



Understanding Urticaria

Measure your urticaria impact



Take control of your treatment journey with HiveHelper

Only available via www.helpforhives.co.uk

Help for Hives, including the HiveHelper chat tool has been created and funded by Novartis Pharmaceuticals UK Ltd.

The information provided on this website is designed to raise awareness and provide information on Urticaria and CSU. It does not replace clinical advice and recommendations from healthcare providers. If you have any questions or concerns, please contact your healthcare provider.

This non-promotional educational leaflet has been initiated and funded by Novartis Pharmaceuticals UK Ltd.

What is urticaria?

Urticaria, also known as hives, are itchy, raised patches on the skin. Many people with urticaria also experience skin swelling, known as angioedema.

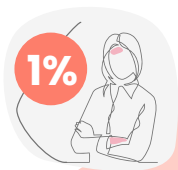
Urticaria does not usually affect general health, but the rash's appearance, and the itch itself can be extremely distressing. As a rule, urticaria tends to improve and become less troublesome over time. Individual hives can clear within 24 hours, but the overall rash may last longer.



What is CSU?

Chronic spontaneous urticaria (CSU) is a spontaneous disease that, on average, lasts up to five years, but sometimes patients suffer for much longer. It is linked to the immune system.

CSU affects the skin and can also have a huge impact on patients' mental health. CSU should be managed in consultation with a doctor, and with treatment, symptoms may be alleviated which may restore quality of life.



CU can affect up to **1%** of the population



Women are **2x** more likely to experience urticaria than men



Up to **1** in every **3** (4 to 33%) people with **CU** may have **chronic inducible urticaria (CIndU)**



2 in every **3** (up to 93%) people with **CU** may have **CSU**

What causes CSU and urticaria?

CSU

The causes of CSU are unknown. The redness, swelling and intense itching and/or burning associated with the condition occurs when immune cells are stimulated, causing the body to release certain chemicals in an abnormal way, making blood rush to the skin.

Urticaria

The physical symptoms of urticaria are caused by triggers that raise the levels of histamine, a chemical released from mast cells which are a type of white blood cell within your immune system. Mast cells are abundant not only in the skin, but also in tissues such as the tongue and lips. They are located close to blood vessels and contain high amounts of histamine and various other chemicals.

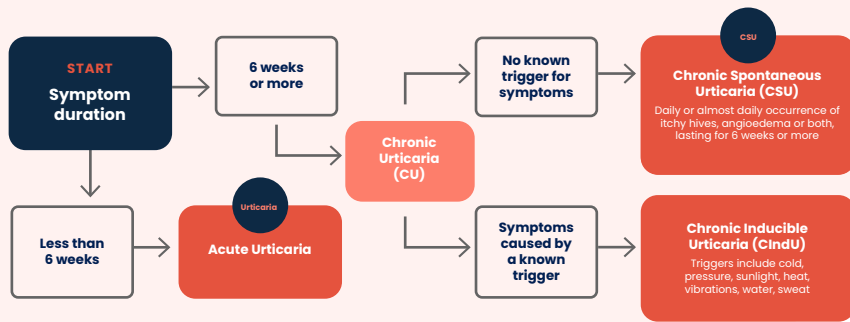
When mast cells release histamine, the local blood vessels widen and increase blood flow to the area. Histamine also stimulates local nerves in the skin, causing itching and occasionally pain.

Triggers can include:

- eating certain foods
- contact with certain plants, animals, chemicals and latex
- cold – such as cold water or wind
- hot, sweaty skin – from exercise, emotional stress or eating spicy food
- a reaction to a medicine, insect bite or sting
- scratching or pressing on your skin – such as wearing itchy or tight clothing or an infection
- a problem with your immune system
- water or sunlight – but this is rare



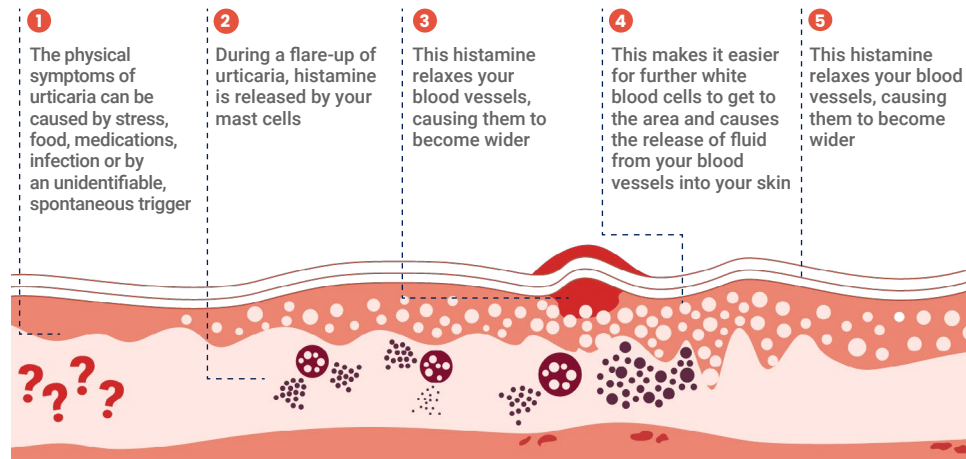
Urticaria can differ in duration and cause



The above diagram is not a diagnosis tool – only a guide. If you think you might have any of the conditions mentioned above, you should seek medical advice from your doctor.

Is CSU caused by an allergy?

No, CSU is not caused by an allergy. Unfortunately, the cause of the histamine release in CSU remains unknown, hence the term ‘chronic spontaneous urticaria’.



What are the symptoms of urticaria and CSU?

Symptoms of urticaria are itchy, raised patches on the skin that can vary in shape, size and colour. They can appear anywhere on your body and can sometimes be painful.

Many people with urticaria also experience pronounced swelling of the deeper layers of the skin. This is called angioedema, and most commonly affects the eyes, lips, face, genitals, hands and feet. Angioedema can often be mistaken for anaphylaxis, a severe allergic reaction.

Some people with CSU may experience anxiety or depression. This is often due to the unpredictable nature of the disease such as when a flare-up will occur and for how long it will last. This may affect different aspects of life such as work, sleep and relationships. Therefore, it is important to see a doctor who can work with you to understand and help manage your condition.

Many people with CSU live with symptoms for up to two years or more before receiving a correct diagnosis, so if your symptoms don't clear up in six weeks it is worth seeking medical advice as soon as possible.



Urticaria (Hives)



Angioedema

How urticaria and CSU can affect your life

Due to the unpredictable nature of the disease, many people with CSU live expecting a flare-up and fearing that their life is on hold, not knowing how long the condition will last. Work, sleep and relationships may suffer, and without proper care, the stress could lead to anxiety or depression. Therefore, it is important to see a doctor who can work with you to understand and help manage your condition.

The impact of urticaria and CSU on daily life is often underestimated, and the effects don't just stop at physical symptoms. Urticaria and CSU can have a major impact on your feelings and quality of life.



Anxiety



Social isolation



Emotional upset



Sleep deprivation



Lack of energy



Depression

You're not alone

Visit www.helpforhives.co.uk to hear stories from other patients with CSU and links to further support (e.g. patient organisations).

Laura



Mark



Coping with emotional impact

There are many things you can do to cope with the emotional impact brought on by the symptoms of urticaria and CSU. It is important to take a positive stance when thinking about your condition. Below are some ideas of how you can shift your mindset about urticaria and CSU.

Consider reaching out to your local healthcare service (e.g. GP, talking therapies) or helplines for emotional support.

Share experiences with others, particularly those who are going through a similar situation

This may help support you when you're feeling low and may give you some treatment tips. Speak to your friends and family, or even join any of the numerous online communities for people living with urticaria. For more information about online communities, search Facebook, Google or contact a charity such as Allergy UK (see [page 8](#) for further support).

Explain your CSU

Negative responses to skin conditions can come from general lack of understanding and concerns that it might be contagious. Taking the time to explain CSU can help dispel any worries and help people understand the condition better.

Try not to focus on the opinions of others

Self-consciousness doesn't have to bring you down – it can encourage positivity too. By being more aware of your feelings and actions, you can see when you're holding yourself back. Only with this recognition you can change and enjoy a social life despite your skin.

Wearing comfortable clothes

This should help you to relax. Remember to wear clothes that will keep you cool if you find your hives are worse when you get hot.

If it helps you, hide your hives with loose-fitting clothes where possible, or use make-up to cover visible hives

If you want to use make-up, test a small amount of it on your skin first to make sure it doesn't irritate your skin further.

Stay positive

This is the most important thing you can do since it can help you avoid negative thoughts. It can be amazing how others around you respond differently when you are positive. One way to do this is to take the time to do things you love doing and remind yourself of the things you enjoy in life.

Your patient pathway with urticaria

It can help to familiarise yourself with the expected patient pathway for urticaria treatment. As with any chronic condition, CSU needs ongoing management. Even if you feel happy with your care, it's important to attend all your check-ups and keep communicating with your doctor so they can monitor your progress and adapt their approach if and when necessary. If you feel you aren't getting any better being managed by your doctor, ask to see a specialist.

Finding the right treatment for you

CSU should be managed in consultation with a doctor. With treatment, symptoms can be completely controlled and sustained, restoring quality of life.

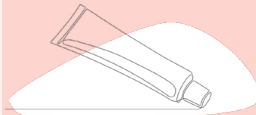
Don't put off telling your doctor about those things that you cannot do anymore because of your CSU and what you want from a treatment to help you with these things. Treatment recommendations will be based on the information you give them, and they are willing to listen if you tell them your current care plan isn't doing enough for you.

There are many 'stepwise' treatments and dosing options available for CSU. It is important to regularly measure how well your treatment regimen is working in order for your healthcare professional to 'step up' or 'step down' treatment. You and your doctor can work together to find the best treatment plan for you. Shared decision making will allow you to be involved in finding the best way forward to gain the control you need to live the life you want. Here are some options your doctor might recommend based on your condition.



Antihistamines

- Typically, the first treatment a doctor will prescribe for CSU
- Provides relief for many
- Some may need dosage adjusted before they experience relief



Steroids

- Can help control symptom flare-ups
- Not suitable for long-term use



Immunosuppressives

- May be added to antihistamine treatment



Biologics

- Injectable therapy may be added to antihistamine treatment if not experiencing effective relief after 1-2 months, often after other options fail

The importance of regularly measuring the impact of urticaria

Keeping a regular record of the severity and frequency of your symptoms will really help your healthcare professional gain a deeper understanding of your condition. It can even help them diagnose you with CSU if your symptoms have persisted for more than six weeks.



DLQI Quality of life

A short questionnaire of 10 questions used to assess how CSU has impacted your quality of life over the past week. Can be tracked weekly.

UCT Disease control

A short questionnaire of 4 questions used to measure the extent to which your CSU has been 'under control' in the past 4 weeks. Can be tracked every 4 weeks.

UAS7 Disease activity

A short questionnaire of two questions to be answered daily for 7 days to assess the level of disease activity. Can seek to complete a UAS7 score every week, or as directed by a healthcare professional.

Measuring the impact of urticaria with these tools **regularly** will help your healthcare team to adjust your care accordingly. Always consult your healthcare professional for any changes to your treatment.



Visit helpforhives.co.uk

for more information and to access the HiveHelper tool that can help you measure your urticaria impact, alongside downloadable DLQI/UCT/UAS7 digital PDF questionnaire alternatives if preferred (can also be printed as necessary).

Further support

Visit these independent sites for more information about urticaria:

Allergy UK
www.allergyuk.org

British Association of Dermatologists
 (BAD) Patient Hub
www.skinhealthinfo.org.uk

British Skin Foundation
www.britishtskinfoundation.org.uk

DermNet NZ
www.dermnetnz.org

International UCARE patient websites
 (Urticaria Centres of Reference and Excellence)
www.urticariaday.org and www.ucare-4u.com

Patient
www.patient.info

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Terminology at a glance

Term	Definition
Chronic spontaneous urticaria (CSU)	A condition linked to the immune system that can cause an itchy rash anywhere on the body and painful skin swelling.
Hives (urticaria)	Itchy rash that can appear anywhere on the body, which may appear raised, streaky or red.
Angioedema	Swelling of soft tissue, typically causing the lips, eyelids, hands or feet to swell.
Spontaneous	Occurring without apparent external cause.
Flare-up	Sudden appearance of symptoms.

Visit www.helpforhives.co.uk for more information.

Mast cells – the science behind urticaria and CSU

CSU is an internal disease linked to an overactive immune system.

1

Your immune system protects you from unfamiliar things and includes many key players:

Immunoglobulin E or IgE

Immunoglobulin E (IgE) are antibodies produced by the immune system.

Mast cells

A mast cell (also known as a mastocyte or a labrocyte) is a resident cell of connective tissue that contains many granules rich in histamine and heparin.

Basophils

Basophils are one of the several kinds of white blood cells you have in your body. Basophils are a part of your immune system and are created inside your bone marrow. They are found in tissues where allergic reactions occur.

What happens with CSU?

2

In the presence of allergens, IgE binds to mast cells and basophils

3

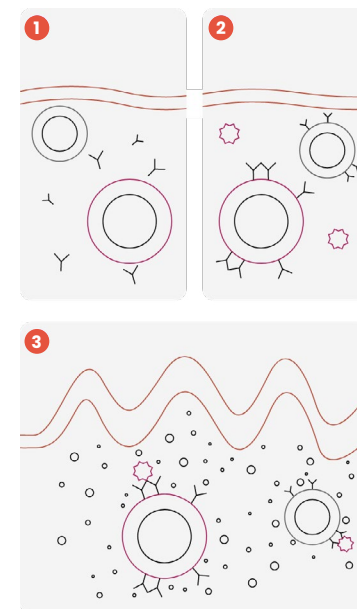
Allergens bind to IgE present on mast cells and basophils

When IgE on mast cells and basophils are activated by an allergen, powerful mediators such as histamine are released

- This leads to a physical inflammatory reaction on the skin

How your body responds to histamine and other mediators

Itching	Hives
Redness	Angioedema



Notes

Don't forget to visit helpforhives.co.uk and try out the HiveHelper tool!
