CONDITION

Dermatitis herpetiformis

Dermatitis herpetiformis is an intensely itchy, blistering skin condition caused by an immune reaction to gluten.

WHAT IT IS
Chronic autoimmune blistering skin condition linked to gluten

BODY SYSTEM
Skin and digestive system

MAIN SYMPTOMS
Intense itching, grouped blisters, bumps, burning skin

WHAT CAUSES IT
Immune reaction to gluten

HOW IT IS DIAGNOSED
Perilesional skin biopsy with direct immunofluorescence

MAIN TREATMENT
Lifelong gluten-free diet and symptom-controlling medicine

CAN IT BE CURED?
No - gluten sensitivity remains lifelong

IS IT AN EMERGENCY?
Sometimes - breathing trouble or blue lips during treatment

LONG-TERM OUTLOOK
Usually well controlled with lifelong gluten avoidance

Overview

Dermatitis herpetiformis is a long-term skin condition that causes very itchy bumps and small blisters. Despite its name, it is not caused by the herpes virus and is not contagious.

The condition is an autoimmune response to gluten. Gluten is a group of proteins found in wheat, barley, and rye. The immune system mistakenly reacts to gluten and produces antibodies that collect in the skin, leading to inflammation and blistering.

Dermatitis herpetiformis is considered the skin form of coeliac disease. Coeliac disease causes immune-related damage to the lining of the small intestine after gluten is eaten. Many people with dermatitis herpetiformis have little or no digestive discomfort, but they may still have intestinal damage.

The condition matters because controlling the rash alone does not address the underlying reaction to gluten. A strict gluten-free diet helps treat both the skin and the intestine. Medicine may also be used to settle the itching while the diet takes effect.

Symptoms

The main symptom is severe itching. Burning or stinging may begin before bumps or blisters can be seen. Scratching often breaks the blisters quickly, so you may notice crusts, scratch marks, or small sores rather than intact blisters.

The rash commonly appears in matching areas on both sides of the body. Typical locations include:

The bumps often occur in small groups. New patches may appear as older ones heal. The skin can be so itchy that it affects sleep, concentration, and daily activities.

Healing areas may leave temporary light or dark marks, especially after repeated scratching. Permanent scarring is unusual unless the skin has been deeply injured or infected.

Digestive symptoms are not required. Some people have bloating, abdominal discomfort, diarrhoea, constipation, tiredness, or unexplained nutrient deficiencies. Others have no obvious intestinal symptoms at all.

- Elbows and forearms
- Knees
- Buttocks and lower back
- Scalp or hairline
- Shoulders

Causes and risk factors

Dermatitis herpetiformis develops when a person with a genetic tendency eats gluten. The immune system makes immunoglobulin A, or IgA, antibodies. These antibodies react with proteins called transglutaminases and collect in the upper layers of the skin, where they trigger the rash.

The condition is not caused by poor hygiene, an allergy to skin products, or contact with someone who has a rash. You cannot pass it to another person.

Genes play an important part. Dermatitis herpetiformis and coeliac disease are more likely in

people who have a close relative with either condition. They are also associated with other autoimmune conditions, including autoimmune thyroid disease and type 1 diabetes.

Iodine does not cause dermatitis herpetiformis, but large amounts may worsen the rash in some people. Do not remove iodine from your diet or stop prescribed products without medical advice. Iodine is an essential nutrient, and unnecessary restriction can be harmful.

Diagnosis

Because several conditions can cause itchy bumps or blisters, the appearance of the rash alone cannot confirm dermatitis herpetiformis.

The key test is a skin biopsy for direct immunofluorescence. A clinician removes a very small sample of normal-looking skin beside a fresh blister. The laboratory uses fluorescent markers to look for the characteristic granular pattern of IgA deposits. Sampling skin beside the rash is important because damaged or inflamed skin may give a less reliable result.

A second biopsy from an affected area may be examined under a microscope, although direct immunofluorescence is the main confirmatory test.

Blood tests can look for antibodies associated with coeliac disease, such as tissue transglutaminase IgA. Total IgA may also be measured because some people do not make the usual amount of this antibody. Further tests may be needed if IgA is low or if the results do not match the clinical findings.

You may be assessed for anaemia, vitamin deficiencies, thyroid problems, or changes in bone health. A small-bowel biopsy is not always needed when the skin findings clearly establish dermatitis herpetiformis, but it may be considered in some circumstances.

Do not begin a gluten-free diet before testing unless a healthcare professional has advised it. Avoiding gluten can reduce antibody levels and make skin or blood tests harder to interpret.

Treatment and management

A strict, lifelong gluten-free diet treats the underlying condition. This means avoiding wheat, barley, rye, and foods contaminated with them. Gluten can be present in sauces, processed foods, drinks, supplements, and medicines, so label reading is important.

A dietitian with experience in coeliac disease can help you build a balanced diet and avoid hidden gluten. Oats are naturally gluten-free but are often contaminated during growing or processing. If oats are included, they generally need to be clearly labelled gluten-free and

introduced according to professional advice.

The rash may take months or longer to fully settle after gluten is removed. Accidental exposure can trigger symptoms again.

Dapsone is commonly used for faster control of itching and blistering. It is a sulfone medicine that reduces inflammation in the skin. It often works much sooner than dietary treatment, but it does not heal gluten-related intestinal damage. As the gluten-free diet becomes effective, the amount of medicine needed may be reviewed.

Dapsone can affect red blood cells, oxygen transport, the liver, and, rarely, infection-fighting blood cells. Blood tests are needed before and during treatment. Testing for glucose-6-phosphate dehydrogenase, or G6PD, deficiency may be performed because people with this inherited enzyme deficiency have a greater risk of red blood cell breakdown.

Other sulfone or sulfonamide medicines may sometimes be considered when dapsone is unsuitable. Topical corticosteroids may ease limited itching, but they do not treat the underlying gluten reaction.

Skin care can reduce discomfort. Keeping nails short, using cool compresses, and gently covering scratched areas may limit skin damage. Fragrance-free moisturisers can soothe dry or healing skin.

Complications

Repeated scratching can cause bleeding, disturbed sleep, and bacterial skin infection. Signs of infection include increasing pain, warmth, swelling, pus, or spreading redness.

Because dermatitis herpetiformis is linked to coeliac disease, untreated intestinal inflammation may reduce the absorption of nutrients. Possible effects include iron-deficiency anaemia, low folate or vitamin B12, and reduced bone strength. Regular follow-up can identify problems before they cause major symptoms.

People with coeliac disease have an increased risk of certain uncommon intestinal lymphomas. The overall risk is still low, and long-term adherence to a gluten-free diet is associated with a lower risk.

Treatment can also cause complications. Dapsone commonly causes some breakdown of red blood cells. More serious reactions include severe anaemia, reduced oxygen delivery, liver injury, major skin reactions, or a sharp fall in white blood cells. Monitoring is intended to detect these effects early.

Prevention

The inherited tendency to develop dermatitis herpetiformis cannot currently be prevented. There is no recommended way to prevent it in someone who has never had symptoms.

Once the condition is diagnosed, strict gluten avoidance can prevent many flares and help protect the small intestine. Small or occasional amounts of gluten may still activate the immune response, even when they do not cause immediate symptoms.

Avoiding gluten without a confirmed diagnosis is not a reliable prevention strategy. It can make testing less accurate and may lead to an unnecessarily restricted diet.

Living with it and what to expect

Dermatitis herpetiformis is usually a lifelong condition, but it can often be controlled well. Dapsone may relieve the rash quickly, while the gluten-free diet works more slowly. Over months or years, successful dietary treatment may allow symptom-controlling medicine to be reduced or stopped under medical supervision.

The tendency to react to gluten usually remains even when your skin is clear. Returning to gluten can restart skin inflammation and intestinal injury. A lack of digestive symptoms does not mean gluten is harmless.

Accidental exposure is common, especially when eating away from home or sharing a kitchen. A dietitian can help with food labels, cross-contact, travel, and maintaining enough fibre, iron, calcium, and vitamins.

Routine follow-up may include a review of skin symptoms, dietary adherence, blood antibody levels, blood counts, nutrient levels, thyroid health, and bone health. People taking dapsone need additional laboratory monitoring.

Most people can continue their usual work, exercise, travel, and relationships. The early period after diagnosis often requires the most adjustment. Support from coeliac organisations, dietitians, and others living gluten-free can make long-term management easier.

When to get medical help

Arrange a routine appointment if you have a persistent, intensely itchy rash, especially when it affects both elbows, knees, buttocks, or the scalp. Seek assessment before removing gluten from your diet if possible.

Contact your healthcare team promptly if:

Get urgent or emergency help while taking dapsone if you develop blue or grey lips, breathing difficulty, fainting, confusion, severe weakness, or chest pain. These can indicate reduced oxygen delivery.

Fever, a severe sore throat, widespread blistering, facial swelling, or a rapidly spreading rash during treatment also needs urgent medical assessment. Do not wait for a routine follow-up appointment.

- A diagnosed rash is worsening despite treatment
- You repeatedly react after possible gluten exposure
- Scratched skin becomes painful, hot, swollen, or produces pus
- You develop ongoing diarrhoea, weight loss, marked tiredness, or other new symptoms
- You are taking dapsone and notice increasing fatigue, pale skin, dark urine, or yellow skin or eyes

Common questions

Is dermatitis herpetiformis a type of herpes?

No. The name refers to the grouped appearance of the blisters. It is an autoimmune condition linked to gluten, not an infection with a herpes virus. It is not contagious.

Can I have dermatitis herpetiformis without stomach problems?

Yes. Many people have no obvious digestive symptoms, even though tests may show immune activity or damage in the small intestine. Skin symptoms can be the main sign of coeliac disease.

Will the rash go away if I stop eating gluten?

A strict gluten-free diet usually improves the rash, but improvement can be slow. Medicine may be used while the diet takes effect. The rash can return after accidental or deliberate gluten exposure.

Do I need to avoid gluten for life?

Usually, yes. The immune tendency does not disappear when the skin clears. Lifelong gluten avoidance helps prevent skin flares and ongoing intestinal injury.

Why is my rash still itchy after starting a gluten-free diet?

Skin inflammation can take time to settle, and hidden or cross-contact gluten may continue to trigger it. Another skin condition or an ineffective treatment plan is also possible. Persistent

symptoms should be reviewed rather than managed by making increasingly broad food restrictions yourself.

Can dermatitis herpetiformis leave scars?

Permanent scars are uncommon. Scratching may leave temporary colour changes, and deep scratching or infection can sometimes scar. Controlling the itch and protecting broken skin reduces this risk.

Sources

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