



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 eruption.

What causes dermatitis herpetiformis?

Dermatitis herpetiformis is associated with a bowel disorder known as coeliac disease. Virtually all patients with dermatitis herpetiformis probably 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 generally does not require any complicated investigations. In both conditions the patients are sensitive to gluten, a protein found in wheat and rye flour. An immunological reaction to gluten plays an important part in causing the rash of dermatitis herpetiformis.

Is dermatitis herpetiformis hereditary?

1 in 10 patients with dermatitis herpetiformis have 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 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, tense 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 - sometimes improving, sometimes getting worse - but it may go away eventually.

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 or a change in diet. 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 when the treatment is stopped.

How can dermatitis herpetiformis be treated?

1. **Diet.** Most doctors recommend that all patients with dermatitis herpetiformis should be on a gluten-free diet. This is complicated and your dermatologist will involve specialist dieticians. The diet is slow to work but should:
 - 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.
2. **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 cells) levels. This is usually dose-related and monitored with blood tests. However, a few get a rapid fall in their blood counts. 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 you will have to keep strictly to your diet for a long time. About 80% of patients with dermatitis herpetiformis do well 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 will be able to come off dapsone completely.

Where can I get more information?

Links to patient support groups:

www.dermatitisherpetiformis.org.uk/

Web links to detailed leaflets:

www.emedicine.com/DERM/topic95.htm

www.dermnetz.org/dna.dh/dh.html

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: its contents, however, may occasionally differ from the advice given to you by your doctor.

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