



How You Can Support People with Chronic Spontaneous Urticaria

A Guide for Family and Friends



SUPPORT THOSE AFFECTED BY CSU

A family member or friend in your family or circle of friends has **chronic spontaneous urticaria (CSU)**. This is an inflammatory, chronic skin condition with no identifiable triggers, in which red, itchy hives and swelling form on various areas of the skin. Symptoms vary from person to person—and the type of support needed can also change from day to day.

Your understanding and support can make a real difference—for example, by encouraging the person affected to continue treatment as agreed, helping with daily tasks, or accompanying them to appointments.

Open communication is particularly important in this regard. If you listen and ask questions regularly, you'll be better able to understand what kind of support your family member or friend needs right now.

This brochure provides insights into what people with CSU may experience and offers practical tips on how you can help.



PRACTICAL WAYS TO SUPPORT THOSE AFFECTED BY CSU

CSU can interfere with work, sleep, and daily activities. On days like these—or when flare-ups make daily life difficult—practical support can make a big difference.

Here's How You Can Support Those Affected

General:

- Help with everyday tasks such as cleaning, doing laundry, or grocery shopping.
- Cook or plan meals together.
- Offer to run errands or help with other tasks.
- Help the person affected think about how to discuss their illness with their employer or in their personal life.
- Just be there and listen.

Regarding the treatment:

- Remind your family member or friend to take their medication as prescribed.
- Help write down questions for the next doctor's appointment.
- Offer to go along to appointments—to provide support and accompany them.
- Be on the lookout for any changes in mood or symptoms so that your family member or friend can explain to the doctor exactly how the illness is manifesting itself.



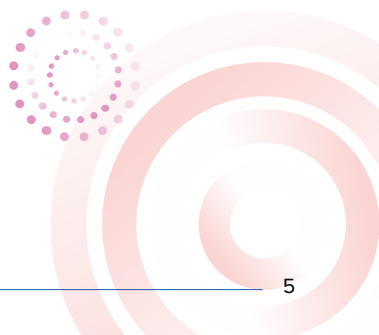


PROVIDING EMOTIONAL SUPPORT

A large part of the burden associated with CSU stems from the unpredictability of symptoms and flare-ups. Your understanding and encouragement can make a real difference in supporting the emotional well-being of the person affected.

Here's How You Can Provide Emotional Support

- Keep communication open and honest—both about how the person affected is doing and how he or she is coping with the treatment.
- Listen actively and give them space to express their feelings openly and without judgment.
- Spend time doing activities that you both enjoy—such as watching a movie, going out to eat together, or spending a quiet evening at home if your family member or friend doesn't want to go out.
- Offer to be there when the person affected talks to friends or family about their illness.
- But also respect when your family member or friend needs some time to themselves.





Supporting People with CSU During Their Doctor's Appointment

Doctors don't always realize how much CSU affects the daily lives of those affected. Your presence and encouragement can help your family member or friend feel safer and better understood.

- Offer words of encouragement: The symptoms are real and should be taken seriously. Some people with this condition downplay their symptoms (e.g., by saying, "They're just hives"). Encourage them to describe openly how much the CSU affects their daily lives.
- If helpful: Please remember to bring copies of medical reports, test results, or a symptom diary to the appointment.
- Offer to take notes during the appointment so that your family member or friend can focus on the conversation.
- If you can't come along: Afterward, ask how the appointment went.
- Promote understanding: When new medications are prescribed, help ensure that the person affected understands how to take the medication and what to expect from the treatment.



THINK ABOUT YOURSELF, TOO

When you're in a support role, it's normal to feel tired or overwhelmed sometimes. You may need to process new information, help resolve complaints, or take on additional tasks.

Over time, this can lead to what is known as “caregiver burnout”—emotional or physical exhaustion that can make it harder to be there for others.

Tips for Preventing “Caregiver Burnout”

- Pay attention to how you're feeling. Writing in a journal or talking to someone you trust can help you process your feelings.
- Take time to do things that bring you joy: Listen to music, go for a walk, meditate, get creative, or unwind by watching your favourite TV show.
- Stay in touch: Stay in touch with friends, family, or others who offer you encouragement and understanding.
- Get support: Interacting with others in a community for family members or patients can help people share their experiences and find helpful strategies.

It can be difficult to recognize signs of anxiety or depression in yourself. Be on the lookout for new feelings such as hopelessness, a loss of interest in hobbies, fatigue or a loss of energy, trouble concentrating, excessive worrying, unexplained weight changes, sleep disturbances, anger, or frustration. If you are concerned about these possible signs, talk to a doctor or a psychotherapist.





KEY POINTS AT A GLANCE

- CSU is unpredictable. The amount of support needed can vary from day to day. Please be understanding if the needs of the person involved change suddenly.
- Open communication is crucial. Encourage your family member or friend to talk openly about how the illness is affecting them—by creating opportunities for them to express themselves.
- People with CSU may experience anxiety, shame, distress, or stress, especially due to visible symptoms. Therefore, avoid making judgments or jumping to conclusions.
- When you're taking care of someone else, it's easy to neglect your own well-being. Please take care of yourself as well, so that you can continue to provide the best possible support to the person affected.



Stay informed

You can also find more information about urticaria at hautwende.de/urtikaria.



The “Hautwende” community on Facebook and Instagram also serves as a virtual meeting place, providing up-to-date information on skin health and helpful tips for chronic spontaneous urticaria.







**DO YOU HAVE ANY MEDICAL QUESTIONS
about Novartis products or a condition that
is being treated with Novartis products, e.g.:**

- Taking the medication
- Effectiveness
- Possible side effects or complaints
- Combinations, interactions with other medications?

**Please feel free to contact us, the Novartis
Pharma Medical Information Service, at:**

(Mon-Fri: 8.00 a.m. – 6.00 p.m.).

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