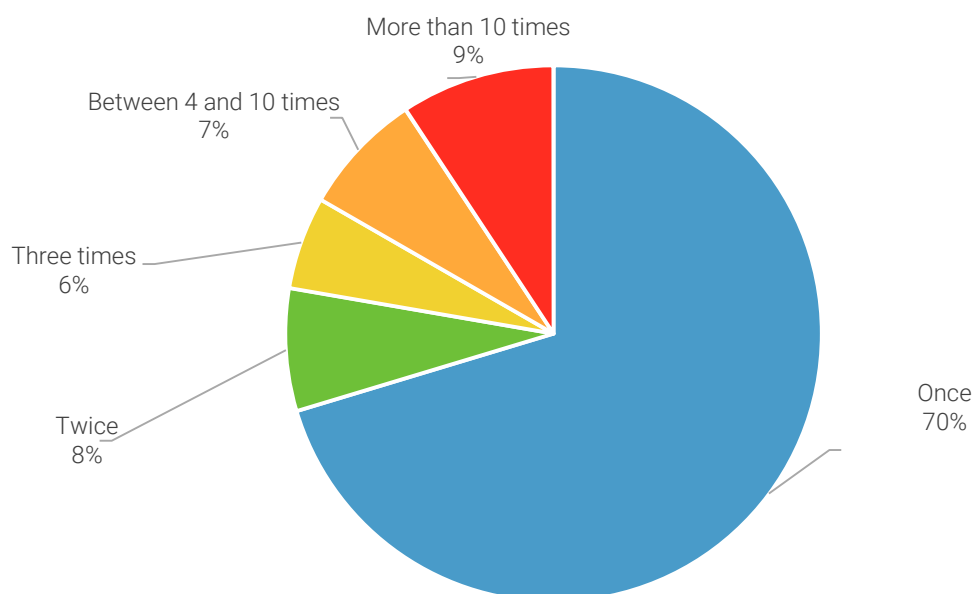
## No official diagnosis of RHS

206 people from the UK took part in this survey, 152 with an official diagnosis of Ramsay Hunt syndrome are reported on above. 54 people did not have an official diagnosis of RHS from a health professional and self-diagnosed. We report on important statistics for this segment below.

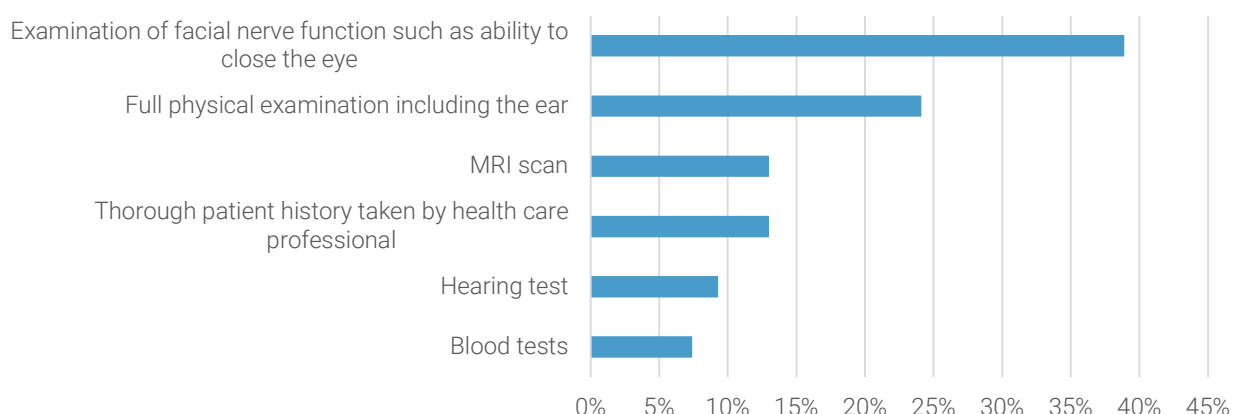
**Diagnosis given by health professional to 54 people never officially diagnosed with RHS**



## Number of episodes of facial paralysis



## Checks carried out by a health professional

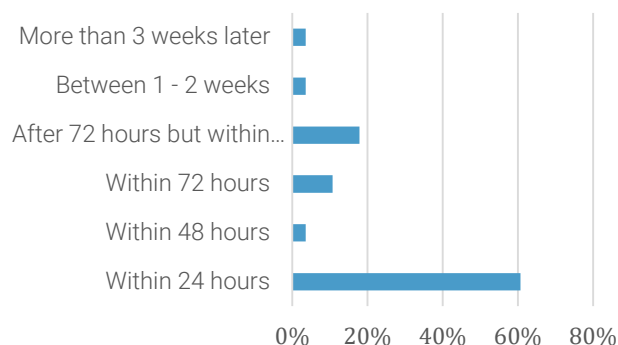
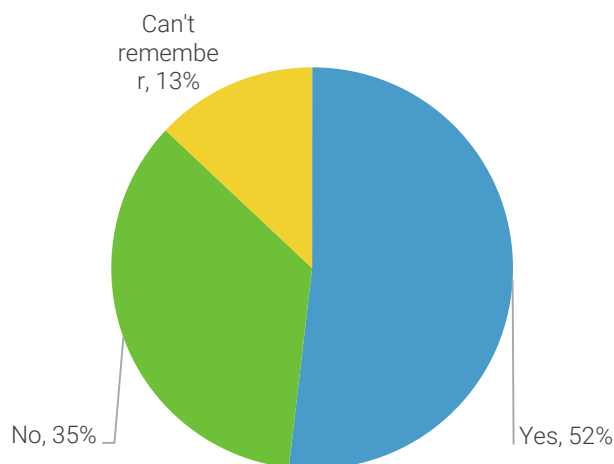


## 18 people had made a self-diagnosis based on these specific symptoms

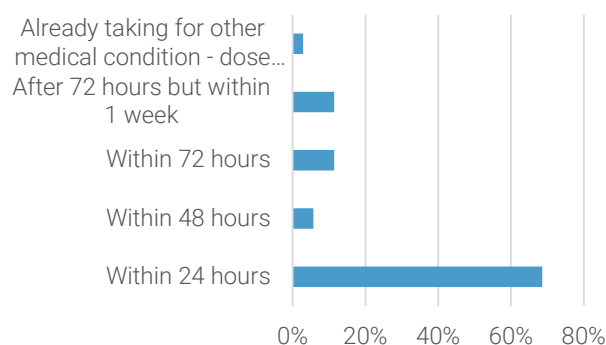
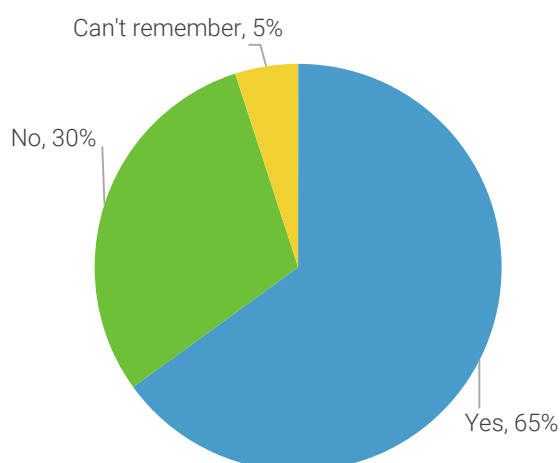
| Symptoms                           | Percent of whole segment (54 people) | Number reporting these symptoms |
|------------------------------------|--------------------------------------|---------------------------------|
| Rash in/behind ear                 | 11.1%                                | 6                               |
| Blisters on tongue/in mouth        | 9.3%                                 | 5                               |
| Vertigo                            | 9.3%                                 | 5                               |
| Severe pain                        | 9.3%                                 | 5                               |
| Pain in ear                        | 7.4%                                 | 4                               |
| Tinnitus                           | 5.6%                                 | 3                               |
| Better fit with symptoms generally | 3.7%                                 | 2                               |
| Blisters in hairline               | 1.9%                                 | 1                               |
| Fatigue                            | 1.9%                                 | 1                               |
| Rash on back of head               | 1.9%                                 | 1                               |

## Medication

Were antivirals prescribed and how quickly?



Were steroids prescribed and how quickly?



| Statistics about the 54 people who suspect they have RHS but not officially diagnosed |   |   |
|---|---|---|
| 51.9% routinely followed up by GP or hospital   | 80% officially diagnosed with Bell's palsy                                    | 65% prescribed steroids   |
| 44.4% sought help outside the NHS   | 22% said no further help offered via NHS                                      | 52% prescribed antivirals   |
| 26% reported shingles on another part of their body in the past                       | 78% of people who had tried Botox injections said they made a big improvement | 13% thought a private health care professional would be more knowledgeable            |
|   |   | 38% of people who still had symptoms after a year are receiving no follow-up support. |

## Health issues

Health issues reported by 54 people who do not have an official diagnosis of RHS

| Health issue   | Percent | Number |
|--|---------|--------|
| Facial paralysis (unable to make facial expressions) | 85.20%  | 46     |
| Ear pain   | 75.90%  | 41     |
| Eating & drinking problems                           | 74.10%  | 40     |
| Muscle tightness/tension/facial pain                 | 72.20%  | 39     |
| Dry eye  | 72.20%  | 39     |
| Numbness on the face                                 | 72.20%  | 39     |
| Fatigue  | 72.20%  | 39     |
| Self-consciousness                                   | 66.70%  | 36     |
| Anxiety  | 66.70%  | 36     |
| Speech problems                                      | 61.10%  | 33     |
| Low self-esteem                                      | 61.10%  | 33     |
| Tinnitus   | 55.60%  | 30     |
| Neck pain  | 55.60%  | 30     |
| Hearing problems                                     | 50.00%  | 27     |
| Uncontrolled facial movements/twitching              | 48.10%  | 26     |
| Depression   | 46.30%  | 25     |
| Vertigo  | 44.40%  | 24     |
| Vision problems                                      | 37.00%  | 20     |
| Pins and needles                                     | 35.20%  | 19     |
| Dental problems                                      | 33.30%  | 18     |

Health issues still a problem six months after diagnosis (two people had recovered by six months, nine people had not had the condition for six months. Percentages are based on 43 people).

| Health issue  | Percent | Number |
|---|---------|--------|
| Muscle tightness/tension/facial pain                        | 72.09%  | 31     |
| Fatigue   | 65.12%  | 28     |
| Facial paralysis (unable to make facial expressions)        | 58.14%  | 25     |
| Uncontrolled facial movements/twitching                     | 58.14%  | 25     |
| Anxiety   | 58.14%  | 25     |
| Dry eye   | 53.49%  | 23     |
| Tinnitus  | 51.16%  | 22     |
| Hearing problems  | 51.16%  | 22     |
| Ear pain  | 51.16%  | 22     |
| Numbness on the face  | 51.16%  | 22     |
| Eating & drinking problems                                  | 51.16%  | 22     |
| Self-consciousness  | 51.16%  | 22     |
| Low self-esteem   | 51.16%  | 22     |
| Neck pain   | 44.19%  | 19     |
| Vertigo   | 44.19%  | 19     |
| Depression  | 39.53%  | 17     |
| Speech problems   | 34.88%  | 15     |
| Pins and needles  | 34.88%  | 15     |
| Vision problems   | 32.56%  | 14     |
| Dental problems   | 27.91%  | 12     |
| Permanent corneal damage diagnosed by a health professional | 6.98%   | 3      |

### Top 3 health issues

For 34 people who have had facial paralysis **more than 12 months** and have never been officially diagnosed with RHS, their 'Top 3' health issues are:

- 1) Facial paralysis (unable to make facial expressions)
- 2) Muscle tightness/tension/facial pain
- 3) Uncontrolled facial movements/twitching

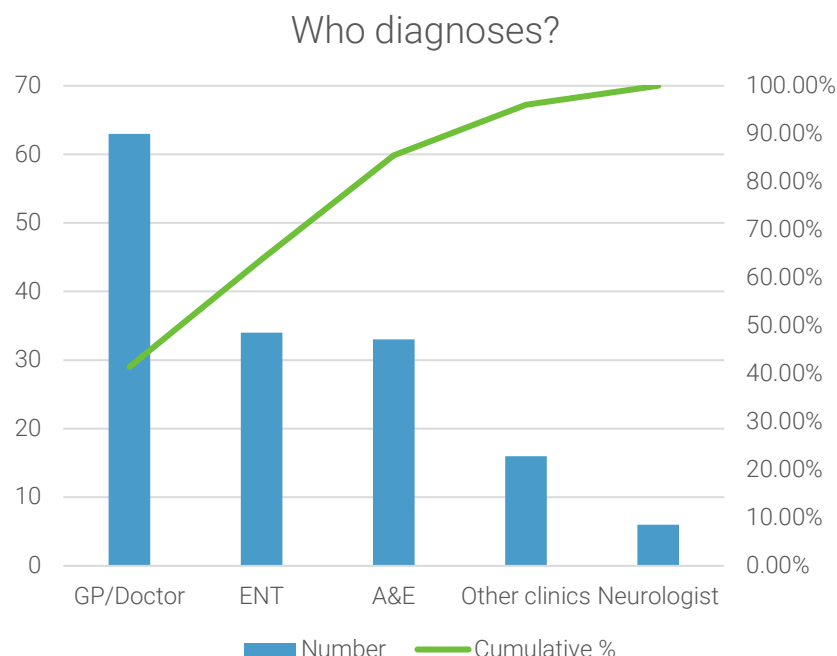
*"Every day for 22 years I have to cope with tight face and pain which causes tiredness. It makes me feel low and lacking self-esteem. I loathe the winter because of the coldness and I still feel restricted due to the restrictions it puts on my daily life."*

*"I can rarely wear eye make-up because my eye runs constantly. When outside it runs to such an extent that my vision is very blurred even though I wipe my eye. However my eye dries at night and is very sore when I wake. I take gabapentin for nerve pain. I am very sensitive to loud noises such as knives and forks banging together. I do not have full movement in my face and suffer horrific cramps and twitching. If I yawn without being careful my mouth goes into spasm and I have trouble closing my mouth, this also causes extreme pain. When I'm tired I cannot drink out of a cup because the drink runs down my face. I am asthmatic and when taking my inhaler I have to hold the one side of my mouth closed using my fingers because I cannot make a seal on the inhaler. These are just some of the continued problems I face. I have no support from a doctor or other health professional."*

*"People say I pull faces but I don't it does it by itself and I don't realise it."*

# Summary

## Diagnosis



### Key points:

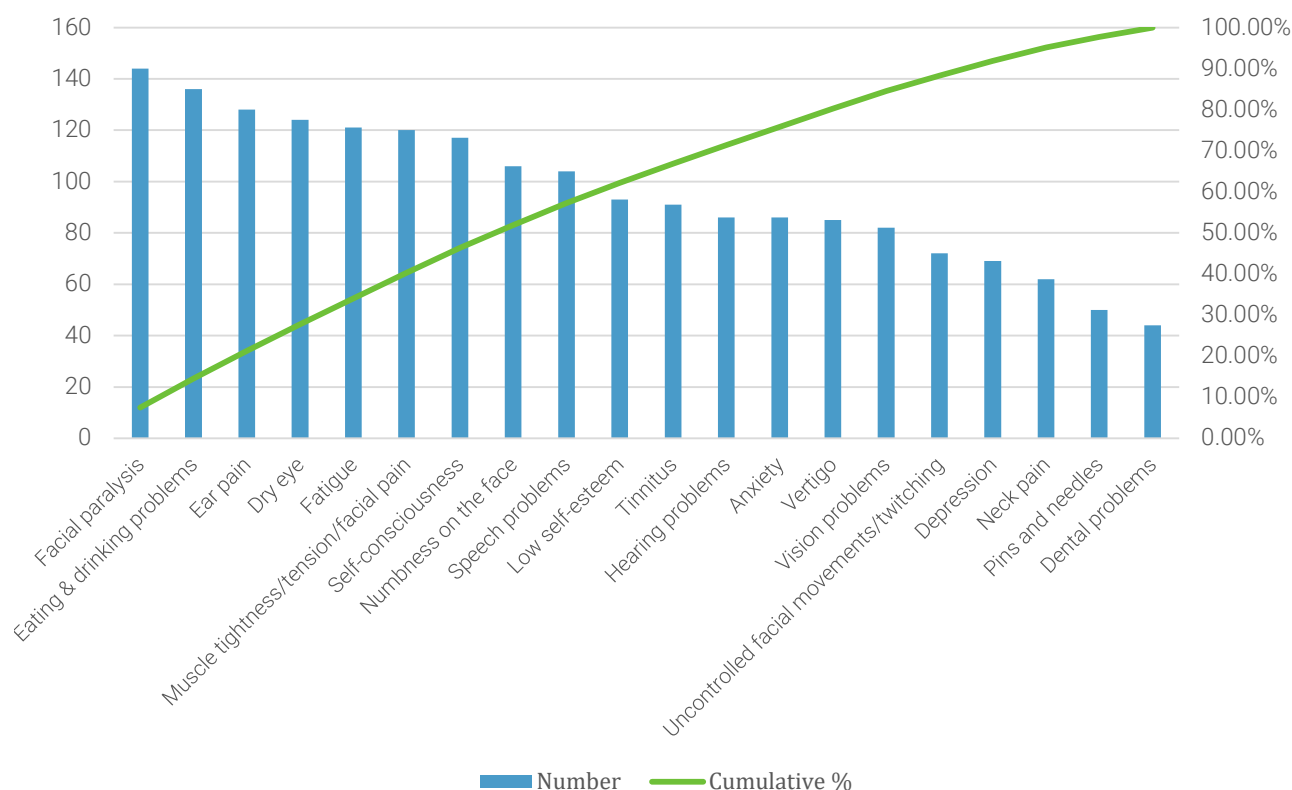
- 43% of people surveyed were initially misdiagnosed.
- 52.6% of those officially diagnosed had no other health issues before RHS.
- Better awareness and testing is needed to ensure this condition is treated promptly.
- Only 38.8% were officially diagnosed within the 72 hour window when antivirals are most effective.
- Only 52% received antivirals within the 72 hour window.

### Actions:

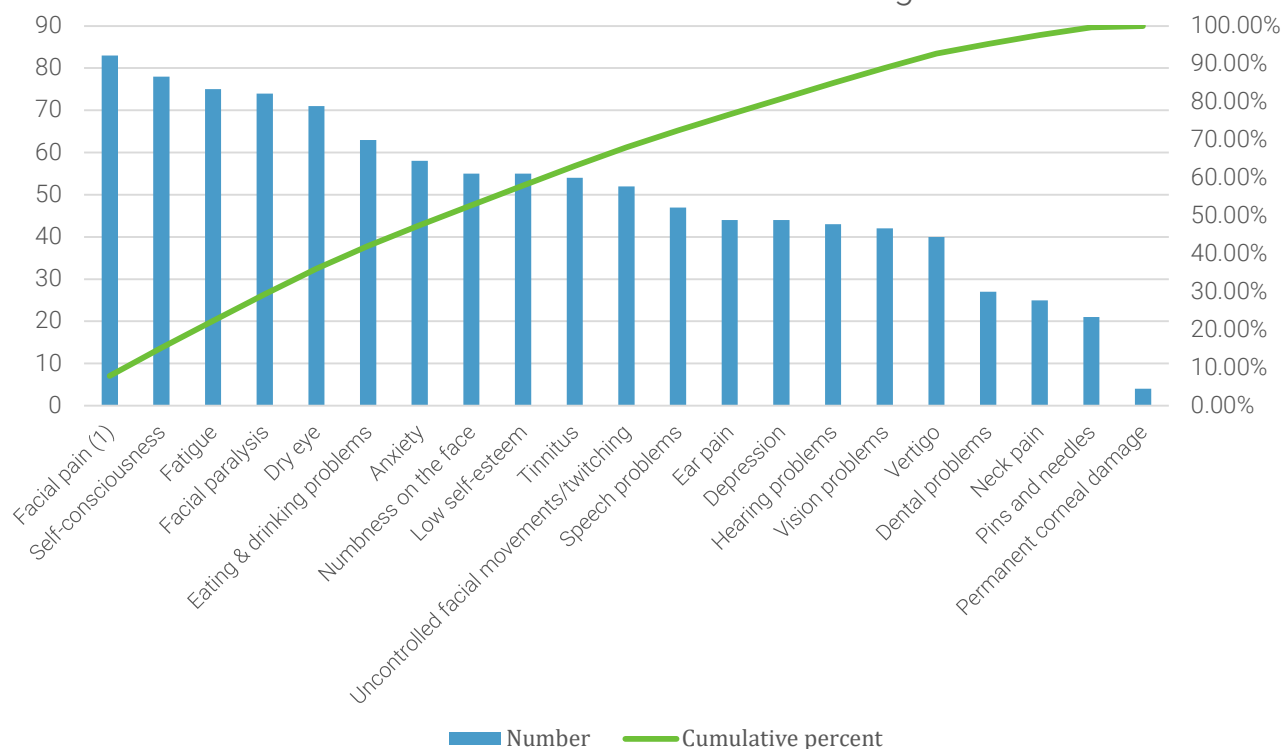
- 1) Facial Palsy UK to raise additional funds to increase awareness with GPs. Distribute Facial Palsy UK Ramsay Hunt syndrome patient guides to GP surgeries and/or raise awareness via shingles information leaflets distributed via NHS England.
- 2) A flow-chart for diagnosis would be helpful for GPs on FPUK's new Health Professionals' website.
- 3) Campaign for dedicated page on NHS website for facial nerve palsy with information about Ramsay Hunt syndrome and other causes. Information about RHS is currently only on the shingles page. If the shingles rash appears later (or not at all) patients may be misdiagnosed with Bell's palsy.

## Health issues

Health issues - immediately after diagnosis



Health issues - six months after diagnosis

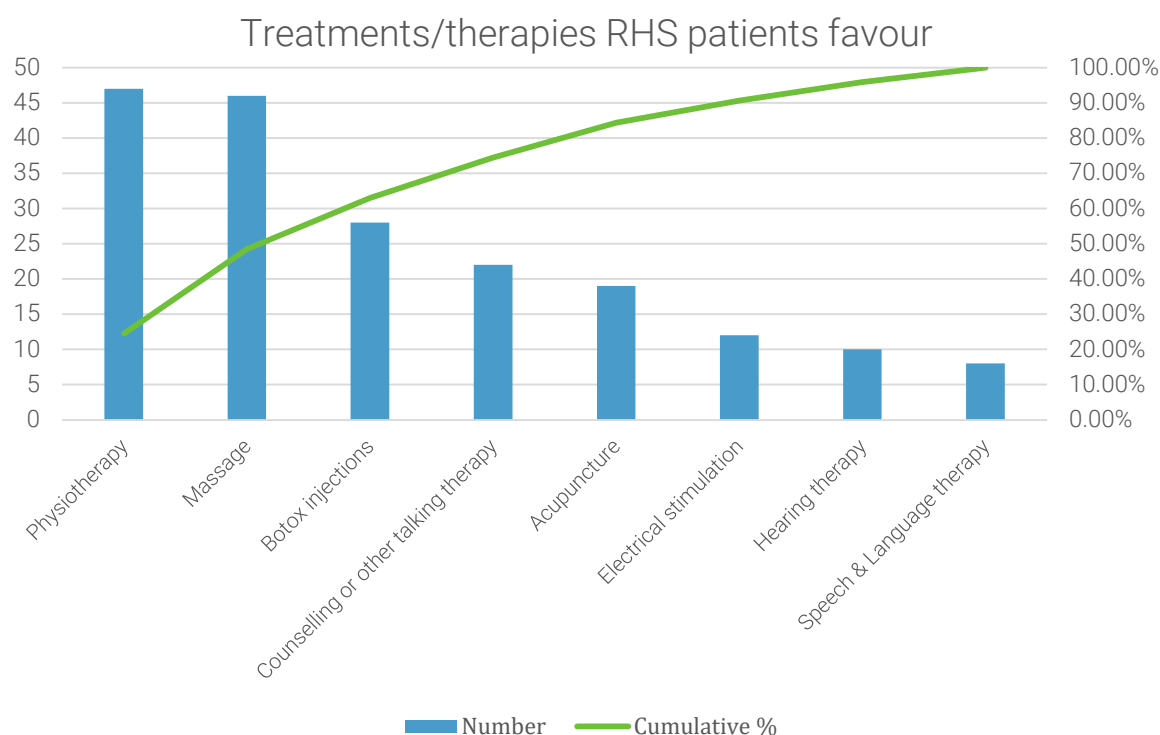


1 = Muscle tightness, facial pain & tension.

#### Actions:

- 1) Highlight the ongoing physical and emotional 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 being denied funding for treatments that can help.

## Treatments and therapies

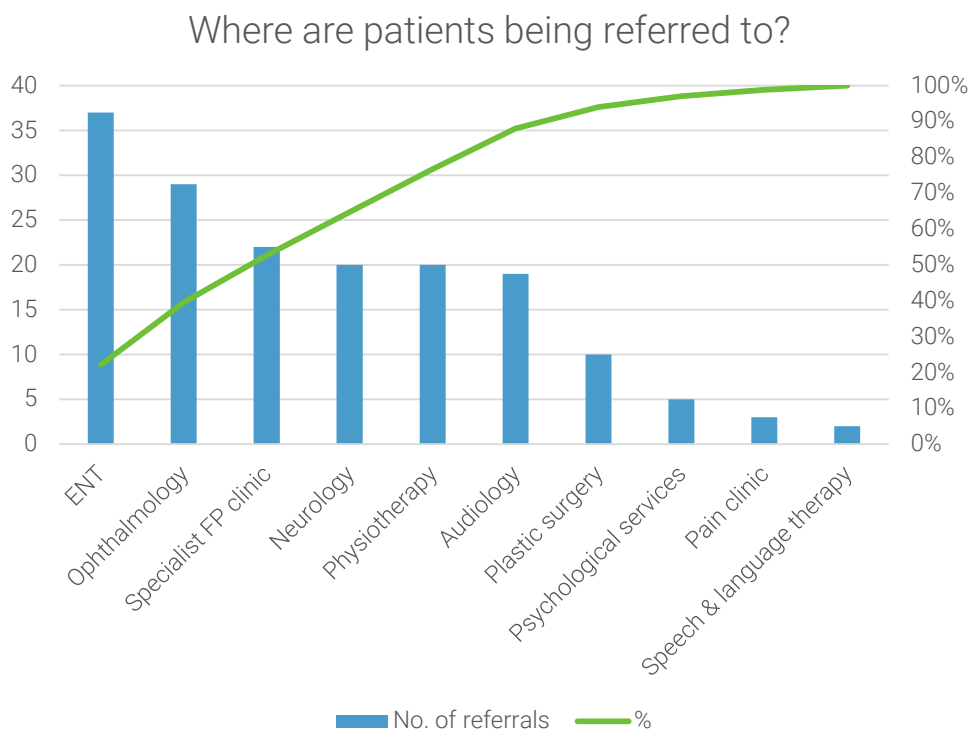


#### Actions:

- 1) Facial therapy for facial palsy is a postgraduate specialism usually carried out by specially trained physiotherapists or speech therapists. Facial Palsy UK to investigate ways of supporting specific training in facial palsy rehabilitation for therapists. Online training resources and supervised practical experience are required.
- 2) NHS/NICE guidance needed to ensure patients are only referred to facial therapists with specialist skills to avoid causing irreversible complications such as synkinesis.
- 3) Campaign for more research into outcomes with specialist facial therapy to manage facial pain/spasms/synkinesis.
- 4) Campaign for more research to show the benefits of botulinum toxin injections to treat facial palsy.
- 5) Speak to Botulinum toxin companies about possible sponsorship to raise awareness.



## Patient referrals



### Actions:

- 1) Getting the patient to the right place first off reduces NHS costs, i.e. avoids unnecessary referrals. 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) In the interim Facial Palsy UK to prioritise raising awareness with ENT UK about support and treatments available so patients can be referred to specialist clinics.

## Other key points and actions

### Key points:

- 27.4% of people who have had RHS for 12 months or more and have ongoing related health issues are not receiving ongoing support from the NHS to manage their symptoms.
- 40.8% of those officially diagnosed who have discussed the condition with their dentist said their dentist had not heard of it before.

### Actions:

- 1) PR campaign to highlight lack of support for this patient group.
- 2) Facial Palsy UK to raise awareness with dentists about the condition, e.g. via social media and dental conferences.