

Chronic Spontaneous **URTICARIA**



You have recently been diagnosed with
Chronic Spontaneous Urticaria.

This patient information leaflet has
been written to help you understand
more about your condition.



What is Chronic Spontaneous Urticaria (CSU)?

You may not be familiar with the name, but you may recognise the red, itchy hives (a form of rash, also known as wheals or welts).

Chronic spontaneous urticaria (CSU) is defined by an itchy, raised rash on your skin that suddenly appears and persists, sometimes on and off, for at least 6 weeks.

Sometimes it can be accompanied by a swelling in the deep layers of the skin, for instance in places like your lips and eyelids. This is known medically as angioedema.

It is called chronic because it stays with you for 6 weeks or longer and, whilst the disease can go away, there is currently no cure. It is called spontaneous because it suddenly appears and can flare up without warning, and unlike an allergy, has no known external triggers.

CSU is also known by two other terms. The old name for the disease is 'chronic idiopathic urticaria', or CIU, and is still used by some doctors, particularly in the USA. Idiopathic is simply a medical word that means the cause of the condition is uncertain.

'Chronic urticaria' is another term you may hear, but this also includes other conditions that are similar to CSU but are not considered spontaneous, because they have a known trigger.

What are the symptoms of Chronic Spontaneous Urticaria?

Everyone's skin is different and so everyone's experience of CSU is different.

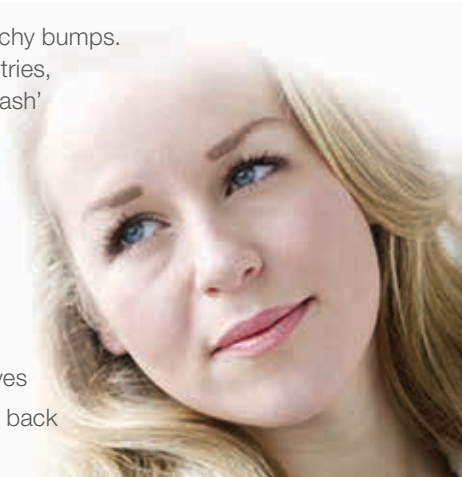
Rash

People with CSU will frequently experience raised, itchy bumps. Naturally, most people call this a rash. In some countries, like Germany and the UK, it has been called 'nettle rash' as it looks very similar to the reddish, itchy rash resulting from contact with stinging nettles.

Your doctor however, will probably call it urticaria - which we'll talk about next.

Hives (Urticaria)

- Raised, red itchy skin
- Most people with CSU will have outbreaks of hives
- Outbreaks last at least six weeks and can come back



Hives is the most common word used by doctors to describe the rash, but they might also call them wheals, welts or just urticaria. Not everyone's hives look the same.

There are different factors to consider:

- Size:** They range from the tiny (couple of millimetres) to the big couple of centimetres)
- Colour:** Hives can be red, pink, or have a red outline with a paler centre
- Shape:** They're not just circular, they can form all kinds of shapes
- Location:** Hives can appear anywhere on your body, from your feet to your face
- Coverage:** Sometimes you'll have a small flare-up, at other times you may have one that covers a large area of your skin
- Duration:** Hives can appear briefly, lasting a few hours, or longer remaining for up to 24 hours. However, as the individual hives clear up, often others reappear somewhere else, meaning they can be present for weeks at a time

Swelling (Angioedema):

- Sudden, and sometimes painful, swelling (angioedema) in the deeper layers of the skin
- Many people with CSU (33-67%) suffer from swelling (angioedema) alongside their hives
- The eyelids and lips are the most commonly affected areas of the body
- The swelling (angioedema) usually goes down within 72 hours

If you suffer from CSU, you may experience a sudden, sometimes painful swelling in the deep layers of the skin that can appear alongside hives. Your doctor will probably call this angioedema.

Although it can appear unrelated to your hives, angioedema affects between 33-67% of people with CSU and even people who don't have hives can have angioedema - this happens in about 1-13% of people.

61% ONLY HIVES

33% HIVES & SWELLING

6% ONLY SWELLING



Pruritus (Itching):

Beyond the fact that hives and angioedema can lead to temporary but pronounced disfigurement, particularly in the face, pruritus or itchiness is the largest problem for patients with urticaria.

Night itchiness above all else can be extremely irritating, since it robs the person of sleep.

Take note of your symptoms using the terms we've outlined, and use them when speaking to your doctor - they might help you get the treatment you need.

In general, CSU is not an allergy

Unlike other conditions with hives, CSU has no known external trigger. It is not an allergy. But the lack of a clear cause means that even during periods of clear skin the threat of a sudden outbreak hangs over people with CSU. It's not only during the bad days that CSU can be an emotionally demanding condition.

How common is CSU?

We've all had bad skin days where we have felt self-conscious, but most of us haven't considered how we would cope if a bad day turned into bad weeks.

Urticaria is more common than you may think. Around 20% of people will experience it at some point in their lives, although for most it's short-lasting and does not come back.

A small proportion of people (roughly 0.5-1%), go on to develop CSU and have to live with bad skin for days and weeks at a time.

Although anyone can develop CSU, some people have an increased chance of being affected:

Gender

Nearly twice as many women as men suffer from CSU.



Age

People of all ages can be affected by CSU, but the incidence peaks between 20-40 years.



Associated symptoms



More than just a skin condition

Impact on quality of life

Unpredictable, itchy and sometimes painful. It is no surprise that CSU can have a serious impact on people's lives.

Under the surface

The impact of CSU doesn't end with the physical symptoms, it can have a major effect on how people are feeling and their quality of life.

Daily life

The discomfort of CSU can lead to disturbed sleep and a lack of energy.

Mental health

People with CSU are more likely to suffer from depression and anxiety.

Personal life

CSU can severely impact the private lives of sufferers, with the majority feeling their condition affects their ability to take part in physical activities, socialise, as well as having an impact on their relationships. As a result, an increased sense of isolation and loneliness may be felt by people with CSU.

Work life

Less sleep and itchy skin may impact people with CSU at work.

They are also more likely to take days off, affecting them financially and possibly even jeopardising their job.

The severe and chronic physical impact of CSU can lead to a significant detrimental effect on quality of life upon those living with the condition. Research suggests the negative impact to people with CSU is similar to patients with heart disease, with patients feeling a similar lack of energy, social isolation and emotional upset.

Other, negative physical and emotional effects of CSU on quality of life include sleep deprivation and depression.

The frequent failure to identify a specific underlying cause of CSU, its unpredictable symptoms and a high disease burden lead to frustration among people with CSU and their doctors.

How long will CSU last?

CSU is unpredictable in nature and so the length of time someone suffers from it varies. For most people it lasts between 1 and 5 years.

Treatment options

Antihistamines:

You may be prescribed antihistamines – or you can buy them over the counter at a pharmacy. These will reduce the itching in most people.

If, after initial treatment, your symptoms do not improve, your doctor may prescribe a different type of antihistamine or increase the dose. Your doctor may prescribe more than one type of antihistamine at the same time.

Histamine blockers or immunosuppressants:

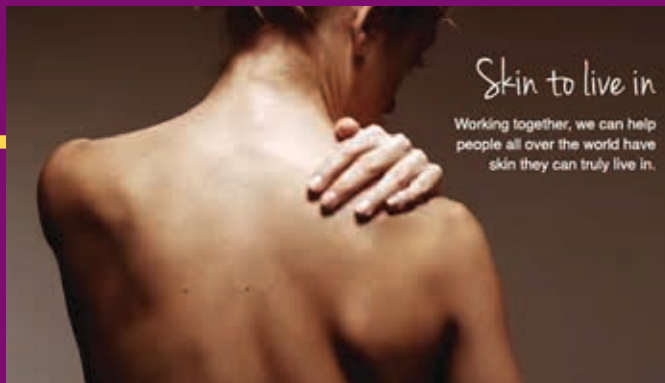
If antihistamines are not helpful, you may be prescribed other medicines, which may include other types of histamine blockers or immunosuppressants.

Xolair (omalizumab) is indicated as add-on therapy for the treatment of chronic spontaneous urticaria in adults (12 years and above) with inadequate response to antihistamine treatment. Omalizumab is a man-made protein that is similar to natural proteins produced by the body; it belongs to a class of medicines called monoclonal antibodies.

If your urticaria is more severe, you may be prescribed a short course of steroid tablets* (max. 10 days), in addition to antihistamines, to help the symptoms go away more quickly.

* Unlicensed for treatment of CSU.
This means that the medicines have been tested for effectiveness and safety, but are not specifically licensed to treat urticaria.





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