Hello and welcome to the FAQs for the urticaria subreddit!

This document aims to summarise advice for frequently asked questions from folks who have been on this journey managing their urticaria (hives) for a while. It is an evolving document and will be added to and updated over time.

Many people in this subreddit are actively discussing different solutions for chronic urticaria and there's a lot of support and information available in existing threads. Please check out this document and use the subreddit search function first to see if you can easily find answers to your question before starting a new thread.

All feedback on this doc is welcome and if you would like to contribute to it directly please message u/ecotist77.

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Do I have hives (urticaria)?

Hives are raised, itchy, red or pale welts on the skin. These welts (or "wheals") can vary in size and shape, often appearing suddenly and disappearing within a few hours. Urticaria is typically a result of an allergic reaction or they can be associated, but it can also be caused by physical triggers such as pressure, temperature changes, or stress. If the individual wheals last more than 24hrs then it's not hives (though some swelling/ angiodema that can be associated with hives can last longer).

You can see images of typical hives <u>here</u>, <u>here</u> and <u>here</u>. Feel free to post a photo of your skin if you're still not sure if what you have is hives.

When severe, hives can be incredibly debilitating but are not life threatening unless they are in the throat/ tongue and obstructing air flow. If you are having any trouble breathing from swelling in the mouth, you should seek immediate medical assistance.

If you are getting hives for less than 6 weeks it is considered acute urticaria - longer than 6 weeks is considered chronic urticaria.

Acute Urticaria is most commonly triggered by allergens like food, medications, insect stings, or infections. The condition may resolve on its own once the underlying cause is identified and addressed. Post viral hives are rather comms and can happen during or shortly after a cold or flu and usually resolve within a few days or can last up to 2 weeks.

Chronic urticaria (CU) is more persistent and can last for months or even years. In contrast to acute urticaria, the exact cause of chronic urticaria is frequently unknown, and in many

cases, the condition can be considered `idiopathic" (without a clear trigger). Chronic urticaria can significantly impact quality of life, causing discomfort, stress, and difficulty with sleep due to persistent itching. It is often combined with swelling in a deeper layer of the skin than hives (angioedema), which can feel more like bruising. It is not unusual to have hives/angiodema on the palms of your hands and soles of your feet and this can make standing and walking and working with your hands very uncomfortable.

Inducible Urticaria: Some hives and swelling can appear 4-6hrs after significant pressure has been applied to the skin. Carrying a bag, tight fitting clothes or shoes that rub, long periods of standing or walking especially in shoes that rub/ dig into the skin around your feet - can trigger hives or angioedema. This variation of hives is called Delayed Pressure Urticaria (DPU) and can often be alongside Spontaneous Urticaria. The average duration of DPU is 9 years.

Other inducible urticaria can be caused by sun, heat or cold exposure and some can be triggered by exercise and sweating. Reducing triggers as much as possible is the first step but often it is impossible to avoid all triggers.

What is the root cause of my hives?

As stated above, in many cases, the condition can be considered 'idiopathic" (without a clear trigger). Many specialists run a myriad of tests and often find no indication of the cause. However, sometimes urticaria can be attributed to an autoimmune disorder, a mast cell disorder, histamine intolerance, diabetes or heavy metal toxicity. The parasite H. Pylori is also associated with chronic hives so often people get tested for that. There is also some research that points towards a link between being overweight/ obese and urticaria. And some claim that gut dysbiosis (imbalance of gut bacteria/ "leaky gut") can play a key role. *All these possibilities will be explored further below (when I have some more time!*).

What can I do about my hives?

If you are only just experiencing hives for a few hours, days, weeks - and you are looking for solutions, the first thing you might want to try is identifying and removing possible triggers or waiting for them to resolve: animal dander, pollen, medicines, foods (eg. shellfish, fish, nuts, eggs, milk), emotional stress and viral infections like the flu or Covid can all cause acute hives.

Loose fitting clothing, cold showers, ice packs, oatmeal baths, keeping the skin moisturised with soothing lotion can help. Sprays that contain lidocain or pain relieving/ numbing active ingredients can help. Some people find relief with anti-itch or cooling creams containing menthol or calamine lotion. Hydrocortisone cream (1% over-the-counter or stronger prescription creams) can reduce inflammation and itching but should be used sparingly on small areas of the skin and only for short periods (to avoid serious side effects).

Sadly, for many people suffering from severe hives - these methods can provide little to no relief.

Medication Options

Over-the-counter antihistamines

Loratadine, Cetirizine or Fexofenadine (brand Allegra). These are new generation, non-drowsy antihistamines can often be very effective at relieving symptoms.

Some people prefer older generation antihistamines that can have a drowsy effect (eg. diphenhydramine/ Benadryl, chlorphenamine maleate/ Piriton) and they may prefer taking these at night time. Speak to your doctor before mixing old and new generation antihistamines in a 24hr period and ask about maximum dosage. Over-the-counter dosage can be increased but should be done with your doctor's advice. Many folks with severe urticaria take 2-4 times the regular dosage which can be spread out over the day.

Prescription antihistamines

More powerful antihistamines are available on prescription like Levocitirizine and Desloratadine and Rupatadine. It can be worth trying several different antihistamines before resorting to a second line of defence medication (see below). Many people in the Reddit Urticaria subgroup report greatest relief of symptoms with Fexofenadine (Allegra), or Rupetadine (Rupall).

For ongoing hives you need to see a specialist. An allergist, immunologist or dermatologist will be able to diagnose and treat your hives but sometimes it can be hard to get the help you need from them so it's good to be prepared, research your options and ask specific questions. If you want to try a specific medication and they are not willing to prescribe it right away - keep pushing and advocating for yourself.

Additional medications

If antihistamines are not helping enough you might be prescribed a short course of corticosteroids and this could be extended if the hives are not going away. However this is not a long term solution as Prednisone can have serious side effects.

The most common prescription medications that can be used to control symptoms (often in addition to regular (H1) antihistamines) include:

- H2 antihistamines such as Famatodine
- Hydroxyzine an old generation antihistamine with a drowsy effect (best taken at night)
- Leukotriene receptor antagonists such as montelukast
- Omalizumab (brand: Xolair) is a monoclonal antibody that selectively binds to human immunoglobulin E (IgE) and stabilises mast cells (which are part of the histamine/ inflammatory response that causes urticaria).

Immunosuppressants like Cyclosporine or methotrexate

In most cases these medications are prescribed in that order as second, third and fourth line of defence when the first line of defence isn't working well enough (H1 antihistamines). Some countries/ doctors will prescribe Cyclosporine before Omalizumab due to insurance protocol while others will leave immunosuppressants as the last thing to try.

Other less commonly prescribed medications that people have tried for Urticaria are listed below.

Xolair - the "wonder drug"

Xolair (omalizumab) is a monoclonal antibody that is increasingly used in the treatment of **Chronic Spontaneous Urticaria (CSU)**, particularly in cases that are not responsive to antihistamines or other standard treatments.

The success rate of Xolair in CSU varies, but studies indicate that about **60-80% of patients** experience significant symptom improvement, and many see complete resolution of their hives. Specifically, studies have shown that **40-50% of patients** achieve **complete control** of their symptoms (defined as no hives and no itching) after 12-16 weeks of treatment with Xolair.

Xolair is generally well-tolerated, but it requires regular injections (typically every 4 weeks), and it can be quite costly. Despite its high success rate, not all patients will respond to Xolair, and for those who do, the treatment may need to be continued long-term to maintain symptom control.

Many people take Xolair together with other medications to achieve symptom control.

Other medications you could ask your doctor about:

Alternative (less commonly used) antihistamines

Blexten (Bilastine)

- Type: Second-generation antihistamine
- Use for Urticaria: Commonly prescribed for chronic spontaneous urticaria (CSU) to reduce itching and hives.
- Effectiveness: Works well for many patients, but some may need higher doses or additional medications if symptoms persist.

Doxepin

- Type: Tricyclic antidepressant with strong antihistamine effects (H1 and H2 blocker)
- Use for Urticaria: Used for chronic urticaria and urticaria resistant to standard antihistamines.
- Effectiveness: Can be very effective for severe cases, especially those with sleep disturbances due to itching, but causes drowsiness.

Immunosuppressants (that are not Cyclosporine)

Cellcept (Mycophenolate mofetil)

- Type: Immunosuppressant
- Use for Urticaria: Used in severe refractory cases of autoimmune urticaria where antihistamines and biologics fail.
- Effectiveness: Can be effective for autoimmune-mediated chronic urticaria, but long-term immunosuppression risks (e.g., infections) must be considered.

Methotrexate

- Type: Immunosuppressant (anti-inflammatory, anti-folate)
- Use for Urticaria: Used in chronic refractory autoimmune urticaria, often combined with antihistamines.
- Effectiveness: Can help reduce steroid dependence in severe cases, but has potential liver and blood-related side effects requiring monitoring.

Hydroxychloroquine

- Type: Anti-malarial with immune-modulating effects
- Use for Urticaria: Used mainly for autoimmune urticaria and urticarial vasculitis.
- Effectiveness: Some benefit in autoimmune-related urticaria, but takes weeks to show effect and requires eye exams due to retinal toxicity risk.

Biologics (that are not Xolair)

Dupixent (Dupilumab)

- Type: Monoclonal antibody (IL-4 and IL-13 inhibitor)
- Use for Urticaria: Not officially approved for urticaria but is being studied, especially
 for chronic inducible urticaria or CSU that doesn't respond to antihistamines or
 biologics like Xolair (Omalizumab).
- Effectiveness: Early studies suggest it may help patients with severe cases, especially those with other allergic conditions (e.g., eczema, asthma).

Anakinra

- Type: IL-1 inhibitor (biologic)
 Use for Urticaria: Used in auto-inflammatory syndromes (e.g., Schnitzler syndrome, urticaria associated with periodic fever syndromes).
- Effectiveness: Works well for specific inflammatory urticaria cases but is not a first-line treatment for CSU.

Non-medical solutions. Diet/ Nutrition/ Supplements/ Gut microbiome connection - to be added...

Disclaimer:

This is a summary of information gathered by a moderator of the subreddit /urticaria (Ecotist) - after suffering from CSU and DPU since 2023, learning from this subreddit and doing a lot of individual desktop research.

Hyperlinks to sources are deliberately not added as you are encouraged to use this document as a guide for doing your own research and not take this as "gospel" as the science is always evolving and latest up to date findings will not necessarily be added here.