

Never
Just
Hives

My Chronic Hives Journal

Images are not actual people with chronic spontaneous urticaria (CSU), also called chronic hives.

**Navigating life with chronic hives:
a resource for reflection and symptom tracking**



Download to desktop or print out.
Mobile functionality varies by device.



“I’ve had this condition for five years and there seems to be no rhyme or reason to why it happens!”

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Introduction

Chronic hives with no known external trigger, also known as chronic spontaneous urticaria or CSU, is a serious condition. It can feel isolating, but you are far from alone—about 400,000 people in the United States* still struggle with symptoms despite treatment.

*Calculated estimate based on people treated with antihistamines.

Why is journaling important?

During this challenging journey, it helps to have a space to collect your thoughts, track your symptoms, and set goals. Journaling comes highly recommended by medical experts as a way to process your thoughts and emotions.

Understand your chronic hives

Gain clarity and insight into your experience with chronic hives by tracking your symptoms and reflecting on your journey so far. Chronic hives works in mysterious ways. The crucial part is how you understand it.

Process the impact

Anxiety, depression, and isolation are all common for people with chronic hives. Use this space to open up about the various challenges you face and process the emotions that come with them.

Set yourself up for success

When you keep track of your symptoms and their impact, you can have a more informed dialogue with your health care provider, even if you don't have any symptoms on the day of your appointment.

Instructions

This is your journal; use it any way that's helpful for you.

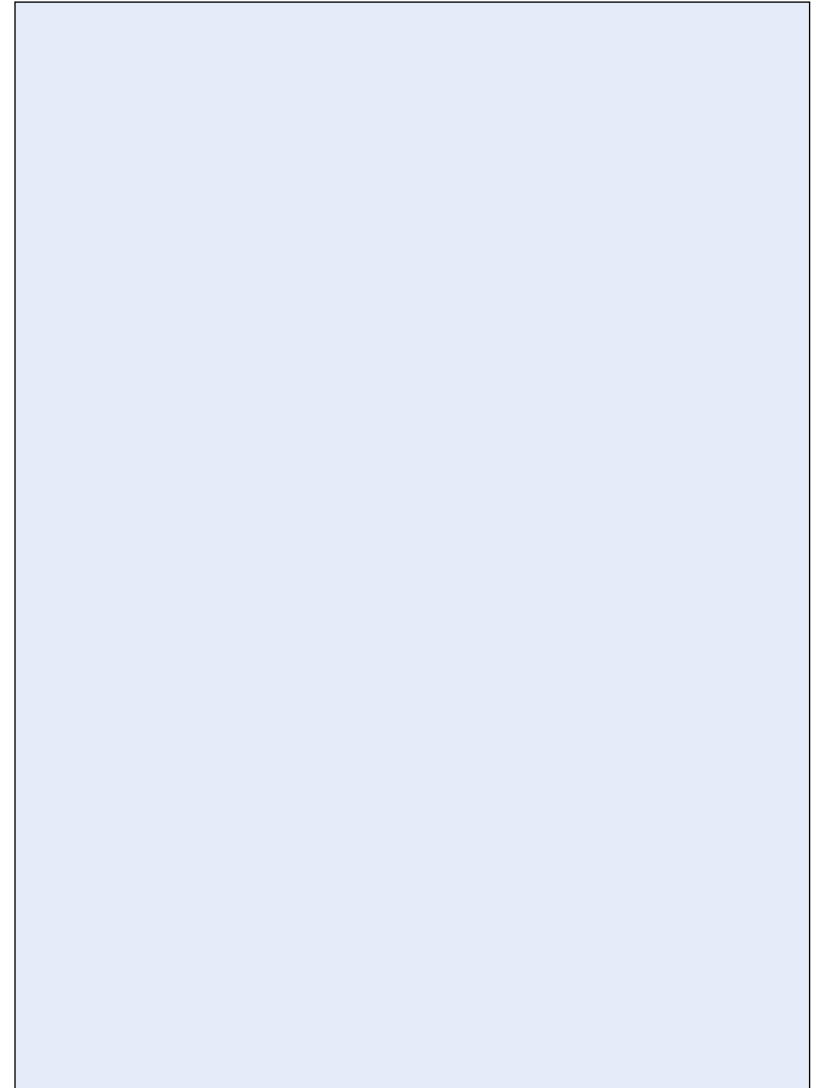
- Use the symptom tracker to log symptoms and measure their impact
- Choose one or multiple journaling prompts to detail your experience
- Fill out the tracker on your device or print it out, then share with your health care provider via email or on your device, or bring a printed copy to your next appointment
- Lastly, utilize the tips on how to prepare for your next appointment and effectively share your experience with your health care provider

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

Getting started

“My hives made me so irritable that I was constantly getting into fights with my partner over the silliest little things.”

Take a moment to consider where you are today in your journey with chronic hives. How long have you had symptoms? How do you feel about your progress? Are you able to control your symptoms? Write down your thoughts below.



Symptom tracker

Since CSU comes and goes, it can be helpful to track your symptoms. Use each row to capture one of your ongoing symptoms: hives or swelling. Log its severity and location, how long it lasted, and when it occurred.

Hives or swelling (one symptom per row)	Symptom severity	Symptom location	Symptom duration	Date
Select symptom <input type="text"/>	1 - 10 <input type="text"/>	Example: Lips	Example: 2 hr	
<input type="text"/>	<input type="text"/>			
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Measuring symptom activity and impact

Prior to your next appointment, check one box for each question to describe your recent symptoms.

Since your last visit to a health care provider:

1. How often have you suffered from itchy hives (welts) and/or swelling?

- Very often
- Often
- Sometimes
- A little
- Not at all

5. How much did your symptoms affect your personal relationships?

- A lot
- Somewhat
- A little
- Not at all

2. How often have your symptoms affected your daily activities?

- Very often
- Often
- Sometimes
- A little
- Not at all

6. How much did your symptoms affect your productivity at school/work?

- A lot
- Somewhat
- A little
- Not at all

3. How well did your treatment control your symptoms?

- Very well
- Well
- Somewhat
- A little
- Not at all

7. How unpredictable have your symptoms been?

- Very
- Somewhat
- A little
- Not at all

4. Overall, how well have you had your symptoms under control?

- Very well
- Well
- Somewhat
- A little
- Not at all

8. Have you noticed any symptom improvement?

- A lot
- Somewhat
- A little
- Not at all

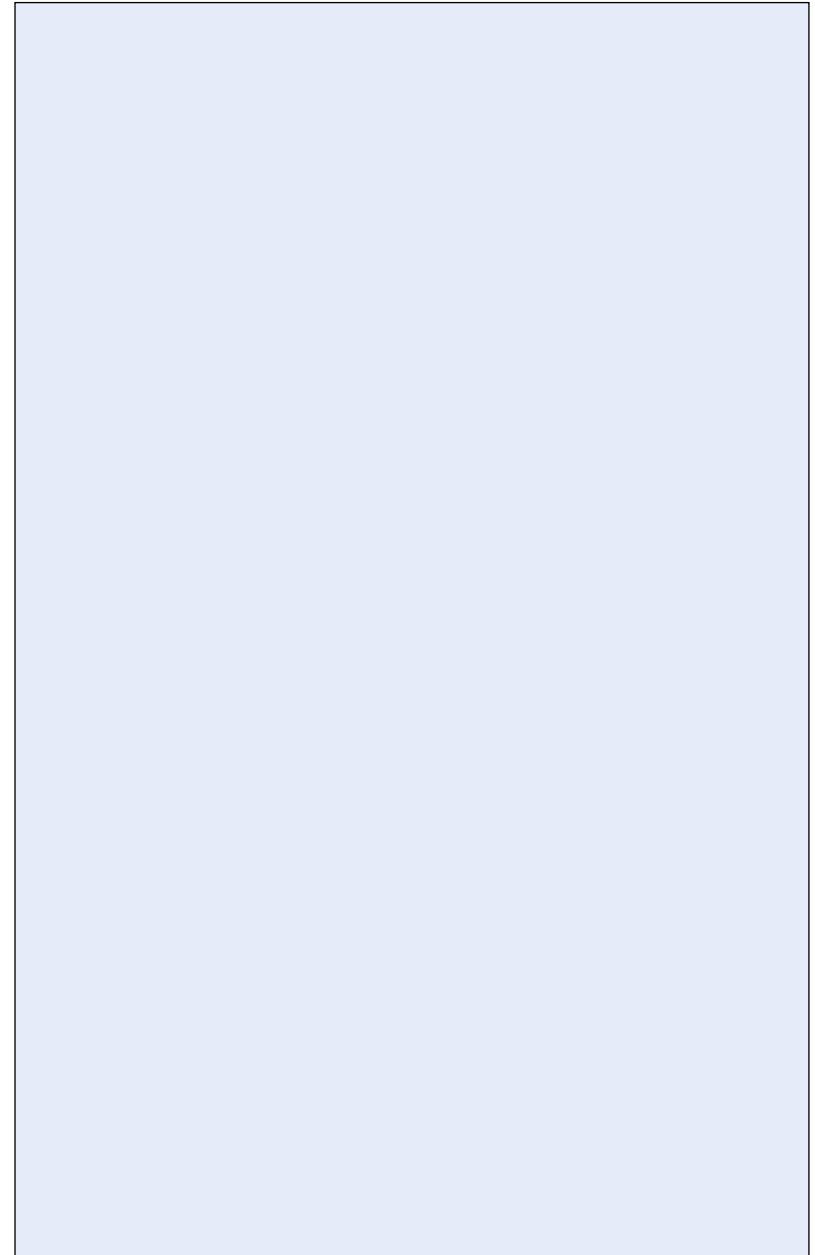


Journaling

It's not always easy to find the right words for a condition with symptoms that can change every day. Below are some prompts to help get you started. Use the space to the right to write out your response. Be as detailed as you like—the more specific, the better.

Prompts: describing the impact

- Describe one of your most challenging flares as of late. How did it feel? Where were you when it happened? How long did it last?
- Has living with chronic hives:
 - Made you feel depressed, stressed, anxious, and/or isolated?
 - Disrupted your sleep?
 - Prevented any physical activities or exercises?
 - Created challenges in social situations or caused you to cancel plans?
 - Caused any changes in your relationships with friends or family members?
- Are there any unexpected ways chronic hives has impacted you?
- How do you cope with your symptoms?

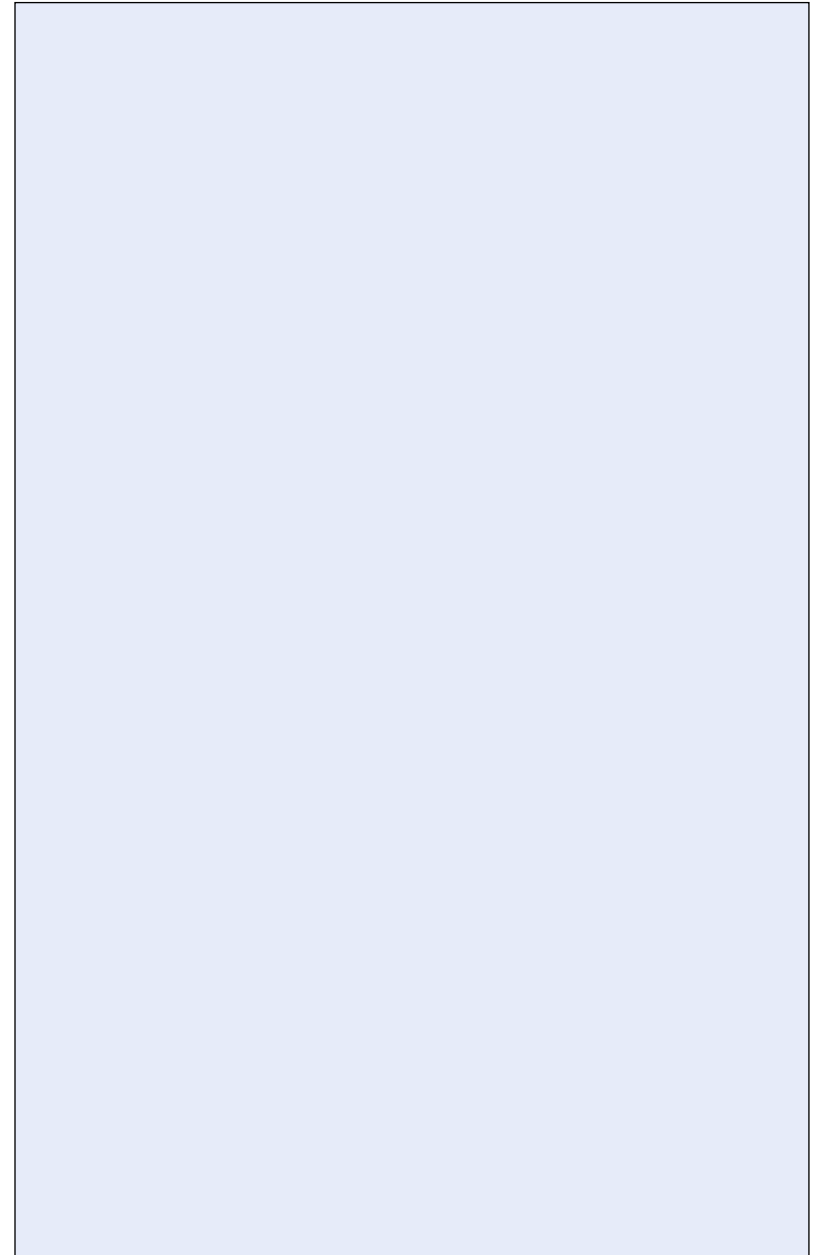


Journaling

Take a moment to consider your overall journey so far. If there are areas that you have found difficult to talk about with your health care provider, these prompts can be a helpful way to start that conversation.

Prompts: reflection

- Have you experienced emotional or psychological trauma as a result of symptoms from chronic hives?
- Have you ever downplayed your symptoms, saying “it’s fine” when you knew it wasn’t? If so, what did you really want to say?
- Have you ever felt your symptoms were looked at and treated as less severe than they felt?
- What are your goals for treatment? How do you define success?
- Do you have any upcoming events in your life that you’re worried might be ruined by symptoms?
- Have you experienced any kind of pain or suffering from this condition that you haven’t shared with your health care provider?



Preparing for your next appointment

Here are some steps you can take to make sure you get the most out of your next appointment.

- * **Record everything**

Capture all your symptoms as they happen. Your health care provider should see it all.

 - Keep a photo diary to track what's happening with your skin
 - Always log any sleepless nights, life impairments, and emotional distress—such as anxiety or depression—that result from symptoms
 - This journal can be used for documenting your symptoms and their impact
- * **Connect with the community**

Any of the online groups [↗](#) for people with chronic hives are great spaces to connect, [↗](#) share your experience, and get input from people in a similar situation as you.
- * **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.
- * **Stay informed**

Chronic hives, or CSU, is not caused by external triggers. Many experts believe a potential cause of chronic hives [↗](#) is an overactive immune system. Learning about what's driving your symptoms is a step toward finding relief.

Talking with a health care provider

In addition to coming prepared with your journal, these tips can help make conversations with your health care provider as productive as possible.



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



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.



Be vulnerable


Don't be afraid to open up about the emotional and mental struggles caused by your condition. The deeper burden is an important part of the dialogue.



Stay motivated

Chronic hives is a tough condition to control. The journey can be very frustrating. It's important to never give up on the goal of achieving symptom relief.

Never
Just
Hives

You are not alone. Learn more
about the burden of chronic hives at
neverjusthives.com 



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