#### PATIENT INFORMATION LEAFLET

### PEMPHIGOID (ALSO KNOWN AS BULLOUS PEMPHIGOID)



#### WHAT ARE THE AIMS OF THIS LEAFLET?

This leaflet has been written to help you understand more about pemphigoid. It explains what it is, what causes it, what can be done about it, and where you can find more information about it.

#### WHAT IS PEMPHIGOID?

Pemphigoid is a rare blistering disorder that usually affects people of age 70 years and over. Blisters appear on the skin and, less often, inside the mouth too.

#### WHAT CAUSES PEMPHIGOID?

An event, such as sunburn or a reaction to a drug, can trigger the blisters, but usually spontaneously. It is not caused by an infection or allergy, cannot be passed from person to person and is not affected by diet or lifestyle. It is not hereditary so it cannot be passed on to your children.

#### IS PEMPHIGOID HEREDITARY?

No.

# WHAT DOES PEMPHIGOID LOOK AND FEEL LIKE?

- A rash may be present for weeks before any blisters appear. The rash may be itchy and look like eczema or, more commonly, like the red weals of nettle rash (urticaria).
- Most commonly, pemphigoid causes red skin patches on which blisters can appear. Any part of the skin can be involved, but the most common sites for the blisters are the body folds, hands, feet and the skin on the abdomen (belly area). In severe cases, the blisters can occur all over

the body or in the mouth. If pemphigoid blisters do appear in the mouth, gums or other moist areas (known as mucous membranes), you may be affected by a rare condition called mucous membrane pemphigoid – you must check with your doctor to confirm this.

- Blisters are firm and filled with a fluid. Most commonly, the fluid is clear but, in some people, it can be bloodstained. As more fluid builds up in them, the blisters become larger and tense, and eventually burst. The skin left behind can be sore. When the skin blisters heal, they do not leave scars but there might be skin colour changes seen after the inflammation has settled down.
- Roughly a quarter of patients with pemphigoid have blisters or sore areas in the mouth.

#### **HOW IS PEMPHIGOID DIAGNOSED?**

Usually, the look of the rash is enough for your GP to make the diagnosis, but further investigations may be performed including a blood test or skin biopsies (under local anaesthetic).

#### CAN PEMPHIGOID BE CURED?

No. However, different treatments can control the condition well, rather than curing it completely. However, pemphigoid can often spontaneously resolve after one to five years.

#### **HOW CAN PEMPHIGOID BE TREATED?**

Treatment has three aims – to stop new blisters; to help heal the blisters that are already there; and to use the lowest possible dose of a medicine to control the condition and reduce the risk of side effects.

- The blister should be burst and dressed by a nurse to help relieve some of the pressure and discomfort. You can do this yourself once shown how to do this safely and hygienically.
- A steroid cream (for example, clobetasol propionate also known as Dermovate® and Clobaderm®) are prescribed if the blisters appear in small areas. Oral steroids may be given if the blistering if extensive and creams are not enough. Steroid creams or ointments are much less likely to cause side effects than steroid tablets.
- Antibiotics called tetracyclines can also help reduce inflammation
- A medicated mouthwash may be given if you have blisters in your mouth.
- For more extensive blistering, high doses of steroid tablets may be needed to get the pemphigoid under control. Some patients can come off their treatment gradually, usually after a few months; others will need to continue with lower doses for a number of years You may be given tablets to protect your bones (depending on your age, risk and length of steroid course) and an antiacid tablet to protect your stomach lining.
- Other tablets that affect the immune system can be used at the same time as the steroid tablets. Examples of additional tablets that can be used in this way are azathioprine,

mycophenolate mofetil and dapsone.

#### **SELF-CARE (WHAT CAN I DO?)**

- Do not change the dosage of the steroid tablets you are taking, unless you have instructions to do so, without talking first to your doctor. Ask your doctor about what dose of steroids to take if you are unwell, these may be known as 'sick-day rules'
- Avoid spicy, acidic or salty foods if you have sore areas in your mouth.
- If your mouth is sore and might be affected by pemphigoid, please refer to the patient information leaflet on mucous membrane pemphigoid for information on self-care.
- If you are on steroid tablets ask your pharmacy or doctor for a steroid alert card, which you can keep in your purse or wallet.
- If you are on long term steroid tablets and suddenly cannot take them (e.g. if misplaced or you are vomiting) you should contact 111 or your GP urgently.

## WHERE CAN I GET MORE INFORMATION ABOUT PEMPHIGOID?

Weblinks to patient support groups:

The International Pemphigus and Pemphigoid Foundation

Web: www.pemfriends.org.uk

Weblinks to detailed leaflets:

www.emedicine.com/derm/topic64.htm

www.medicinenet.com/Bullous\_Pemphig oid/index.htm

www.dermnetnz.org/immune/pemphigoid.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: 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

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