

DERMATITIS HERPETIFORMIS

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 eruption.

What causes dermatitis herpetiformis?

Dermatitis herpetiformis is associated with a bowel disorder known as coeliac disease. Virtually all patients with dermatitis herpetiformis are likely to have subtle changes of this condition. In some it will be clinically apparent, but in most it will be so mild that it causes no symptoms and may only be demonstrated by a biopsy of the intestine. In both dermatitis herpetiformis and coeliac disease, patients are allergic to gluten, a protein found in wheat, rye and barley flour and in some other grains such as couscous and bulghur. An allergic reaction to gluten plays an important part in causing the rash of dermatitis herpetiformis.

Is dermatitis herpetiformis hereditary?

One in 10 patients 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.
- Symptoms of an associated coeliac disease may be present in a minority of those with dermatitis herpetiformis, but are usually mild. They may include weight loss, abdominal discomfort and pale-coloured bowel motions.

What does dermatitis herpetiformis look like?

Dermatitis herpetiformis usually occurs in young and middle-aged adults but is occasionally seen in children. The rash consists of small red spots, tiny fluid-filled blisters and weals. The most common sites are the backs of the elbows, the fronts of the knees, the scalp, bottom and back. If it is not treated, dermatitis herpetiformis usually runs a very long course, over many years, at times varying in severity.

How is dermatitis herpetiformis diagnosed?

The rash can be hard to diagnose – it is often confused with more common conditions such as scabies, eczema and other very itchy skin disorders. A skin biopsy taken by a dermatologist is usually needed to confirm the diagnosis. It is important to do this as treatment may involve long-term tablets and a change in diet, or occasionally diet alone. The biopsy usually involves two separate laboratory tests. Blood investigations are usually performed too. A small specimen may also be taken from the inner lining of the bowel to check for the type of inflammation that is seen in coeliac disease.

Can dermatitis herpetiformis be cured?

No. All traces of dermatitis herpetiformis may go away with treatment, but they will come back if the treatment is stopped.

How can dermatitis herpetiformis be treated?

Diet: Most doctors recommend that all patients 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 (bowel specialist). The diet is slow to work but should give relief from symptoms. A gluten-free diet is not the burden that it used to be; most good supermarkets stock a range of gluten-free bread, biscuits, cakes, etc. The diet may:

- decrease and eventually remove the need to take tablets
- reduce any bowel symptoms
- cut the risk of getting a bowel lymphoma – a complication that may rarely occur if coeliac disease remains untreated for years

Medication: Dermatitis herpetiformis may also be treated with a drug called dapsone; however, this may have side effects, so treatment does not usually start until laboratory tests have confirmed the diagnosis. All patients on dapsone get some decrease in their red cell count and haemoglobin (the oxygen-carrying part of the red cell). This is usually dose-related and monitored with blood tests. However, a few get a rapid fall in their blood count. For this reason, blood tests are performed weekly to begin with, and patients are asked to report any unusual symptoms (sore throat, dizziness or faintness) urgently to their doctor. Dapsone also causes some patients to have headaches.

What can I do?

Remember that once diagnosed you will have to keep strictly to the diet for your lifetime. About 80% of patients with dermatitis herpetiformis can reduce their need for medication with a gluten-free diet, but it may take as long as a year before they are able to drop their dapsone dosage. After that, some of them may be able to come off dapsone completely.

Where can I get more information?

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

Links to patient support groups:
www.dermatitisherpetiformis.org.uk/