

Never
Just
Hives

More canceled plans. But “it’s just hives.”

When it comes to CSU, it’s never just hives

Images are not actual
people with chronic hives.

Your guide to understanding CSU

This guide can help you find answers and navigate life with chronic hives with no known external trigger, also called chronic spontaneous urticaria, or CSU.

Living with chronic hives can be isolating, but about 400,000 people in the United States* still struggle with symptoms despite treatment.

*Calculated estimate based on people treated with antihistamines.



Click or tap underlined words
to open the glossary.



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Chronic hives with no known external trigger is also called chronic spontaneous urticaria, or CSU.



What is chronic hives?

Chronic hives is a serious condition that can cause repeated flares of itchy bumps (wheals) and/or swelling (angioedema), which may be painful.

Chronic spontaneous urticaria (CSU) is a form of chronic hives that has no known external trigger. CSU flares typically last less than 24 hours but come and go for more than 6 weeks, often for several years.

The serious physical symptoms of chronic hives



Itchy hives

Red or skin-colored raised, itchy bumps that appear on the outer layer of skin and can vary in size, shape, and color. They can appear and disappear daily or almost daily, without warning. Your skin will usually return to normal within 30 minutes to 24 hours.

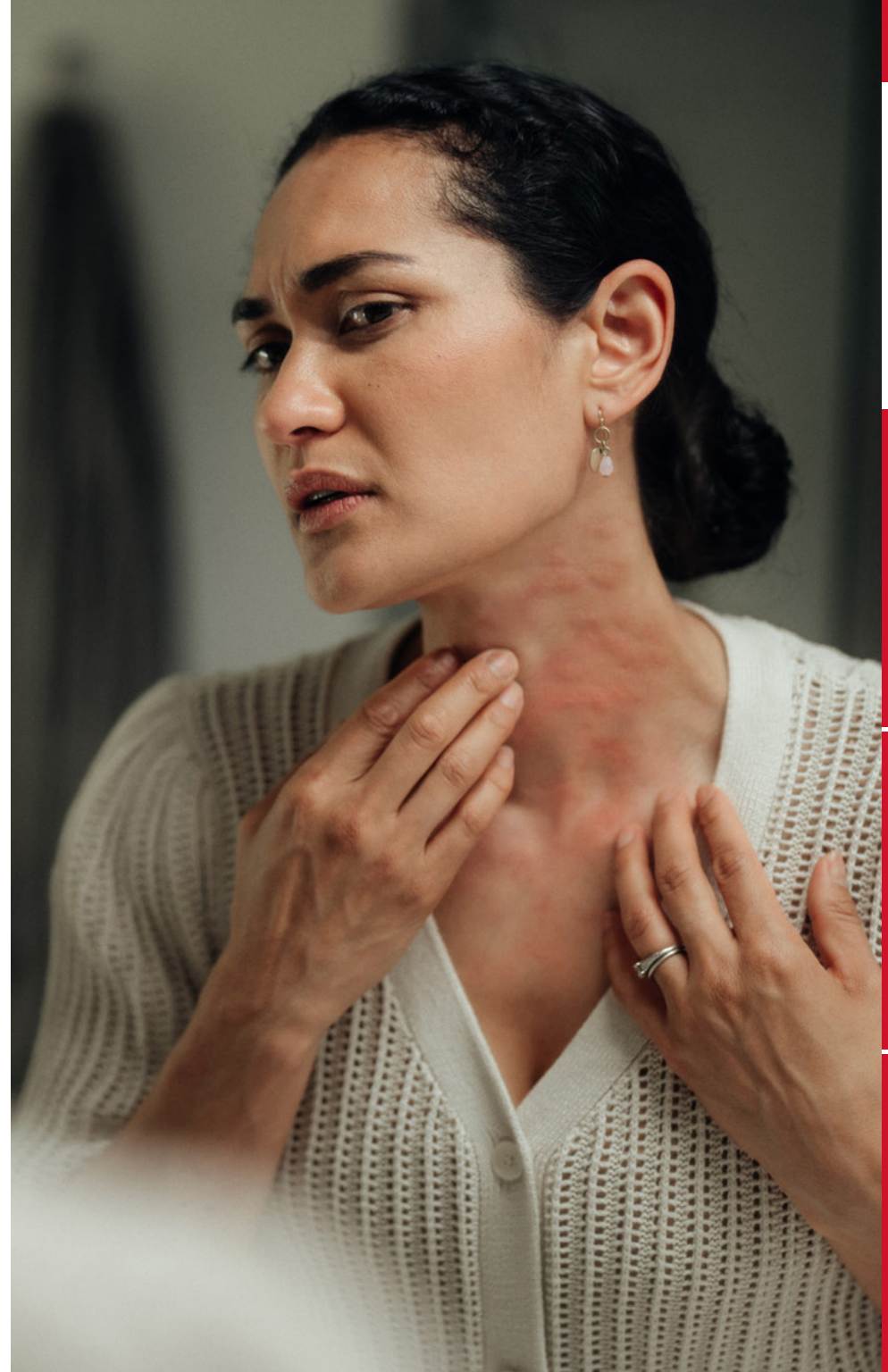
Hives can show up anywhere on the body for no apparent reason.



Swelling

Severe swelling, also called angioedema, occurs in deeper layers of skin on the lips, eyelids, hands, feet, and other areas. It can last up to 72 hours.

Approximately 40% to 50% of people with chronic hives experience swelling.



Key facts about chronic hives

Chronic hives affects some people more than others



About 50% of people taking increased doses of antihistamines for chronic hives still experience symptoms.



Women are nearly 2x more likely to experience chronic hives than men.



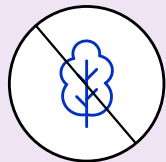
Chronic hives often lasts 1 to 5 years, but some people struggle with their symptoms for decades.

What makes CSU different

Unlike other forms of chronic hives, CSU is not triggered by external factors

It's natural to look for what causes your chronic hives. But with CSU, what you ate, wore, or touched does not start or trigger flares.

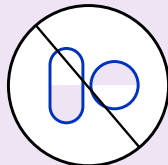
The factors below do not trigger flares, but some of them may worsen symptoms for certain people:



Allergies



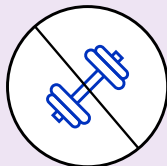
Friction



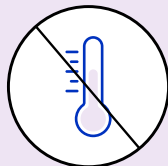
Certain drugs



Stress



Exercise



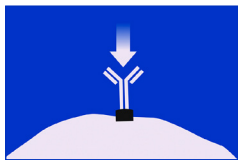
Temperature



If you've been diagnosed with CSU, searching for external triggers won't help you find relief.

What may cause CSU

While the exact cause is unknown, your own immune system may be driving your symptoms



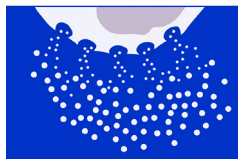
Overactive immune system

CSU is believed to start with the immune system getting confused by an unknown internal cause and mistakenly reacting to an internal trigger.



An unnecessary immune response

Like a chain reaction, the mistaken signal is passed through the immune cells.



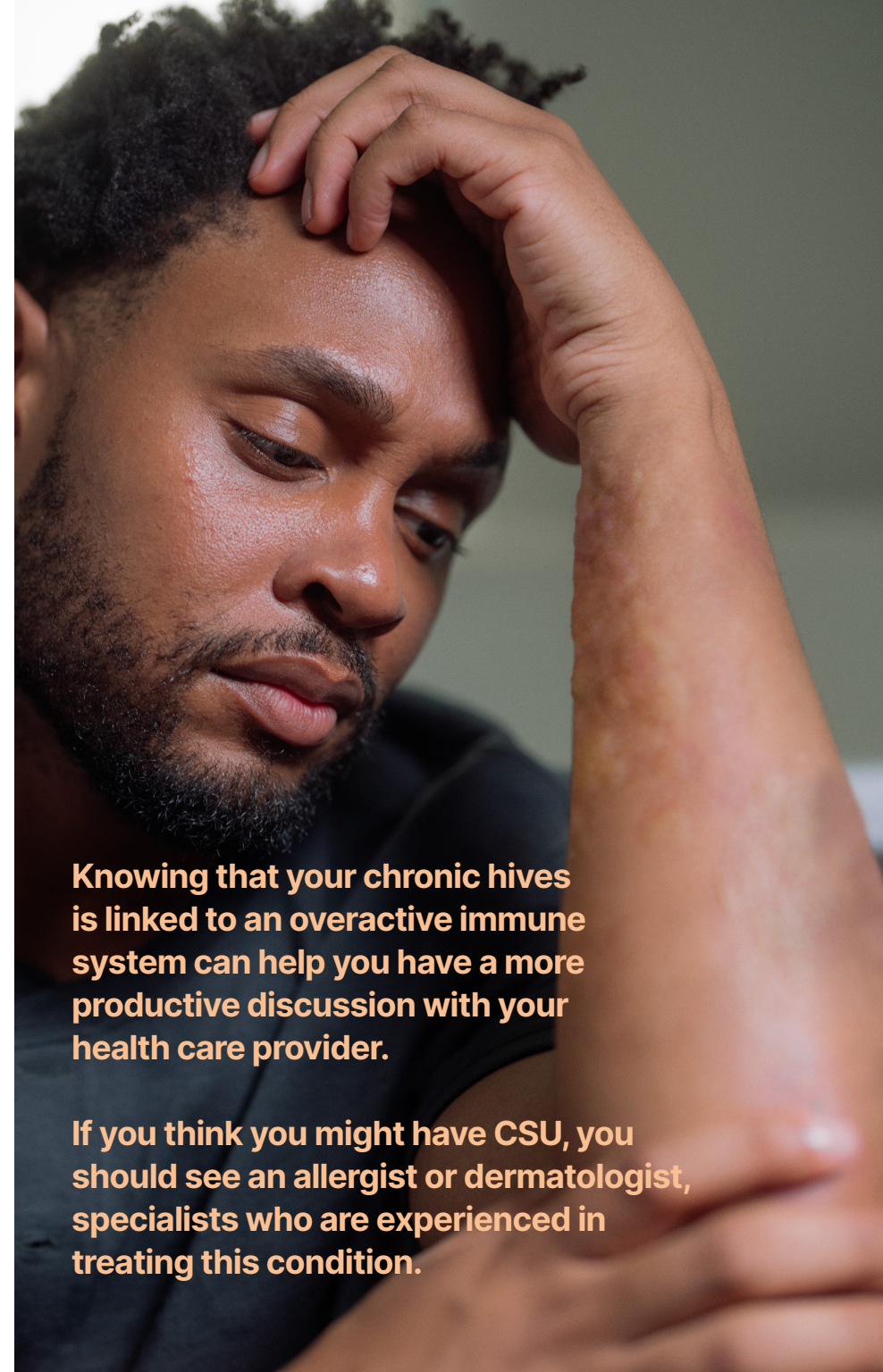
Histamine release

The signal causes the cells to release a large amount of histamine.



The common symptoms

The result is the common symptoms of CSU, including itchy hives and severe swelling under the skin (angioedema).



Knowing that your chronic hives is linked to an overactive immune system can help you have a more productive discussion with your health care provider.

If you think you might have CSU, you should see an allergist or dermatologist, specialists who are experienced in treating this condition.

Impact of chronic hives



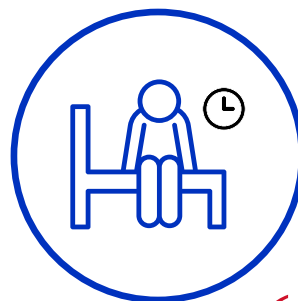
The impact of CSU is never just hives. It goes beyond symptoms like itch and swelling, and can affect pretty much every aspect of life.



Are you feeling depressed or anxious?

The symptoms of CSU come and go, but the emotional and mental toll may never go away. 70% of people living with chronic hives also report anxiety and/or depression.

“Not wanting to live in your own skin is truly one of the worst feelings.”

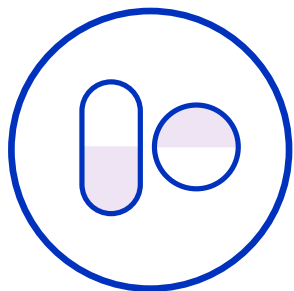


Is itch keeping you up at night?

Sleep deprivation from intense itch is very common in chronic hives. This can lead to lack of energy, which impacts your daily activities.

“I would stay up until 4 or 5 in the morning some nights scratching my feet with a hairbrush.”

Impact of chronic hives (cont)



Are you tired of trying different antihistamines?

According to one survey, most people who take antihistamines for their CSU end up switching from one antihistamine to another.

“Antihistamines just make me feel like a zombie; I’m always in a daze.”



Did you miss work this week?

One out of 5 people have missed at least 1 hour of work this week due to their chronic hives, according to a patient-reported survey.

“I would often call out sick or tell my manager I had to be offline for hours.”



Managing chronic hives

When it comes to living with chronic hives, knowing your treatment options is essential. Getting informed can help you have better discussions with your health care provider.

Antihistamines

- Antihistamines work in the body to interrupt the effects of histamine
- Typically, a health care provider will choose antihistamines as the first treatment for chronic hives
- If antihistamines aren't working for you, let your doctor know

~50% of people taking increased doses of antihistamines for chronic hives still experience symptoms.

Steroids

- Steroids can temporarily relieve hives and swelling
- Their long-term use can lead to serious side effects

CSU is a chronic condition, and you need a solution that works long term.

Second-line therapy

- Second-line therapy is sometimes prescribed to people who are still experiencing symptoms on antihistamines
- <20% of people with chronic hives who are still experiencing symptoms on antihistamines receive a second-line therapy

Switching to another treatment can feel like a huge step for some people. Not being ready to take this step doesn't mean you don't deserve relief.



Discussing chronic hives with your doctor

You play an important role in the management of your chronic hives. If you're not sure what to say, here are some ways to get the conversation going.



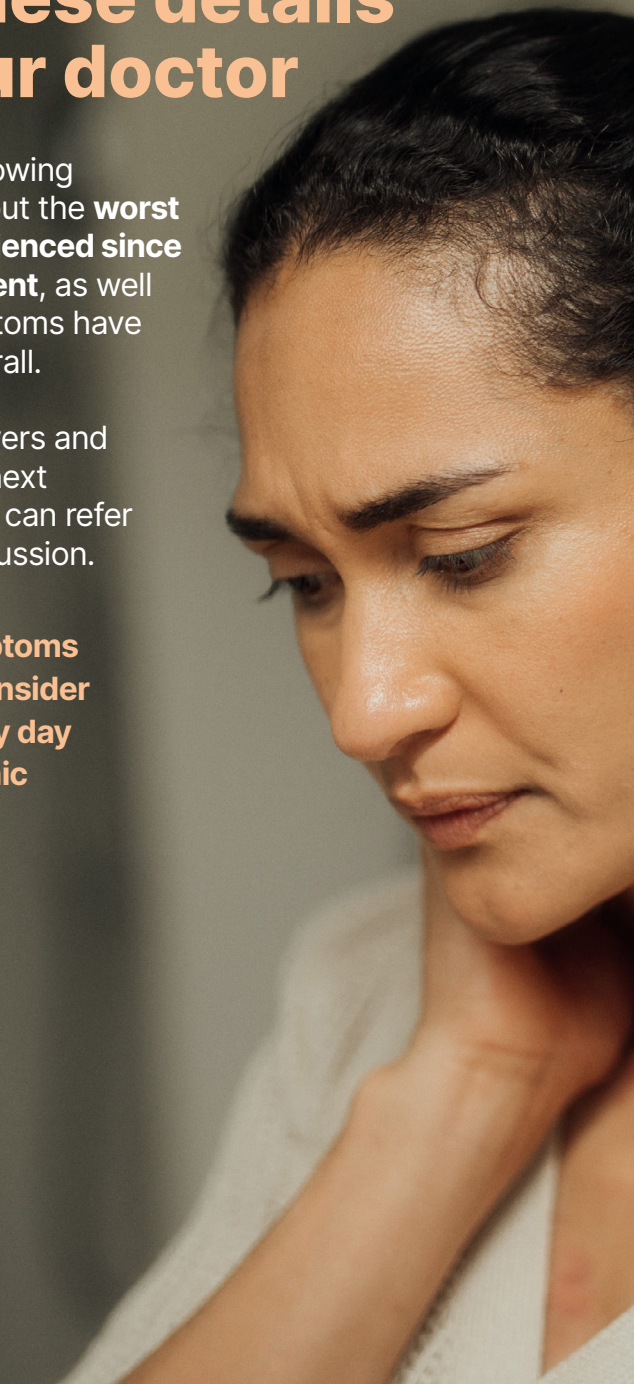
- * Be detailed and specific**
It's not always easy to find the right words for a condition with symptoms that can change every day. Be as specific as possible when talking to your health care provider.
- * Record everything**
Symptoms come and go, so you might not have any to show your health care provider on the day of your appointment. That's why it's important to record your symptoms any way you can, including:
 - Taking photos of your hives
 - Writing notes or using a journal or calendar
 - Answering the questions on the next page to summarize your experience
- * Avoid saying it's "fine"**
What you're going through is far from fine, and you should feel free to express how your life has been affected.
- * Get another perspective**
Ask your partner or a family member about the impact your symptoms have had on their life as well as yours, and share this information with your health care provider.

Share these details with your doctor

As you read the following questions, think about the **worst flares you've experienced since your last appointment**, as well as the impact symptoms have had on your life overall.

Jot down your answers and bring them to your next appointment so you can refer to them in your discussion.

To share your symptoms in greater detail, consider tracking them every day using the My Chronic Hives Journal. [↗](#)



Physical symptoms

- 1 What physical sensations did your hives cause? Itching? Something else?
- 2 How much did your hives bother you? Not at all? A little? A lot?
- 3 If you had swelling (angioedema), where did it appear? On your lips? Eyelids? Hands? Feet? Elsewhere?
- 4 What physical sensations did your angioedema cause? Tingling? Burning? Tightness? Pain?

Impact on your life

- 1 How do symptoms interfere with your daily activities?
- 2 Do flares prevent you from falling asleep, disturb your sleep, or cause you to feel fatigued?
- 3 Have you felt embarrassed about your symptoms? Which ones? Can you describe your feelings?
- 4 How many hours or days of work have you missed due to your symptoms?
- 5 Has living with symptoms left you feeling anxious or depressed? Can you describe your feelings?
- 6 How has living with your symptoms affected your relationships with others?



Glossary

Click or tap any underlined word to go back to the page where it first appears.

Angioedema: Severe swelling that occurs in deeper layers of skin, commonly in the eyes and lips. This may occur in 40% to 50% of people living with chronic hives.

Antihistamines: A medication that works in the body to interrupt the effects of histamine, a chemical released by the immune system that can cause reactions like hives or swelling. For ~50% of people with chronic hives, antihistamines alone are not enough.

Chronic: A type of condition that occurs for a long period of time or comes back frequently.

Chronic spontaneous urticaria (CSU): A recurring condition, also known as chronic hives with no known trigger, that leads to discomfort, pain, and swelling for at least 6 weeks.

External trigger: Identifiable triggers (such as heat, cold, certain foods or drugs) that can lead to a reaction in the immune system. CSU is an internally driven disease with no known external trigger.

Histamine: A chemical released by the immune system that can cause reactions like hives or swelling typically associated with allergic reactions.

Hives: Red or skin-colored raised, itchy bumps that appear on the outer layer of skin and can vary in size, shape, and color.

Immune system: The body's defense system. It is a complex network of organs, cells, proteins, and chemicals that work together to defend the body against infection and other diseases, while protecting the body's own cells.

Second-line therapy: Treatment that is given when initial treatment (first-line therapy) doesn't work or stops working.

Steroids: A class of drugs used to relieve inflammation.

Wheals: Another term for hives.

Never Just Hives

Get the tools and talking points
that can help your health care provider
understand how chronic hives
is impacting your life.

Visit neverjusthives.com 



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