

Supporting Conversations With Your Clinician

Even after receiving a chronic hives diagnosis, you might find it hard to talk with your clinician (medical doctor, physician assistant, nurse practitioner, etc) about your symptoms, concerns, and disease management options. This resource can help you find ways to communicate your experience to those who care about you.



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Introduction

Building a strong, collaborative relationship with your clinician is important to ensure you have the support needed to manage your condition effectively. If you have been searching for answers for a long time before receiving a chronic hives diagnosis, it's understandable to feel frustrated or worn down—acknowledging this can help you and your clinician move forward together.

This resource offers tips to strengthen your relationship with your clinician through open communication. It provides practical advice to help you express your concerns, advocate for your needs, and work together to manage your chronic hives. As you explore this resource, adapt these tips to your own experience and unique circumstances. Keep in mind that cultural differences and other factors can sometimes impact communication, and sharing specific concerns about being heard may help foster understanding and improve dialogue.

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Before the appointment

> Gather information and keep records

- Keep a detailed symptom journal on your symptom frequency and severity
- Take photographs of your symptoms to share with your clinician

> Set clear goals for your appointment

- Prioritize the issues you want to address with your clinician.
 Think about what's causing you the most discomfort or worry and start there
- Write down priority questions for your clinician ahead of your appointment
- Consider talking to clinical support staff for any assistance you may need



Having a discussion

Now that you have set your priorities, consider the tips and examples below to use as prompts for your conversation.

> Identify specific concerns to discuss

Example: "The itching and swelling are severe and are affecting my ability to sleep and concentrate during the day."

Example: "The frequency of my flares is impacting my daily activities."

> Share your goals for disease management

Example: "My goal is to reduce the frequency of flares so I can feel more comfortable going to social events and doing the things that matter to me."

Ask about management options

Example: "I'm interested in exploring different management options, can you share what those could look like?"

Share impact beyond physical symptoms

Example: "I'm feeling more and more anxious because I'm worried about having a flare in public, which is affecting my relationships and daily life."

Example: "I'm feeling overwhelmed and it's affecting my mood and confidence. Can we discuss ways to address the physical and emotional challenges I'm facing?"

Chronic hives refers to the presence of hives that last more than six 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.

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> Encourage respectful dialogue

Example: "I appreciate your expertise and want to work together to find the best approach for managing my condition."

Example: "Thank you for your support today. Are there any other services, like therapy or patient support groups, that you think could help me manage my condition between visits?"

> Redirect the conversation if you feel unheard

Example: "I'd like to talk more about my main concerns. Could we focus on my symptom patterns and how they affect my daily life?"



Tools

The Global Allergy and Asthma Patient Platform (GAAPP) developed a <u>Shared Decision Making Tool</u> to help people navigate conversations with their clinician. It's designed to outline goals, prompt key questions, and support a more active role in determining the best management options for you. This digital aid helps patients and clinicians come to a joint management decision by considering patient values, lifestyle, and budget.

Managing Situations When You Feel Frustrated

> Communicate your feelings

Example: "I feel that some of my concerns might not be fully understood, and I'd like to revisit them to ensure we're on the same page."

> Provide supporting information

Example: "Looking at my symptom journal and photographs, I've noticed that my flares are becoming more frequent."

> Ensure care is centered around your goals

Example: "I know you have many patients, but I'd like to focus a moment on my personal experiences. Could we slow down and talk through how this plan aligns with my goals and lifestyle?"

> Ask for clarification

Example: "Could you explain why you recommend this management plan? I want to understand all my options."



Encouraging Meaningful Support From Your Clinician

Finding a Chronic Hives Specialist

> Encourage open listening

Example: "It helps me when you listen to my experiences and take my symptoms seriously, even if the cause isn't clear."

Ask for patience and understanding

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

> Encourage shared decision making

Example: "I prefer discussing potential management options together so we can find the best fit for me."

> Ask for clarification

Example: "Could we create a plan that reduces symptoms and improves the overall quality of my day to day?"

If you have specific questions about your condition, your clinician should be your primary source of information. Identifying a clinician with experience treating chronic hives will help you manage your condition effectively. Check out the tools below to find information on clinicians who could help you. Please note that Novartis does not own any of the content developed by these organizations.

Allergists

To find allergists or immunologists closest to you, consider using the **doctor finder tool** provided by the American College of Allergy, Asthma, and Immunology or the **find an allergist tool** provided by the American Academy of Allergy, Asthma, and Immunology.

Dermatologists

To find dermatologists closest to you, consider using the **doctor finder tool** provided by the American Academy of Dermatology.

Resources for people with skin of color (melanin-rich skin):

To find a specialist with experience treating skin of color, consider using the **doctor finder tool** provided by the Skin of Color Society.



Living with chronic hives may be hard on your emotions. It's possible that you'll feel frustrated, sad, anxious, or even angry at times. Recognizing these feelings and knowing that emotional support is important can really help. Sharing your feelings and connecting with others can lighten the load.



Patient organizations

Patient organizations are a great source of support for people living with chronic hives. They offer resources to help you manage your condition and can connect you to tools and services for other important parts of life, like handling work challenges, taking care of your emotional health, and navigating the health care system. Check out the organizations below for more information. 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 others, check out the resources we developed on managing conversations with coworkers and loved ones. They offer tips to help you communicate and get support in other important areas of life.



Conclusion

Living with chronic hives can be challenging, but communicating openly with your clinician is key for effective symptom management. They may not always fully understand what you're experiencing or have all the answers, but by sharing your experiences, asking questions, and setting specific goals, you can foster understanding and receive more tailored support.

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 people 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.

