

Tips and Suggestions

TIP number 1

FIND OUT AS MUCH AS YOU CAN ABOUT YOUR DISEASE AND THE TREATMENT OPTIONS.

These are rare diseases and the more you understand how they work and learn to listen to your body the better. You should play an active part in managing and monitoring the disease and your treatments.

TIP number 2

CHOOSE YOUR CONSULTANT

You can choose which expert you are referred to. Find someone who has experience and expertise in immunobullous diseases like Pemphigoid and Pemphigus and ask your GP to refer you to them. Do your research. These are rare diseases and awareness amongst the medical community is generally low. Be prepared to travel to find an expert.

TIP number 3

KEEP A DIARY.

This disease is chronic and can last a long time. It's easy to forget the various eruptions and flares as well as treatments and side effects. Keep a log of your symptoms and medication, as well as any possible triggers

TIP number 4

STAY OUT OF THE SUN. If you do go in the sun, wear high factor sun protection (factor 50) or cover up.

Mouth

This is very frequently reported as the site of most frequent pain. Please have a look at the separate section on foods.

Tip number 5

ENSURE THAT YOU EXERCISE GOOD DENTAL CARE.

Consult your Dentist and make sure they are aware of the damage that trauma from their interventions can produce, but make sure you keep your teeth and gums clean and have a regular appointment with the hygienist. Ensuring good oral hygiene is very important as gingivitis tends to worsen the underlying blistering condition.

Soluble steroids such as flixonase nasules mixed in a little water and swilled around the mouth and gargled with can make a huge difference to the management of mouth erosions. Steroid ointments can be spot applied to particular areas inside the mouth after gently drying the area to be treated with a clean tissue. There is an increased risk of developing oral thrush with regular use of steroid mouthwashes and you may therefore be advised to use a regular mouthwash.

Anaesthetic (analgesic) mouthwashes are available if your mouth is very sore and are particularly helpful if used before meals. Diffiam is helpful.

Antiseptic mouthwash or gel may be recommended to help with plaque control, particularly at times when your gums are sore. Peroxyl mouthwash daily is useful or chlorhexidine twice weekly.

There are several proprietary treatments that may help, but many people find that rinsing their mouth with hydrogen peroxide is very helpful. Gengigel is good, and there is another product called Gelclair which helps to create a protective film over the lining over the mouth.

Try to avoid products containing Sodium Lauryl Sulphate (SLS) or Sodium Laureth Sulphate (SLES). According to Professor Richard Guy, professor of pharmaceutical sciences at the University of Bath: SLS is “a chemical that is a known skin irritant and a commonly used excipient in personal care and household products.”

The list below is not exhaustive and does not come with any guarantees or specific recommendations:

Toothpaste (SLS/SLES free)

Kingfisher Toothpaste

Biotene (for dry mouth)

Bioextra Moisturising Toothpaste (for dry mouth)

Baby BioXtra gel toothpaste

Alcohol free Corsodyl (used weekly as can stain the teeth)

AloeDent toothpaste range

Greenpeople toothpaste range

Mouthwash (SLS/SLES free)

Biotène

Moisturising Mouthwash

Bioxtra Mouthrinse

AloeDent mouthwash

Gengigel

SLS/SLES-free soap suggestions for lips:

Green People No Scent Soft Lips

Jason Lips Bee Healthier

Burts Bees

Beeswax Lip Balm

Lavera basis sensitive lip balm

These are only a small sample of products and should not be viewed as an exclusive listing. However, we hope you find something here to suit you. You may even be able to ask for some of the specialist products on prescription from your GP.

Nasal Care

It can help to rinse out your sinuses or use pure olive or sesame oil to lubricate the nasal mucosa.

Douching (rinsing the nose with salty water) can keep the nose clean, wash out mucous, help reduce inflammation and infection and therefore can help relieve nasal symptoms. It is a safe, natural way to help wash crusts and mucus from your nose. The salty water helps to pull fluid out of any swollen lining of your nose helping you to breathe. This also helps to open up the sinuses.

Other products which may help are:

Neilmed Sinus Rinse

Neilmed nasogel

Sterimar,

Pure Olive or sesame oil in a dropper bottle and Neti-pots.

All of these should be available from a large chemist or many can be obtained on-line.

The following is a solution for you to make at home. All the ingredients are easily available from local shops or supermarkets:

Ingredients

• ½ teaspoon salt • ½ teaspoon bicarbonate of soda • ½ pint of warm clean water

Method

- Mix the ingredients together • Fill a large syringe or the NeilMed Sinus Rinse bottle
- Stand over a sink or in the shower/bath
- Keep your head straight
- put the nozzle of the syringe/ bottle in one nostril
- Try to aim the nozzle towards the back of your head

- Squirt half the mixture into one nostril and then repeat on the other side
- The mixture should come into your mouth – spit this out • If you swallow the mixture it will do you no harm
- Blow your nose gently
- Rinse your nose in this way two or three times a day
- After douching rinse the syringe/ bottle in warm, soapy water

Swallowing

If you have a problem swallowing, then many drugs can be administered in solution. Mycophenolate, for example, can be delivered in this form.

[Cellcept Suspension – Soluble Mycophenolate](#)

Eyes

It is critical to obtain an early diagnosis and find the immunosuppressant treatment that will halt the progress of ocular pemphigoid in particular. The damage can be rapid and is progressive and the drug regime will be managed by an Ophthalmologist. However, there are some things that you can do to ease the pain caused by damaged eyes.

Firstly, do not allow inward pointing eyelashes to scratch the surface of the cornea. A set of tweezers with a light incorporated is a very handy ally, along with a powerful magnifying mirror. Some people find it very difficult to do this themselves, so you might need to recruit a friend with a steady hand or arrange to make a regular visit to the eye clinic.

Blepharitis (where the eyelids become inflamed and may be infected) is a common problem. A warm compress on the eyelid two or three times for around 5 minutes a day is helpful and can be soothing. A hot flannel will suffice, or an eyebag, such as the MGDR which is heated in the microwave can be used. A daily regime for blepharitis is to wipe the lash line (NOT the inner side of the lid) with a cotton bud dipped in boiled water. The use of boiled water containing either baby oil or bicarbonate of soda is sometimes recommended but is probably no more effective than boiled water alone. A commercial product called Blephaclean may also work well for you.

Skin

Use moisturisers that are free from SLS (see mouthcare)
SLS/SLES-free moisturisers suggestions:

Emollients in various formulations can be used as substitutes for soap, moisturising creams, ointments and bath additives. Examples suggested by the British Association of Dermatologists include Cetraben, Diprobase cream, E45 cream, Oilatum and Aveeno bath oil amongst other products.

Other suggestions by fellow patients include:-Faith In Nature replenishing moisturising cream
Jason Aloe Vera Ultra-Comforting Moisturizing Crème
Lavera Basis Sensitive : Organic Moisturising Cream
Dr Hauschka Rose day cream or Moisturising day cream
Biotherm Aquasource skin perfection
L'Occitane Shea butter
Baby lotion from GreenPeople
Lavera Naked Skin Thirst Aid 12 Hour
Moisturiser Liz Earle Skin Repair Moisturiser
Miracell serious skin support cream
Dermol 500 lotion (can be used a wash and is antiseptic)
Some people have reported an allergy to formaldehyde and formaldehyde releasers and recommend:

<http://www.organicsurge.com>

<http://www.yestocarrots.com>

Itching

People report how unbearable the itchiness is and these are the various antihistamine treatments they have found to be effective to varying degrees. The sedating antihistamines are more likely to work better and help more than the non-sedating antihistamines in achieving a reasonable, less itchy night's sleep.

A fan to cool the skin also helps a lot. Staying cool is important.

Over the counter Cetirizine or Loratidine helps in mild cases, as does Doublebase moisturiser. You can also try Eurax and bathing in Dead Sea salts.

Fexofenadine and Atarax are available by prescription and Piriton can also help.

Some people have found products that include menthol, such as Dermacool helpful

Moisturisers that can be sprayed directly onto itchy skin rather than needing to be rubbed in like Emollin spray are also often found to help.

Dressings

TIP No 6

NEVER LET ANYONE DE-ROOF YOUR BLISTERS OR DO IT YOURSELF. If they are very large, swollen and painful, they can be aspirated.

The French support group for Pemphigus and Pemphigoid (The APPF) produce some excellent advice and we suggest **Wound care guidelines: Local skin and mucosal care in pemphigus and pemphigoid (AutoImmune Blistering Diseases - AIBDs)**

[APPF Wound Care Brochure](#)

The YouTube video on the aspiration and dressing of blisters is very good and we attach our translation [Here](#)

[APPF Video](#)

These dressings are recommended for fragile and painful skin by our group.

Allewyn Gentle border Classic (very gentle on the skin)
Smith and Nephew

Mepilex Foam absorbent dressings for chronic and acute wounds
Molnlycke

Ossite Post op dressings
Smith and Nephew

Epaderm Film Plasters

Atrauman (good for drying the blisters then cover with fine dressing) Hartmann

Micropore to stick non-adhesive dressings such as Release, N.A.Ultra, Aeroswab, Inadine, Melolin and Zetuvit.

Huggies DryNites Bed mats are useful for laying on bedsheets and pillows. The Waitrose ones have sticky patches to stick them to the bed sheets. You can get bed covers from Age Concern too.