

dermatitis herpetiformis

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If you would like to become a member or would like more information, contact your state society on 13 ZERO ZERO GLUTEN (1300 458 836).

www.coeliacsociety.com.au



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Facts about coeliac disease & dermatitis herpetiformis



TheCoeliacSociety

dermatitis herpetiformis

Dermatitis herpetiformis (DH) is a chronic skin condition associated with coeliac disease. It is intensely itchy, even in the presence of a mild rash.

The name, dermatitis herpetiformis, is a descriptive name. The rash is not related to either dermatitis or herpes, but is a specific chronic skin condition.

DH has a genetic basis and is not contagious. The rash may be small lumps, like insect bites (papules), some with tiny fluid filled blisters on top. These small blisters are called vesicles. However it can also appear hive-like, persisting in one area, or it may look like a pink and scaly dermatitis.

DH can flare and subside even without treatment. The rash has a characteristic distribution, over the knee caps, on the outer surface of the elbows, on the buttock area, around the ears, the shoulder blades, and in the hairline and eyebrows. It tends to appear symmetrically on both the left and right sides of the body. When the rash subsides, which often occurs spontaneously, it may leave brown pigmentation or pale areas, where pigmentation is lost.

Who gets Dermatitis Herpetiformis?

People are born with a genetic predisposition to develop coeliac disease and/or DH. DH is slightly more common in males than females and generally presents in adult life (15-55 years). It is uncommon to see DH in children, but it can occur.

Less than 10% of patients with DH have gastrointestinal symptoms suggestive of coeliac disease. However biopsies show that the majority of people with DH have some degree of villous atrophy (small bowel damage characteristic of coeliac disease). Recent findings confirm that all patients with DH will display villous atrophy on consumption of a high gluten load. There is a small group of patients with coeliac disease who develop DH even though they have been on a strict gluten free diet for years.

Like coeliac disease, it is unclear why the condition develops at a particular time. Both genetic and environmental factors play important roles in DH.

Does Dermatitis Herpetiformis occur in Families?

About 10% of patients with DH have first degree relatives with either DH or coeliac disease. There is the possibility that atypical or silent coeliac disease could be undiagnosed in the families of patients with DH.



How is the Condition Diagnosed?

The variable presentation of the rash can make diagnosis very difficult, and a referral to a skin specialist (dermatologist) is required. When your doctor suspects DH, a skin biopsy for histopathology and immunofluorescence is performed. This involves taking a small piece of skin, which is sent to a pathologist for testing. The sample of skin will often include a small papule and blister and some normal surrounding skin. This is done prior to commencing treatment. With DH the immunofluorescence test will show deposits of IgA in the skin. Whilst IgA can be found in the skin in other skin diseases, a particular pattern in the IgA immunofluorescence is seen in DH. A positive immunofluorescence test can be obtained in many patients with DH even when the skin disease is in remission and the rash is not visible. There are a number of abnormal serum (blood) antibodies that occur in DH, just as they do in coeliac disease.

How is the Condition Treated?

DH is treated in the same way as coeliac disease: By maintaining a diet free of gluten for life. It may take six months to achieve moderate improvement in the skin condition and up to two years or more to achieve total control by diet alone.

A medication called Dapsone is available to relieve the rash of DH. Within twenty four hours of taking this medication, the itch is often better and the rash may disappear within a few days. Dapsone, however, does not improve small bowel damage (villous atrophy). Dapsone is generally well tolerated but requires careful medical supervision. It has a number of side effects, especially if taken in large amounts for long periods of time e.g. haemolysis resulting in anaemia and chronic tiredness. Sulphapyridine and other sulphonamides are also used. Maintaining a strict gluten free diet is essential to reducing and eliminating the use of medication.

Where compliance with the gluten free diet is strict, the average time for reduction in the use of Dapsone has been shown in one study to be less than a year and can generally be stopped within about two years. Even occasional unintentional gluten intake reduces successful elimination of Dapsone for many patients.

What are the Implications of Dermatitis Herpetiformis?

The majority of patients with DH do not display any symptoms of coeliac disease despite returning an abnormal biopsy result. They are said to have asymptomatic coeliac disease.

Before diagnosis, both DH and coeliac patients may suffer from anaemia secondary to iron or folate deficiency due to malabsorption. There is a small, but statistically higher risk of developing lymphoma of the small intestine, particularly when the condition has been untreated for many years. Patients with DH, particularly females, have an increased risk of autoimmune thyroid disease. 20% of patients with DH have clinical hypothyroidism or hyperthyroidism and about 10% have asymptomatic goiters. Antibodies to the thyroid gland can, at times, also be present. Other autoimmune disease like type 1 diabetes mellitus, vitiligo, sjogrens disease, lupus erythematosus and sarcoidosis also have an association with DH.

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What is Coeliac Disease?

Coeliac disease (pronounced seel-ee-ak) is a genetic auto-immune disease. Auto-immune means the body mistakenly produces antibodies that damage its own tissues. It is a permanent intestinal intolerance to dietary gluten. A number of serious health consequences can result if the condition is not diagnosed and treated properly.

In those with untreated coeliac disease the mucosa (lining) of the small bowel (intestine) is damaged: The tiny, finger-like projections which line the bowel (villi) become inflamed and flattened (villous atrophy). Healthy villi are responsible for the digestion and absorption of nutrients from food. Villous atrophy diminishes the large surface area created by the villi. This can lead to gastrointestinal and malabsorptive symptoms. Long term consequences of untreated coeliac disease can include osteoporosis, infertility and miscarriage, depression and cancer.

Coeliac blood tests are used for initial screening ("coeliac serology and IgA"). If the results are positive or your doctor feels further testing is warranted, a referral to a gastroenterologist will be necessary. The diagnosis must be confirmed by performing a gastroscopy (an endoscope is passed through the mouth into the small bowel), to collect tiny samples (biopsies) from the small bowel. These biopsies are studied under a microscope to determine if coeliac disease is present. A gastroscopy is done in a hospital or day-procedure centre while the patient is sedated (most people find it very straight forward). Taking small bowel biopsies is an essential part of diagnosing coeliac disease as the blood test alone is not definitive. For the blood test and biopsy to be meaningful, gluten must be included in the diet for at least six weeks prior to testing (the equivalent amount of gluten from four slices of standard bread daily for adults).

Notes about the Gluten Free Diet

The only treatment for coeliac disease is a strict, lifelong gluten free diet.

Gluten is the rubbery and elastic protein found in wheat, rye, barley and oats. Gluten is responsible for the cooking and baking properties of these grains.

There are obvious foods which contain gluten e.g. bread, cakes and pasta, but there are also a whole range of ingredients within prepared and commercial foods which can come from a gluten source. To become "ingredient aware" is essential.

Initially the gluten free diet may seem overwhelming. With the information and support available with membership of The Coeliac Society, it will become much easier.

It is recommended you seek the guidance of an Accredited Practising Dietitian with experience in coeliac disease to help you manage your gluten free diet and ensure your diet is nutritionally balanced.

The Coeliac Society

There is a Coeliac Society in each state to provide support and information on the disease, the gluten free diet, ingredients, where to buy, cooking and recipes, overseas travel, education and research material. Specific resources for children requiring a gluten free diet are available.

For further information on coeliac disease and the gluten free diet contact your state Coeliac Society.