



**Ramsay Hunt
syndrome**
and facial palsy

Facial Palsy UK is a national charity for anyone affected by facial palsy, whatever the cause.

We have produced this guide to Ramsay Hunt syndrome to help to explain the condition and how it affects people.

Being diagnosed with Ramsay Hunt syndrome can be worrying and distressing so it is important patients receive the right treatment, information and support.

Helpline

0300 030 9333

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).

What should I do?

Contact your GP, walk-in centre or GP on-call service as soon as possible if you notice facial palsy developing and/or you have a severe ear or head pain with a shingles rash. It can get worse quite quickly.

Treatment works best if it is started within 72 hours from the onset of the first symptoms.

Really Important

What are the symptoms?

- A rash or fluid-filled blisters in or around the ear, scalp or hair line and/or ulcers inside the mouth.
- The rash/blisters are often painful and may cause a sore or burning feeling.
- Dizziness/vertigo.
- Tinnitus. This is the term for hearing sounds that come from inside your body, rather than from somewhere outside. It's often described as "ringing in the ears", although people hear different sounds.

A small number of people may not have a rash. This is called Zoster sine herpete (ZSH). Alert your doctor if you have chronic facial pain and have been diagnosed with Bell's palsy.

On the affected side of the face:

- Ear, face or head pain.
- Weakness which causes the facial muscles to droop.
- Difficulty closing the eye or blinking.
- Altered taste on the tongue.
- Loss of facial expression.
- Pins and needles sensation as another nerve, the trigeminal (face sensation) nerve, can also be affected.
- Difficulty eating, drinking and speaking as a result of weakness in the lips and cheek.
- Hearing loss.

! You may not have all the symptoms or some symptoms may develop later than others.

How is it diagnosed?

Your GP or doctor will ask questions to find out more about your illness and will ask you to move your face in different ways to compare the movement on each side of your face.

They may also suggest some of the following:

- Blood tests.
- Hearing tests.

They may refer you to have additional tests:

- Magnetic Resonance Imaging (MRI) or CT scan to rule out any other cause of your symptoms.
- Neurophysiology tests. These help specialists to work out how well your nerves and muscles are functioning.

What is the treatment?

Antiviral medication is usually prescribed for 7 to 10 days. You may be given a prescription for: Valaciclovir (e.g. Valtrex), Aciclovir (e.g. Zovirax) or Famciclovir (e.g. Famvir), as well as a prescription for steroids, usually Prednisolone and some painkillers.

If this treatment is prescribed within 72 hours of the shingles rash starting, the symptoms may become less severe and clear up more quickly.

It is also important to have plenty of rest, eat a balanced diet and drink plenty of fluids.

"At first my facial palsy got worse even though I had started taking the tablets. My doctor didn't tell me that could happen."

Person with Ramsay Hunt syndrome

Eye care

Eye care is really important, without it your eye will become dry and you risk permanent damage. If you are finding it difficult to blink and close your eye, you should be given a prescription for preservative-free eye drops to use in the day and ointment to use at night. If your eye does not close fully you may need to tape it closed at night.

Find out how to tape your eye closed:

<http://www.facialpalsy.org.uk/support/patient-guides/how-to-tape-eye-closed-adults/>

General eye care information

<http://www.facialpalsy.org.uk/support/patient-guides/dry-eye-advice/>

How did I get this?

After you have had chickenpox, the varicella-zoster virus stays inside your body but is not active. If your immune system becomes weaker and your body is less able to fight off infection, the virus can become active again and cause shingles. You may have a weaker immune system as a result of:

- physical or emotional stress (feeling run down)
- taking certain medication
- having chemotherapy treatment
- a disease that weakens your immune system
- older age

"My recovery is taking so long and no one can tell me when I will be back to normal."

Person with Ramsay Hunt syndrome

Can I give it to other people?

Ramsay Hunt syndrome cannot be passed on to someone else because it is a reactivation of the dormant shingles virus.

BUT if someone who has no immunity to chickenpox touches a shingles rash or blister they can develop chickenpox. Once the blisters have dried up there is no danger of infecting others.

How long will it be until I feel and look better?

Around three-quarters of people given antiviral medication promptly will make a complete recovery. If the damage is more severe, it will take longer to recover and the chance that your face will move, look and feel as it did before is reduced.

"The lack of balance meant I was unable to drive or walk. I couldn't manage on my own."

Person with Ramsay Hunt syndrome

Some people do not make a full recovery and may be left with permanent facial paralysis, hearing loss, balance problems, pain or intense itching and sensitivity around the affected ear. Severe nerve pain (neuralgia) after the rash heals is called post herpetic neuralgia.

You may also have post viral fatigue which can last 12-18 months after the rash has gone.

Synkinesis (pronounced syn-k-eye-nee-sis) is a complication of Ramsay Hunt syndrome. This can make the muscles in the face feel tight and you may notice unwanted link movements such as your eye closing when you smile. A physiotherapist or speech and language therapist with experience in treating facial palsy can help you manage synkinesis.

Are there facial exercises that I can do?

In the early stages it is very important to rest your face – do not force any movements as this could do more harm than good.

Facial massage is the best thing to do. Self-help videos that show you how to do this can be found online at

<http://www.facialpalsy.org.uk/support/self-help-videos/>.

"The fatigue is just crushing. I'm so tired my bones ache. I can function, because I have to, but anything extra leaves me feeling like I have nothing left."

Person with Ramsay Hunt syndrome

Further treatment

If your eye still does not close properly after 2-3 weeks you should be referred to ophthalmology. If you are struggling to care for your eye with tape and eye drops then ask your GP to make an earlier referral.

If the paralysis shows no sign of improvement after one month you should be referred to a facial palsy specialist, this could be a plastic surgeon, neurologist or ENT consultant. Ideally you should be referred to a specialist facial therapist as well. Studies show that botulinum toxin injections^[1] can help with residual facial pain, spasms and involuntary facial movements.

^[1]<https://www.ncbi.nlm.nih.gov/pubmed/28688864>

CHECK FOR:



Blisters on Tongue



Blisters in Mouth



Blisters on Ears

Tell your GP if you have...

- A rash on your face, neck or in your hair.
- Chronic pain, as not everyone has a rash.

FACTS:

- Ramsay Hunt syndrome is often initially misdiagnosed as Bell's palsy.
- Although rare, some people develop Ramsay Hunt syndrome more than once.

A Facial Palsy UK survey found:*

- More than 1 in 2 were initially misdiagnosed with Bell's palsy or other conditions (57%).
- Almost 2 in 3 were diagnosed outside the critical 72 hour window to receive antiviral treatment (61%).
- Approx. 1 in 2 received antiviral treatment within the critical 72 hour window (52%).
- More than 1 in 3 were not routinely followed up by their GP or hospital (37%).

Long term symptoms:

- Don't suffer alone with long term symptoms. There is help available. Ask your GP or hospital clinic to contact Facial Palsy UK if they are unsure where to refer.

* A survey published by Facial Palsy UK in March 2018 of 152 people officially diagnosed with Ramsay Hunt syndrome in the UK

Facial Palsy UK services

Helpline: 0300 030 9333

E-mail: support@facialpalsy.org.uk

Website: www.facialpalsy.org.uk

Further information is available on the website for people with facial palsy and health professionals. This includes personal stories, information about support groups, raising awareness and research.

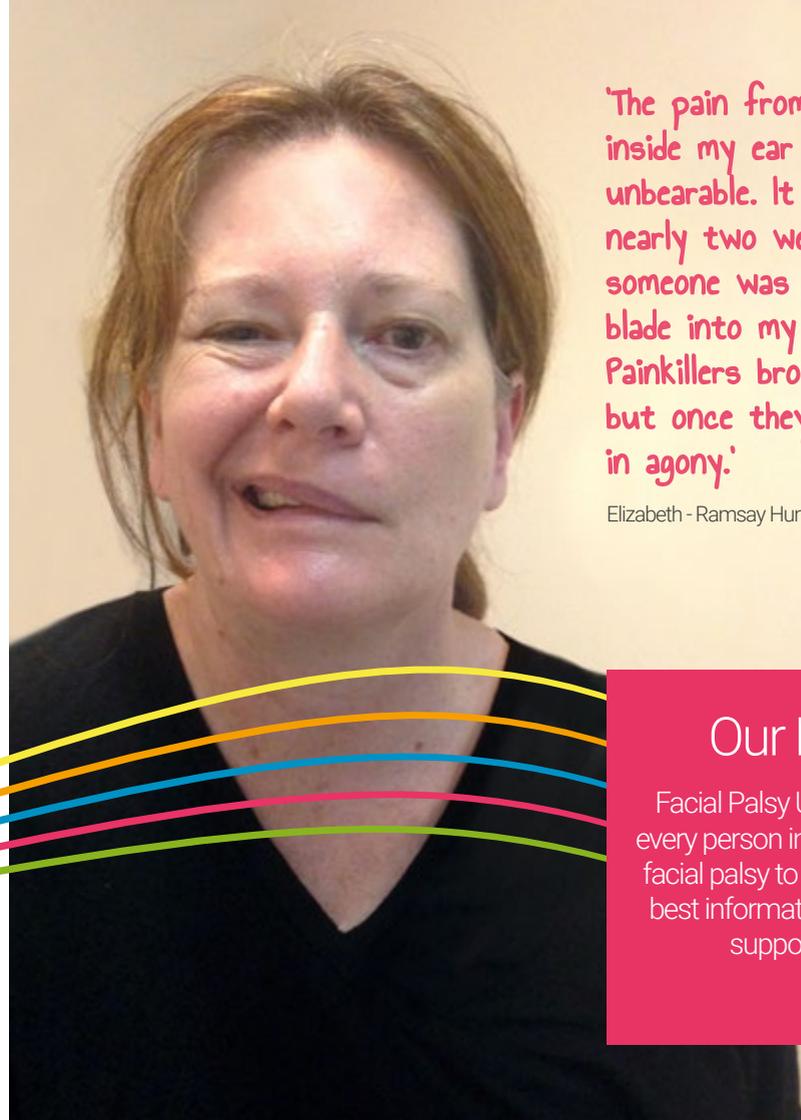
Facial palsy support groups

Facial Palsy UK operate local support groups for adults affected by facial paralysis. You can find your nearest support group on our website:

<http://www.facialpalsy.org.uk/local-groups/>

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'The pain from the shingles inside my ear was almost unbearable. It lasted for nearly two weeks and felt like someone was stabbing a hot blade into my ear and brain. Painkillers brought some relief but once they wore off I was in agony.'

Elizabeth - Ramsay Hunt syndrome

Our Mission

Facial Palsy UK's mission is for every person in the UK affected by facial palsy to have access to the best information, treatment and support available.



Support Facial Palsy UK

We need your help to raise awareness about facial palsy, fund research into its causes and treatments and support people living with facial paralysis and their families. To make a difference donate online at:

www.facialpalsy.org.uk/donate

Or text FPUK25 £3 to 70070

to donate to Facial Palsy UK with JustTextGiving by Vodafone, please remember to ask permission from the bill payer.



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