

# Supporting Conversations With Your Loved Ones

Living with chronic hives may be overwhelming. You might feel hesitant to discuss your condition, unsure of how others might react, or worry about burdening them. This resource can help you find ways to communicate your experience to those who care about you.



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# Introduction

Family and close friends might not fully understand your experience with chronic hives, and they may have their own questions and concerns about your chronic hives. They might want to help, but not know how.

Whether you're ready to have an open conversation or prefer to take things slow, this resource offers advice for these discussions. As you go through it, adjust the tips to fit your own needs and situation.

Finally, as you explore this resource, remember that your experience is uniquely your own. It's not your responsibility to validate how others feel about your personal journey.





Before starting a conversation, consider the following steps to help you feel more confident and comfortable:

#### > Reflect on your feelings

Acknowledging your emotions about your condition and the upcoming discussion can help you express yourself more clearly.

#### > Identify your goals

Determine what you hope to achieve by sharing—it may be emotional support, practical assistance, or simply informing them about your situation.

#### Gather information

Being knowledgeable about chronic hives can boost your confidence in how you will explain it.

#### > Choose the right time and place

Find a setting where you feel comfortable talking with your loved one.

#### Consider your loved one's readiness too

Check in beforehand and ask if they feel ready to have a conversation.

#### Encourage your loved one to share

Invite your loved one to share how chronic hives might impact them, while reassuring them that honesty is welcome.

Keep in mind that others, like your family or friends, may have different ways of talking about health—because of culture, language, or family traditions. Consider adjusting how you talk with different loved ones based on their background and experiences.

Chronic hives refers to the presence of hives that last more than 6 weeks. This term can encompass chronic spontaneous urticaria (CSU) and chronic inducible urticaria (CIndU). CSU occurs without an identifiable cause or trigger, while CIndU is triggered by specific factors such as pressure, temperature changes, or other causes. This resource was developed to support individuals with CSU. However, it can also be used by those living with CIndU.



Talking about your chronic hives might feel difficult, but it's the first step to helping others understand and support you better. Consider some of the steps below when having a thoughtful conversation with loved ones.

#### Initiating the conversation

**Example:** "I've been dealing with a health condition called chronic hives, and I'd like to share what it's been like for me."

## Explaining the impact

#### > Physical impact

**Example:** "I often experience sudden itching and swelling, which can make it hard to focus or do certain tasks."

**Example:** "Hives can look different on different skin tones. My hives make my skin welt and itch, and they are the same color as my skin."

#### > Social and emotional impact

**Example:** "Not knowing when symptoms will appear makes me feel anxious and derails my plans, which can be overwhelming."

#### Navigating disbelief and misunderstanding

**Example:** "I know it's hard to understand what you can't see, but this is real for me. It would mean a lot if you could trust and believe me when I say it affects my life every day."

#### Being open to questions

**Example:** "Please feel free to ask me any questions. I want us to be open, and I'm happy to share what I know."

**Example:** "Is there anything you'd like to know more about or that I can explain better?"



# Setting Boundaries and Practicing Self-Care

Establishing boundaries with those closest to you can be difficult, especially while managing a chronic condition. Here are examples of ways to establish healthy boundaries and practice self-care.

#### Communicating your limits

**Example:** "I might not always be able to join group outings or events, especially if I'm experiencing symptoms."

#### Prioritizing intimacy and connection

**Example:** "Sometimes, my symptoms make physical closeness uncomfortable. I'd like to talk about how we can be intimate in ways that feel comfortable for both of us."

#### Managing sleep challenges

**Example:** "I might need to adjust my sleep schedule or sleep on my own when my symptoms keep me up at night. Thank you for being flexible with that."

# Respecting each other's needs and brainstorming solutions together

**Example:** "Let's find activities that we both enjoy that won't potentially make my symptoms worse."

#### > Avoiding overcommitment

**Example:** "I don't feel up to going today. Can we plan something for another time when I'm feeling better?"



# Giving Advice to Loved Ones on How to Best Support You

Loved ones may struggle with understanding how to support you. Letting your loved ones know what kind of support works best for you can make a big difference. Below are a few examples of how you can communicate your support needs.

#### Listening and believing me

**Example:** "It helps me when you believe how I'm feeling, even if you can't see my symptoms."

**Example:** "I feel supported when you acknowledge the challenges I'm facing."

#### Being patient and understanding

**Example:** "Some days are better than others, and your patience really means a lot to me."

#### Respecting my choices

**Example:** "I appreciate your concern, but I'm following my doctor's advice."

#### Accompanying me to appointments

**Example:** "Would you be able to come with me to my next doctor's visit?"

#### Communicating with children

**Example:** "Sometimes I get hives that show up suddenly for no clear reason. It's not something you can catch, but it can make me itchy, uncomfortable, and tired, so I might need to rest or take it easy some days."

**Example:** "I feel very itchy and tired because of my hives, and I need to rest. It's not your fault. I love spending time with you."

**SECTION 5** 

#### **SECTION 6**





Chronic hives might not only impact you, but also the people who care about you. By openly discussing how it impacts each of you, you can acknowledge each other's feelings, identify shared challenges, and work together to identify solutions. Here are some examples to guide your conversation:

#### > Listening and believing me

**Example:** "I know my symptoms sometimes leave you feeling unsure about how to help. How has it been for you?"

**Example:** "Could we talk about ways you could feel more supported, even when my hives make things difficult?"

Living with chronic hives may be tough emotionally, so having support is important. Your family and friends might not always get exactly how it feels, but talking openly can help you find the right support together.



### Patient organizations

Patient organizations can also be a source of support for people living with chronic hives. Among the resources they provide, they can connect you to tools and services for taking care of your emotional health. Check out the organizations listed in "Section 7: Learn About Chronic Hives Alongside Your Loved Ones" for more information and additional resources that can support you.

If you would like more support for conversations with others, check out the resources we developed on managing conversations with clinicians and coworkers. They offer tips to help you communicate and get support in other important areas of life.





Empathy and support come from a place of understanding. By exploring resources together, both you and your loved ones can develop a stronger support system. Help your loved ones develop a better understanding of chronic hives:

#### **Encourage self-education**

Share links to articles, brochures, or websites such as patient organization websites to improve their understanding of chronic hives.

#### **Patient organizations**

Patient organizations can be a great source of educational resources for you and your loved ones. Check out the organizations below for information on chronic hives. Please note that Novartis does not own any of the content developed by these organizations.

- Allergy and Asthma Network (AAN)
- Asthma and Allergy Foundation of America (AAFA)

If you would like more support for conversations with coworkers and loved ones, explore the other relationship management resources.

Living with chronic hives may present unique challenges, but open communication with your loved ones can improve understanding about your experience and build stronger relationships. By expressing your feelings, setting boundaries, and inviting discussion, you can create an environment of support.

Remember, you're not alone in handling chronic hives. Support is available—both from loved ones who care about you and from resources like the ones above. By exploring these tools together, you and your loved ones can find solutions that help you feel heard, understood, and supported as you navigate your chronic hives.

**DISCLAIMER:** This resource is intended for informational purposes only and does not constitute medical advice. It is not a substitute for professional diagnosis or treatment. Always seek the guidance of your physician or other qualified clinician with any questions you may have regarding your health or medical condition. Do not disregard professional medical advice or delay seeking it because of information you have read in this resource. The content herein is provided by Novartis Pharmaceuticals Corporation and is based on general information related to chronic hives, as well as insights gathered from multiple interviews with patients living with chronic hives. Individual experiences may vary, and any actions taken based on this information are at your own risk. References to third-party resources are provided for informational purposes only and do not constitute an endorsement by Novartis.

