



DERMATITIS HERPETIFORMIS (GLUTEN SENSITIVITY)

What are the aims of this leaflet?

This leaflet has been written to help you understand more about dermatitis herpetiformis. It tells you what it is, what causes it, what can be done about it, and where you can find out more about it.

What is dermatitis herpetiformis?

Dermatitis herpetiformis is a rare, very itchy and persistent blistering skin condition, affecting between 0.4 and 3.5 people per 100,000 of the European population. It typically affects Caucasians aged between 15-40 years and is more common in men, but can occur in all age and racial groups.

What causes dermatitis herpetiformis?

Dermatitis herpetiformis is associated with a bowel disorder known as coeliac disease. Almost all those with dermatitis herpetiformis are likely to have subtle microscopic changes of coeliac disease in their bowel.

In both dermatitis herpetiformis and coeliac disease, patients are intolerant of gluten, which is a protein found in wheat, rye, barley flour and in some other grains such as couscous and bulghur. An auto-immune response to gluten plays an important part in causing the rash of dermatitis herpetiformis.

Is dermatitis herpetiformis hereditary?

One in ten people with dermatitis herpetiformis has a family history of it, or of coeliac disease.

What are the symptoms of dermatitis herpetiformis?

- Intense itching is the first and main symptom.
- A minority will also have mild symptoms of coeliac disease, which may include weight loss, diarrhoea or constipation, abdominal bloating and discomfort.

What does dermatitis herpetiformis look like?

The rash of dermatitis herpetiformis consists of small red spots, tiny fluid-filled blisters and wheals. The most commonly affected sites are the backs of the elbows, the fronts of the knees, the scalp, bottom and back.

How is dermatitis herpetiformis diagnosed?

Dermatitis herpetiformis can be hard to diagnose – it may be confused with more common itchy skin conditions, such as eczema and scabies. When the condition is suspected, a skin biopsy is usually taken to confirm the diagnosis. This is where a small skin sample is taken under local anaesthetic, for microscopic analysis. This may be important, as treatment involves a change in diet and can require long-term tablets. Blood tests are usually performed too. Occasionally a small biopsy may also be taken from the inner lining of the bowel to check for the type of inflammation that is seen in coeliac disease. If required, this investigation is performed by a gastroenterologist (bowel specialist).

Can dermatitis herpetiformis be cured?

No. The skin changes and associated symptoms of dermatitis herpetiformis usually go away with diet changes and medications. Medication can often be gradually withdrawn once a gluten free diet is adopted; however, if gluten is reintroduced to the diet then the rash and symptoms will recur.

How can dermatitis herpetiformis be treated?

Diet. Most doctors recommend that everyone with dermatitis herpetiformis should be on a gluten-free diet. Your dermatologist may arrange for you to see a dietician and may refer you to a gastroenterologist. The diet is slow to work, but usually gives relief from both skin and bowel symptoms.

A gluten-free diet is not the burden that it used to be; most supermarkets stock a range of gluten-free bread, biscuits, cakes, etc. The diet may:

- decrease and eventually remove the need for medical treatments

- reduce bowel symptoms.

Topical Medication. Strong steroid creams can be helpful in alleviating the symptoms of itch, and are usually prescribed as an initial treatment whilst awaiting test results, or to control mild symptoms where oral medications are not necessary.

Oral Medication. A drug called dapson is the treatment of choice and usually reduces itch within a few days. Dapsone is an antibacterial medicine belonging to the sulphonamide class of antibiotics. As this may have side effects, treatment does not usually start until laboratory tests have confirmed the diagnosis. Dapsone usually causes a decrease in the red blood cell count and haemoglobin (the oxygen-carrying part of the red cell). This is usually dose-related, asymptomatic, and is monitored with blood tests. Rarely dapson can cause a rapid fall in red blood count; for this reason blood tests are performed weekly to begin with. Any unusual symptoms, such as fever, sore throat, bruising, bluish lips or breathlessness, should be immediately reported to your doctor. If you are intolerant or allergic to dapson, oral steroids may be given as an alternative treatment.

What can I do?

Once diagnosed with dermatitis herpetiformis, a gluten-free diet for life is strongly recommended. This increases the likelihood of staying symptom free and also optimises the general health of those with gluten intolerance.

Where can I get more information?

Web links to patient support groups:

www.dermatitisherpetiformis.org.uk/

Web links to detailed leaflets:

www.emedicine.com/DERM/topic95.htm

www.dermnetnz.org/dna.dh/dh.html

www.mayoclinic.com/health/gluten-free-diet/my01140

www.coeliac.org.uk/document-library/126-gluten-free-checklist/?return=/gluten-free-diet-and-lifestyle/gf-diet/

This leaflet aims to provide accurate information about the subject and is a consensus of the views held by representatives of the British Association of Dermatologists: individual patient circumstances may differ, which might alter both the advice and course of therapy given to you by your doctor.

This leaflet has been assessed for readability by the British Association of Dermatologists' Patient Information Lay Review Panel

**BRITISH ASSOCIATION OF DERMATOLOGISTS
PATIENT INFORMATION LEAFLET
PRODUCED AUGUST 2004
UPDATED OCTOBER 2009, JANUARY 2013, MARCH 2016, NOVEMBER
2019
REVIEW DATE NOVEMBER 2022**