

Tips for the daily life of patients with an autoimmune bullous disease

These fact sheets were written in collaboration with the Reference Centre for Autoimmune Bullous Diseases and the Pemphigus-Pemphigoïde France patient association.

Skin hygiene

Good personal hygiene is a major asset in healing. It contributes to the prevention of local infections.

Baths or showers when blistering or post-blistering lesions are present are not contraindicated.

Soap is not prohibited.

To avoid skin maceration in the folds (under the breasts, groin folds, armpits etc.), due to skin fragility, it is essential to dry the skin thoroughly by gently patting with a towel.

The appearance of red spots or small dots (purpura), mainly on the legs and arms, is not a recurrence of the disease but a sign of fragility of the skin, secondary to natural aging and/or a side effect of local corticoids.

For men, if there were any facial lesions, it is better to avoid razors and electric shavers during the period when the skin lesions have not yet healed. After-shave lotions should also be avoided as they all contain alcohol.

Hair hygiene

If there are no scalp lesions, you can continue to use your usual shampoo, otherwise apply an extra mild, hypoallergenic shampoo.

If there is no damage to the scalp, artificial hair colouring is possible by protecting the surrounding skin. However, it is preferable to avoid ammonia-based colourings as they can cause irritation, itching and allergies.

Beauty care

You can continue to apply skin care creams or make-up on your face if there is no lesion.

Body moisturizers are an effective way to fight against dryness of the skin, a possible side effect of local corticosteroid therapy and frequently encountered during skin aging.

You can continue to use your usual beauty products if you do not have any skin lesions in the areas concerned (cologne, perfume, alcohol-free deodorants, make-up removers, hand razors, etc.)

Clothing

Depending on the discomfort caused and for your well-being, you should wear loose clothing and cotton.

Sun

In case of exposure to the sun, precautions are those that apply to the general population as a whole, i.e. avoid exposure between noon and 4 p.m. (summer time), stay in the shade, wear protective clothing, and apply sunscreen with an index corresponding to your skin type repeatedly (every two hours on average).

When there are lesions that are healing, sun exposure could result in irreversible white or brownish spots that are not dangerous but unsightly. It is therefore not recommended.

Food

Depending on the treatment of your bullous disease (example: high-dose general corticosteroid therapy), your doctor will prescribe a salt-free or low sugar diet if necessary, adapting it to your age, and your other possible associated health problems.

In the case of mucosal lesions in the acute phase, it is advisable to mix or chop the food and avoid any food that may cause pain or aggravate a lesion during healing. Some foods are to be avoided because they sting the mouth: vinegar, citrus fruits, tomatoes, salt, mustard etc.

In case of undernutrition, due to the decrease in the quantity of food ingested due to oral erosions, a diet rich in protein may be necessary, possibly combined with food supplements in liquid form (such as Fortimel®, Clinutren® etc.)

Physical activity

Regular physical activity is recommended in case of prolonged general corticosteroid therapy to preserve muscle strength. It is advisable to adapt your physical activity or sport according to the damage to your skin and the type of sport practiced. For example, it is advisable to wait until the skin lesions heal before resuming aquatic activity.

Intimate hygiene

It is advisable to wear cotton underwear, avoid underwear that encourages friction, use products adapted to the physiology of the genital mucous membranes (soft and moisturizing, available in parapharmacy in the feminine hygiene section) and carry out a thorough rinse. Dry yourself by gently patting with a towel.

In case of genital lesions, miction (urine) may cause local burns and it will be necessary to renew intimate hygiene more often.

Dental care in case of mucous membrane lesions

Brush your teeth after each meal with a soft-bristled brush, trying to avoid gums and tongue if you still have lesions. Use a toothpaste without mint which may irritate the gums in some people.

When brushing your teeth is difficult, it is possible to use an anaesthetic mouthwash to reduce pain (gargle, for one to two minutes, fifteen minutes before brushing).

When brushing your teeth is not possible, mouthwashes are an alternative for minimal oral hygiene. The mouthwash should not contain alcohol to avoid creating pain (e.g.: Colgate® plax sensitive, Paroex®).

The wearing of a dental prosthesis may be temporarily interrupted while possible mouth lesions located in areas of "conflict" with the prosthesis heal.

Dental care with scaling or any other potentially traumatic dental care should be avoided as long as oral lesions persist. Once the lesions have healed, there is no contraindication to the practice of such care.

Eye care in case of eye damage

The use of contact lenses should be avoided when lesions are present in the eye.

In case of dryness, eye drops (such as artificial tears) to moisten the eye can improve local comfort.

Sometimes when you wake up, there are small deposits at the corner of the eyes due to secretions during the night; gently remove them with a compress moistened with saline solution.

Wearing sunglasses can help reduce the discomfort sometimes caused by too much light.