

Your quick guide to:

Chronic Spontaneous Urticaria (CSU)

Chronic Spontaneous Urticaria (CSU) is a common and distressing skin condition that causes red, raised, itchy and sometimes painful wheals (often referred to as hives, bumps or nettle rash) on the skin with no known obvious trigger. To be considered chronic the wheals (urticaria) must be present daily for at least six weeks and is referred to as 'spontaneous' when the trigger is not known.

Who is affected by CSU?

CSU is thought to affect 1-2 % of the population in the UK, with women more than twice as likely than men to be diagnosed with it. Most people develop symptoms between the ages of 20 to 50 and although CSU can affect children, it's more common in older children, teenagers and adults.

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. Some drinks such as caffeine containing drinks or alcohol can also make symptoms worse, but these do not usually cause CSU itself.

Could allergy be a trigger for CSU?

Allergy is not usually considered a trigger for CSU as if the symptoms are inducible following contact with an allergen, it is no longer considered CSU. CSU is not caused by an allergic reaction to a trigger allergen, although it is an immune response that causes the symptoms. Allergy testing, or elimination diets are not usually helpful in the management of CSU. Some people can identify things that can make their CSU worse, such as stress, infection and medication.

Often there is no obvious external trigger or aggravating factor that causes these symptoms. This is because CSU differs from other urticarial reactions in that there is often no known cause. CSU can be linked to reactions to medications, infections or a medical condition such as autoimmune disorders. As part of your medical review your doctor will consider exploring if there are any investigations that need to be completed to rule out other conditions.

Symptoms of CSU

Raised rash or patches surrounded by red, raised, inflamed skin often called hives or nettle rash and can affect any skin type or tone. There may be tiny bumps or large raised patches of variable sizes which can be white or red in colour with a red flare.

- On darker skin tones the raised patches often match the surrounding skin tone with no red flaring of the skin visible.
- Can affect any part of the body and is usually itchy but can also be painful or have a burning sensation.
- Wheals often change shape before resolving, typically within 24 hours, but as one wheal resolves others can develop and the rash can present for long periods.
- The rash does not cause any lasting damage to the skin, but in darker skin tones post inflammatory hyperpigmentation (darkening of the skin), can occur to the affected area and may take months to settle.
- May also be accompanied by swelling (angioedema) of the face, neck, hands or feet.

Diagnosing CSU

CSU can sometimes be difficult to diagnose, as urticaria can be a symptom of other medical conditions. It may take several visits to your GP or healthcare professional to get a diagnosis or to find a treatment that helps to control your symptoms. Your healthcare professional may carry out diagnostic testing to rule out other medical conditions. They may also ask you to keep a symptoms diary or complete a CSU severity scoring system to help assess the severity of your CSU.

Key facts:

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.

It is important to seek help if...

- Your symptoms are not well controlled, and/or are affecting your day-to-day activities, and/or affecting your mental health.
- Antihistamines are needed continuously (daily) to control symptoms for more than six weeks
- Symptoms are painful and persistent.

CSU symptoms are rarely life threatening, but you should seek urgent medical attention if you are concerned that your tongue or throat is swelling or that your swallow or airways and breathing are affected.

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It is important that if you feel your symptoms are not being managed adequately that you consult your healthcare professional who, if necessary, can refer you to specialist treatment.

Treating CSU

Unfortunately, there is no cure, but there are various treatment options available for CSU, with therapies designed to relieve symptoms. With the right support and treatment plan, many people can achieve good symptom control and regain confidence in managing their condition. There are guidelines and treatment pathways to support the recommended treatments of CSU, and you can discuss with your healthcare professional the most effective regime to find a treatment that will enable patients to enjoy a good quality of life and manage symptoms.

Standard treatment pathways in managing CSU

Step 1: Antihistamines

Antihistamines are the first-line medication offered for CSU. This simple treatment is effective in reducing symptoms for up to 40% of people with CSU. Current guidelines recommend using non-sedating antihistamines in the first instance,

If a once-a-day dose of the antihistamine doesn't reduce symptoms, then medical guidelines recommend that doctors can increase antihistamines up to four times the licensed dose depending on personal circumstances such as other medical conditions, age and general health. However, despite this recommendation, a proportion of patients (40%) will still experience breakthrough symptoms of CSU. It is

important all changes to medication doses are done under the advice of a healthcare professional.

It is advised that once symptoms are completely controlled, they don't make any changes or adjustments to the medication they are taking without consulting a healthcare professional first. They will be able to advise for how long to continue the treatment for and when and how to stop.

Step 2: Biologic therapies

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.

It is important to note that there are ongoing research trials and new medications being explored and considered as new treatment options. 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.

Step 2 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.

Living with CSU

CSU is an unpredictable and debilitating condition. It can affect the daily life of the sufferer in many ways including the ability to carry out simple daily tasks such as walking, sitting, dressing and bathing. It can also have a detrimental impact on sleep, social and intimate relationships and sexual function. Having symptoms of CSU is known to be a

risk factor for mental health issues, including anxiety and depression.

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. The symptoms do not always continue forever. The average duration of CSU is 2-5 years but that the timeline is highly unpredictable and varies from person to person. If your symptoms are not well controlled, ask your healthcare professional whether referral to a specialist service may be appropriate.

Clinical contributions:

Reviewed by:

Anne Biggs, Deputy Head of Clinical Services

Clinically Peer Reviewed by:

Emily Carne, Consultant Nurse Immunology & Allergy

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Allergy UK Helpline

Mon-Fri, 9am-5pm:

Call: 01322 619 898

Email: info@allergyuk.org

Visit us at:

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