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THE HIVE GUIDE

A resource that gives people living with hives the language to describe their symptoms and get the right care.

WELCOME TO THE HIVE GUIDE

The Hive Guide is a resource sharing the language of hives. It is a booklet that teaches you about chronic hives and offers conversation starters to help you confidently discuss it with your doctor.

Living with hives is challenging, but your life doesn't have to be defined by your condition.

The Hive Guide will help you take charge.

HIVES 101

Chronic spontaneous urticaria (CSU), often called chronic hives, is an immune-related skin condition that causes itchy and painful hives that come and go unpredictably, without any external cause. Symptoms can last for at least six weeks, but may continue for months or years at a time.[1]

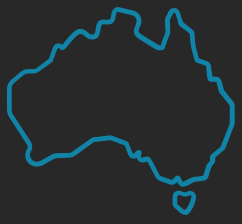
Most common in women and those between the ages of 20 and 40, CSU affects around 1% of the population. CSU is sometimes mistaken for an allergy, but it is actually an immune condition. There is no clear cause or trigger for symptoms.[2]

CSU impacts all parts of life for the people that live with it, from everyday routines to important events. The physical symptoms, especially itch, can disrupt sleep, work, and relationships, while the unpredictability of outbreaks causes stress and anxiety, taking a significant emotional toll.[3,4,5,6,7]

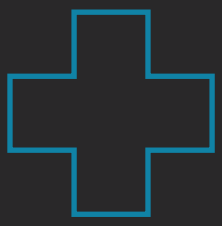
Most people have never heard of CSU. It can take a long time to be diagnosed, during which time many people are wrongly diagnosed with other, similar conditions. This can cause them to suffer in silence, feel alone and lose hope that things can get better. **That's where The Hive Guide can help – by giving you the words to speak up and seek help.**

HIVES 101

DID YOU KNOW?



There are approximately **200,000** Australians living with CSU, with women more likely than men to develop the condition[2]



People living with the condition consult an average of approximately **6 doctors** before receiving a diagnosis[6]

50% of patients continue to experience symptoms **2 years** after onset due to delays in diagnosis[4,8,9]

WHEN IT COMES TO SYMPTOMS, APPROXIMATELY:

1 IN 3*

people avoid social interactions due to symptoms (*31%)[11]

1 IN 3*

people report that CSU negatively impacts their mental and emotional well-being (*36%)[11]

4 IN 5*

people report impaired sleep quality (*79%)[10]

4 IN 5*

people's symptoms remain, despite treatment with antihistamines (*84%)[12]

DIAG-NOSIS

If you have been experiencing hives or any kind of allergic reaction, speak to a GP. They can help you pursue a diagnosis, often by referring you to a specialist. This might be an immunologist or a dermatologist.

It's important to give your doctor all the right information to help minimise delays. Using a diary to write down (track) your symptoms before your appointment can be helpful. Using photos to track symptoms can be helpful too. You can share this diary with your doctor to read, to help them get a full idea of your condition.

Symptoms you may wish to monitor include:

- Physical (redness, itchiness)
- Emotional (frustration, anxiety)
- Social (impacting sleep, relationships)

Use the symptom tracker tool and bring these results to your next appointment.

ASK YOUR DOCTOR

WHEN SPEAKING TO YOUR DOCTOR TO GET A DIAGNOSIS, YOU MIGHT LIKE TO ASK:

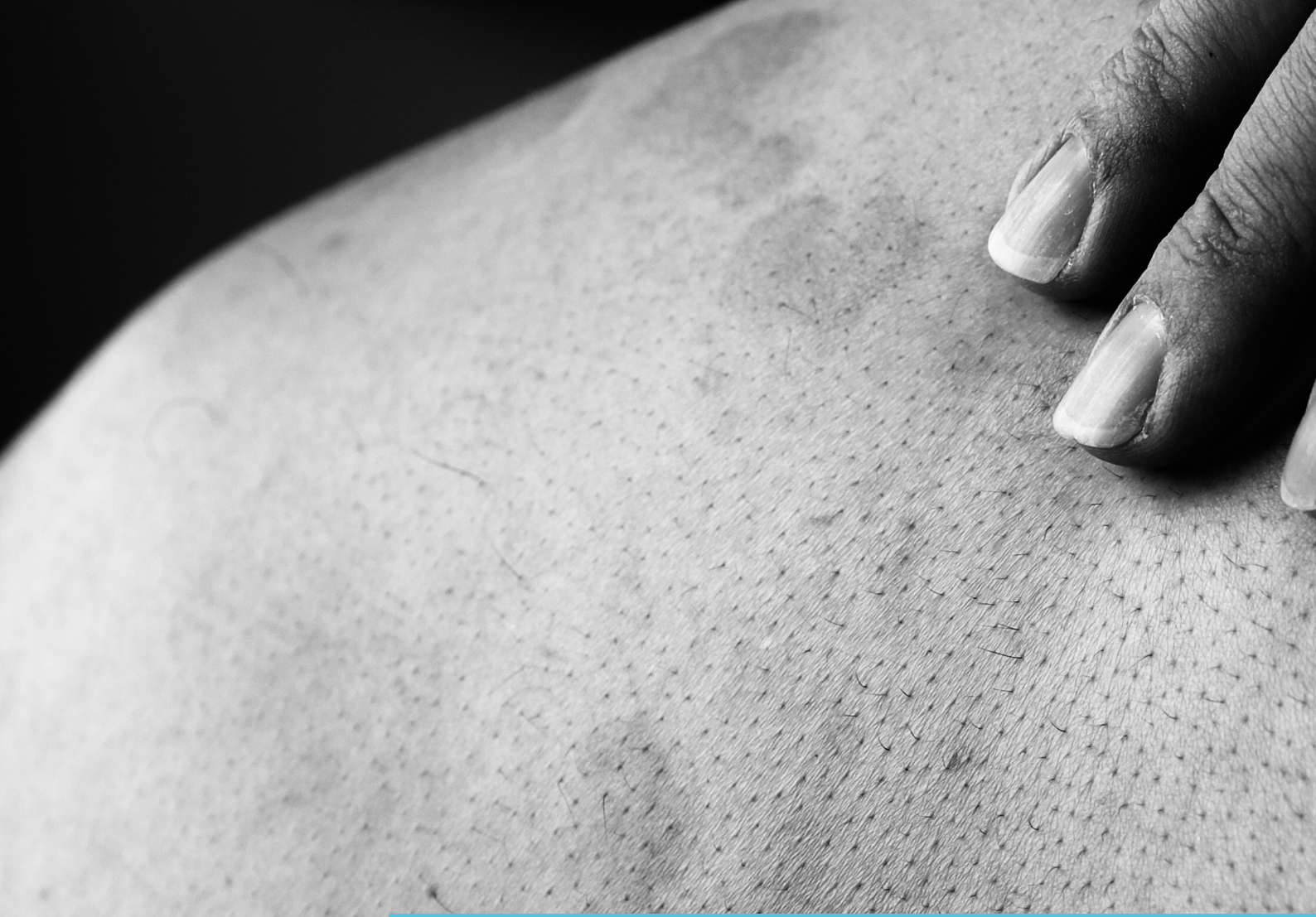
- How do I know if my hives are a response to an allergen? How do I know if they are not?
- Would a test be helpful? What tests are available to me, what will they involve, and how can I prepare?
- How long will I need to wait for test results? What can I do to manage my symptoms while I wait?
- What does the process of diagnosis look like?

LET'S TALK SYMP-TOMS

Hives symptoms can be unpleasant, hard to anticipate and can sometimes escalate. Treatment should help you manage your symptoms, be accessible and suit your lifestyle. If that is not true for you, there may be other treatment options that your doctor can offer you that you may prefer.

Your doctor may not realise how much CSU disrupts your life, so it's important to be honest with your doctor so they can help you manage it. Consider sharing your current treatment (including antihistamines), the length of time you've been using that treatment, if you are still experiencing symptoms while on treatment, and the impact on your quality of life.

If your CSU is making you feel down or depressed, stopping you from doing activities or impacting your social life, sleep or work, it could mean that your symptoms are not as well-managed as they could be. It is important to speak to your doctor about all your symptoms, even the ones they cannot see, so they fully understand how CSU is affecting you and your life and can work with you on a care plan to suit your needs.



ASK YOUR DOCTOR

WHEN SPEAKING TO YOUR DOCTOR ABOUT YOUR SYMPTOMS, YOU MIGHT LIKE TO ASK:

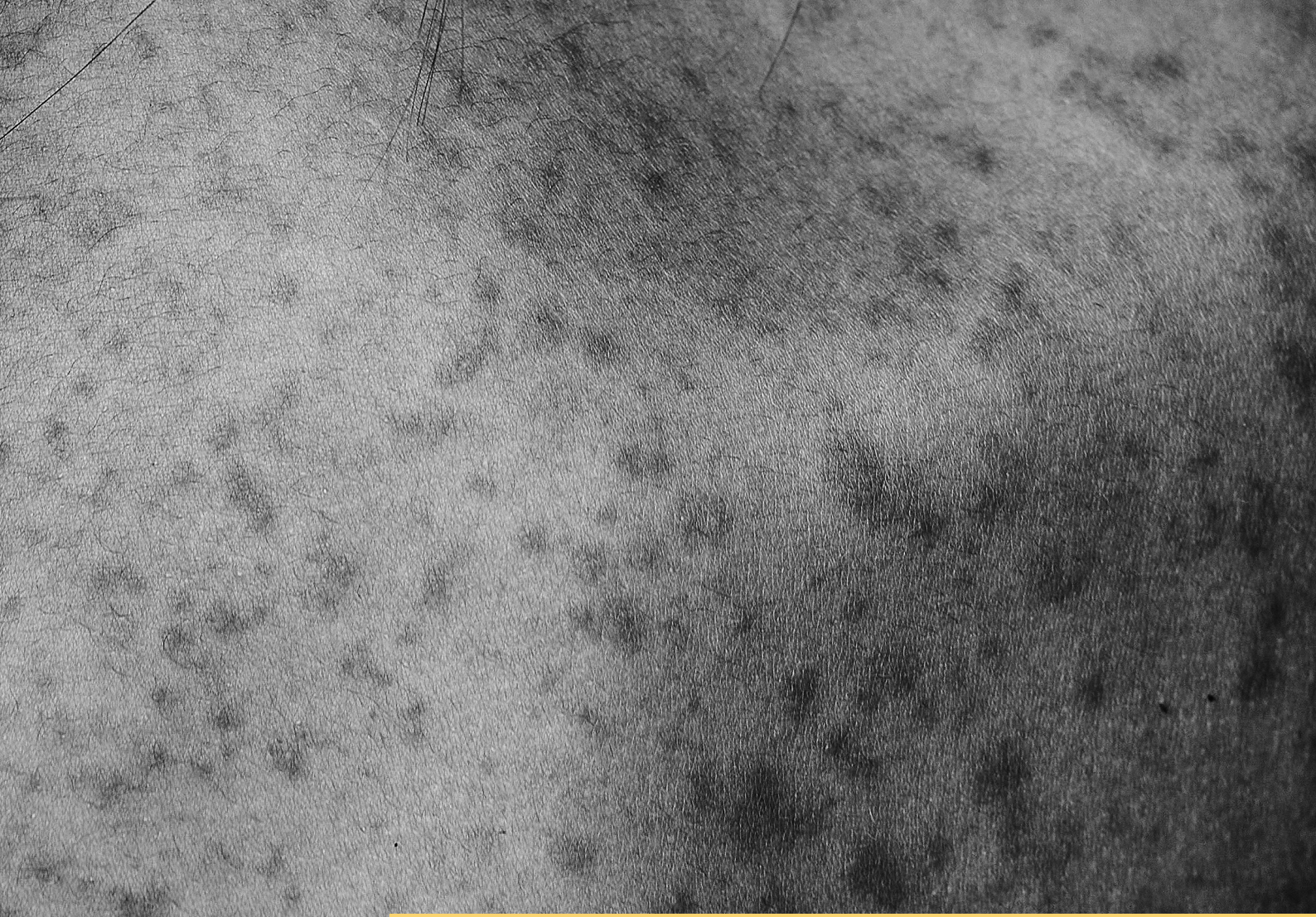
- What should I do if my symptoms don't improve?
- What are the potential side effects of this treatment, and how can I manage them if I get them?
- Are there lifestyle changes I should make while taking treatment?
- Will my CSU get worse again? How can I prepare for this? Are there other treatment options available to me if this happens?

LIVING WITH HIVES

The goal of treating and managing your CSU is to help you get back to your version of normal. Some people with CSU stop having symptoms over time, and some continue to rely on treatment to manage their condition. However you experience CSU, your healthcare team are there to support you, helping you live with CSU without it controlling your life.

In Australia, you may be eligible for Medicare-subsidised mental health care sessions through a Mental Health Treatment Plan. If this sounds like it might be helpful, ask your doctor for more information.

You can also speak with an Allergy Educator at Allergy & Anaphylaxis Australia who can help you get the medical care you need and support you in the process. Call 1300 728 000 or visit this link.



ASK YOUR DOCTOR

WHEN SPEAKING TO YOUR DOCTOR ABOUT YOUR QUALITY OF LIFE, YOU MIGHT LIKE TO ASK:

- Is there a test I can take to determine if there is a treatment option available that is more specific to my condition? (See glossary: biomarker testing)
- Have any new treatments for CSU become available since we last reviewed my treatment plan?
- How will I know if I no longer need treatment?
- What support is available to me?

GLOSS-ARY

ALLERGY

An allergy is an overreaction by the body's immune system to a normally harmless substance.[8] CSU can sometimes be misinterpreted as an allergic reaction and further tests may be required to distinguish between the two.[9]

ANGIOEDEMA

Angioedema involves swelling of the deeper layers of skin (often the face, lips, tongue, throat or genitals), while urticaria (see below) affects the top layers. Angioedema can feel tight or painful rather than itchy, can occur with or without urticaria, and may last longer than urticaria.[10]

ANTIHISTAMINE

Medicines which block the histamine (see below) receptors in your body, whether triggered by an allergen, as part of CSU, or otherwise.[11]

BIOLOGICS

Biological therapeutics, also referred to as Biologicals/Biologics, are a class of medicines which are grown and then purified from large-scale cell cultures of bacteria or yeast, or plant or animal cells.[12] Biologics can be used to treat urticaria that is not adequately managed with other medicines alone.

GLOSSARY CONT.

BIOMARKER TESTING

A test that identifies specific factors driving symptoms, which may indicate which treatment could be used to address those symptoms.[13] Ask your doctor if this might be an option for you.

CHRONIC

In a health context, the word chronic refers to a long-lasting condition with persistent effects. The condition may last months to years at a time or may never be fully 'cured', though symptoms can come and go.[14]

CORTICOSTEROIDS

A type of anti-inflammatory treatment, corticosteroids can be used to treat severe hives symptoms for a short time.[14,15]

FLARES

Flares or flare-ups are described as "waves" of intense itch and swelling, with lesions varying from small spots to large, interconnected patches. Flare-ups can last from a few hours to several days and can be unpredictable. Severity can range from mild itch to debilitating discomfort, which can impact daily life and cause distress.[3,16]

HISTAMINE

A chemical released by your immune system that can cause allergy symptoms but also regulates your sleep-wake cycle and cognitive function.[17]

SPONTANEOUS

In a health context, the word spontaneous refers to a symptom or illness that appears without apparent cause.[14]

TRIGGER

Something that can cause symptoms to flare. CSU is termed "spontaneous" because flares occur without consistent external triggers. If the trigger is consistent and predictable, the hives may be termed 'inducible'.[18]

URTICARIA

Urticaria, more commonly known as hives, are raised itchy bumps or welts, ranging in size from small spots to large patches. They appear when the immune system releases histamine in response to triggers.[19]

WHEAL

The raised bump or welt.[20]

THERE IS HOPE FOR A LIFE CLOSER TO YOUR NORMAL

Your doctor can help you reduce symptoms, so they don't affect your everyday life. Asking for help could reveal a new, better way forward.

Armed with the knowledge and language above, make an appointment with your doctor today.

NOTES

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notjusthives.com.au

Allergy & Anaphylaxis Australia was consulted during the development of this resource to provide feedback on patient information needs and usability. Novartis Australia provided financial support for this engagement.

For more information about hives and related conditions, visit Allergy & Anaphylaxis Australia at **allergyfacts.org.au**

This resource is not intended to replace medical advice. Please speak to your healthcare professional for more information. National Allergy Helpline: 1300 728 000.

References: 1. Novartis. Not Just Hives. https://notjusthives.com.au/ **2.** Centre for Community-Driven Response (CCDR). Personal Experience Expectations and Knowledge (PEEK) study: Chronic urticaria. Volume 7, Issue 3 (2024) **3.** Maurer M, *et al. Allergy.* 2011;66:317-330. **4.** Maurer M, *et al. Allergy.* 2017;27:2005-2016. **5.** Kang M, *et al. Ann Dermatol.* 2009;21:226-229. **6.** Balp M, *et al. Patient.* 2015;8:551-558. **7.** Balp M, *et al. Dermatol Ther* (Heidelb). 2017;7:535-545. **8.** Winders TA, *et al.* Flash talk presented at EAACI 2024, May 31-June 3; Valencia, Spain. FT 11. **9.** Wagner N, et al. Dermatol Ther (Heidelb). 2021;11:1027-1039. **10.** Sánchez-Díaz M, et al. Int J Environ Res Public Health. 2023;20:3508. **11.** Winders TA, *et al.* Presented at EADV Congress 2024, 25-28 September; Amsterdam. Abstract P3623. **12.** Bernstein J, *et al*. Abstract presented at: ACAAI 2023 Annual Scientific Meeting, November 9 13, 2023 in Anaheim, California, USA. D006. **13.** Allergy & Anaphylaxis Australia. What is an allergy? Allergy facts. https://allergyfacts.org.au/about-allergies/what-is-an-allergy/ Accessed 6 May 2026. **14.** Australian Society of Clinical Immunology and Allergy. Chronic Spontaneous Urticaria (CSU). https://www.allergy.org.au/patients/skin-allergy/urticaria-hives-chronic Accessed 6 May 2026. **15.** Allergy & Anaphylaxis Australia. Urticaria (hives). Allergy facts. https://allergyfacts.org.au/__interest/urticaria/ Accessed 6 May 2026. **16.** Health Direct. Antihistamines. https://www.healthdirect.gov.au/antihistamines Accessed 6 May 2026. **17.** World Health Organisation. Biologicals. https://www.who.int/health-topics/biologicals#tab=tab_1 Accessed 6 May 2026. **18.** Xiang, YK., Hu, M., Elieh-Ali-Komi, D. *et al.* Biomarkers in Chronic Spontaneous Urticaria: Are We Ready for its Use in Clinical Practice?. *Curr Treat Options Allergy* 12, 15 (2025). **19.** Australian Institute of Health and Welfare. Chronic disease. AIHW. https://www.aihw.gov.au/reports-data/health-conditions-disability-deaths/chronic-disease/overview Accessed 6 May 2026. **20.** Healthdirect. Steroid (corticosteroid) injection. https://www.healthdirect.gov.au/steroid-corticosteroid-injection Accessed 6 May 2026. **21.** Powell RJ, Leech SC, Till S, *et al.* BSACI guideline for the management of chronic urticaria and angioedema. Clin Exp Allergy 2015; 45: 547-565. **22.** Cleveland Clinic. Histamine. https://my.clevelandclinic.org/health/articles/24854-histamine Accessed 6 May 2026. **23.** Zuberbier T, *et al. Allergy.* 2022;77(3):734-766. **24.** Healthdirect. Hives (urticaria). https://www.healthdirect.gov.au/hives Accessed 6 May 2026. **25.** Better Health Channel. Hives. https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/hives Accessed 6 May 2026.

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