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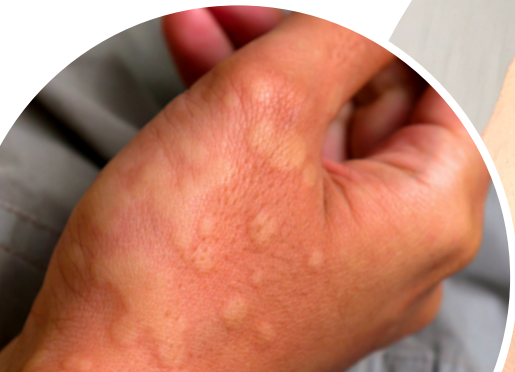
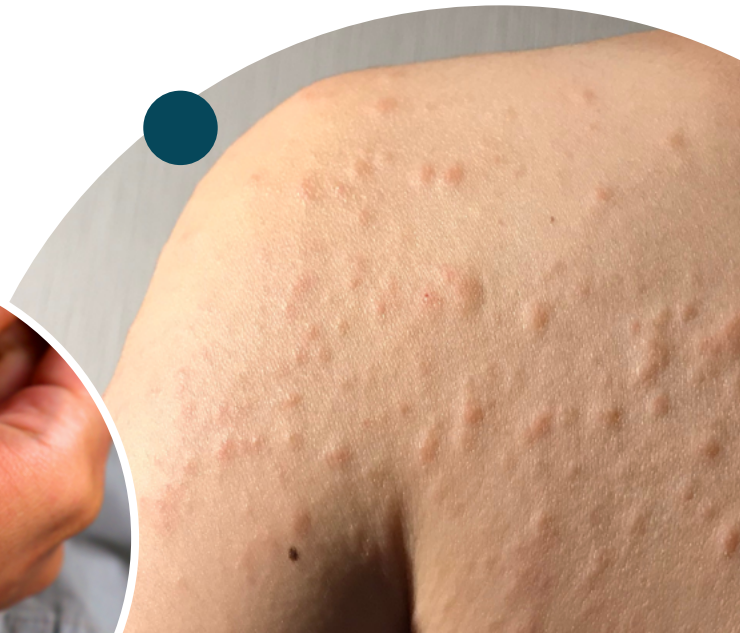
Understanding

Chronic Spontaneous Urticaria (CSU)





What is Chronic Spontaneous Urticaria (CSU)?

Chronic Spontaneous Urticaria (CSU) is a common and distressing skin condition that causes itchy, red and sometimes painful hives or wheals (raised patches or rash) on the skin without an obvious cause or trigger.

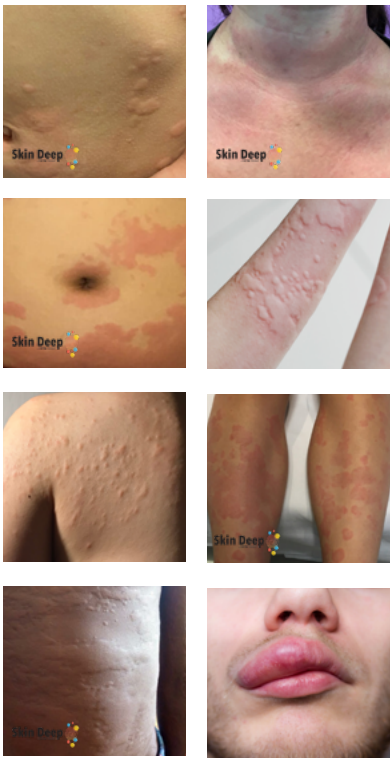
The rash can appear as small bumps or larger raised patches of different shapes and sizes and can affect any part of the body. Some people also experience swelling beneath the skin called angioedema, which commonly affects the face, lips, hands, feet or eyelids.

To be diagnosed with CSU, symptoms must occur regularly for at least six weeks. It is called "spontaneous" because there is no identifiable trigger causing the symptoms.

What does CSU look like?

CSU can look different from person to person and may appear differently on different skin tones.

- Raised, itchy patches or wheals (hives).
- Small bumps or larger patches of varying shapes and sizes.
- Redness or inflammation around the rash.
- Burning, stinging or painful sensations.
- Wheals that change shape and location, disappearing within 24 hours while new ones appear elsewhere.
- Swelling beneath the skin (angioedema).
- In darker skin tones, redness may be less visible and affected areas may appear similar in colour to the surrounding skin.
- In some people with darker skin tones, temporary skin darkening (post-inflammatory hyperpigmentation) can occur after rashes settle.



Who can develop CSU?

Research suggests that:

1 - 2%

of the UK population may be affected

Women are around twice as likely as men to develop CSU

CSU can affect children & adults

It's more common in older children, teenagers and adults

People aged 20-50 are are most commonly affected

How long does CSU last?

CSU varies from person to person, and it is not possible to predict how long symptoms will continue. While some people experience symptoms for a relatively short period of time, others may have CSU for several years.

Although CSU can be a long-term condition, effective treatments are available that can help control symptoms and improve quality of life. If your symptoms are not well controlled, speak to your healthcare professional about the treatment options available to you.

What causes CSU?

CSU occurs when immune cells called mast cells release chemicals, including histamine, into the skin. This causes the itching, redness, swelling and raised rash associated with urticaria.

Mast cells are a normal part of the immune system and help protect the body from infection and support healing. In CSU, these cells become activated when they should not, leading to symptoms.

Some factors may make symptoms worse in certain people, including stress, infections and some medications, but these do not usually cause CSU itself.

How can CSU affect daily life?

CSU is often unpredictable and can have a significant impact on quality of life. It may affect:

- sleep, leading to tiredness, poor concentration and irritability
- mood, causing feelings of frustration, anxiety, isolation or low mood
- social activities, hobbies and work because of discomfort, pain or concerns about appearance
- relationships, particularly when skin discomfort makes physical contact unpleasant
- confidence and overall wellbeing

Can allergy trigger my CSU?

No. CSU is not caused by allergens (substances which cause an allergic response) or an allergic reaction.

Because of this, allergy testing, elimination diets, and avoidance of the usual triggers are not always useful in trying work out the cause or manage symptoms.

Some people notice that certain things make their symptoms worse, but these do not cause CSU. Unlike other types of urticaria, there is often no identifiable trigger for CSU.

What can I do to help manage my symptoms?

Soothe the skin:

- Use cream-based emollients or anti-itch products.
- Apply a cool compress or ice pack to itchy areas.
- Take a cool bath if cold temperatures do not worsen your symptoms.

Avoid scratching:

Scratching causes the release of more histamine, which can make itching worse and can lead to skin damage and colour changes.

Some people find that relaxation techniques, mindfulness or other distractions can help them cope with itching.

Wear comfortable clothing:

Loose, lightweight clothing can improve comfort.

Identify factors that worsen symptoms:

Some people find symptoms are aggravated by:

- stress
- alcohol
- caffeine
- recreational drugs
- extreme temperatures

Always speak with your healthcare professional before stopping any prescribed medication.

What do I do if I think I might have CSU?

If you think you may have CSU, make an appointment with your GP or healthcare professional. They may:

- ask about your symptoms and medical history
- arrange tests to rule out other conditions
- ask you to keep a symptom diary
- use a symptom scoring tool to understand how severe your symptoms are

Because CSU can come and go, it may take more than one appointment before a diagnosis is confirmed.

How to get the most from your healthcare appointment

Before your appointment:

- ☑ Make a note of when symptoms started.
- ☑ Record how often symptoms occur and how long they last.
- ☑ Keep a diary of anything that makes symptoms better or worse.
- ☑ Take photographs of any rash or swelling on your phone with you to your appointment.
- ☑ Make a list of all medications, supplements and over-the-counter medicines you take.

Useful questions to ask:

- Can you explain CSU to me?
- What treatment options are available?
- Am I receiving the most appropriate treatment for my symptoms?
- Are there any additional treatments available if my current treatment is not working?
- Will treatment affect any medication I already take?
- Do I need any tests or investigations?
- What can I do to manage my symptoms more effectively?

What treatments are available?

There is currently no cure for CSU. Treatment focuses on controlling symptoms and improving quality of life.

Step 1: Non-sedating antihistamines

A daily non-sedating antihistamine is usually the first treatment offered.

If symptoms continue, healthcare professionals may increase the dose up to four times the usual licensed dose in line with clinical guidelines, this must only be done under the supervision and advice of a healthcare professional.

Step 2: Additional medication

If antihistamines do not adequately control symptoms, a leukotriene receptor antagonist may be considered. A short course of corticosteroid tablets may occasionally be prescribed for severe flare-ups. Repeated courses can have adverse health effects in the long term; therefore they are not given frequently.

Step 3: Biologic therapies (started in specialist centres)

For people whose symptoms remain difficult to control, biologic therapies may be prescribed by specialist hospital teams. These treatments target specific parts of the immune system involved in CSU.

Step 3 continued: Immunosuppressant treatment (started in specialist centres)

Specialist treatments such as ciclosporin may be recommended. These treatments reduce immune system activity and require regular blood-test monitoring.

It is important to note that for many medical conditions, there are ongoing research trials and new medications being explored and considered for new treatments. This is the case for CSU, this is why seeing your GP and when appropriate getting a referral to a specialist team is very important in exploring the best treatment options for you.

When should I seek help?

Speak to your healthcare professional if:

- your symptoms are affecting your daily activities, sleep, work or mental wellbeing
- your symptoms are painful, persistent or not improving
- you feel your current treatment is not working well enough

Seek urgent medical attention if:

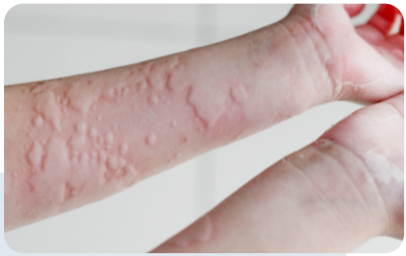
- your tongue or throat is swelling
- you have difficulty swallowing
- your breathing or airway is affected

Living with CSU

Living with CSU can be challenging, but it is important to remember that you are not alone. Although the condition can affect sleep, work, relationships and emotional wellbeing, effective treatments and specialist support are available.

If your symptoms continue despite treatment, speak to your healthcare professional about the options available to you and whether a referral to a specialist is appropriate.

With the right support and treatment plan, many people can achieve good symptom control and regain confidence in managing their condition.



Key points to remember

- CSU is a chronic skin condition that causes recurrent hives (raised itchy rash) and sometimes swelling, without an obvious trigger.
- Severe itching and unpredictable flare-ups can have a significant impact on daily life, sleep and emotional wellbeing.
- Symptoms must be present for at least six weeks before CSU can be diagnosed.
- CSU is not caused by allergies.
- There is no cure for CSU, but effective treatments are available to help control symptoms and improve quality of life.
- If your symptoms are not well controlled, ask your healthcare professional whether referral to a specialist service may be appropriate.

Trusted Information Creator

Patient Information Forum

AllergyUK

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Skin Deep A DFTB PROJECT

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