

Questions to Molly

Molly's answers in bold italics

1. What sort of steroids cream should I use on various parts of my body?

Depends on the area of the body/ site. In general, we like to use a weaker steroid on the thinner parts of the skin (for example, the face, neck) and a stronger one for thicker parts of the skin – soles of feet, hands, trunk.

For the oral areas – you can use a variety of steroid rinses (sometimes come as dispersible tablets or sometimes use nasal steroids).

In general, we would use ointments for skin that tends to be dry – as this adds more moisturizing factors and contains less preservatives that might irritate the skin.

For more weepier areas, or areas where blisters might be prone to bursting (for example, on the feet), we generally would use creams, as this can help 'dry' those areas.

2. How do I resolve the horrible itching?

Itch can have a huge impact on a person's quality of life. Some treatments, like topical corticosteroids, can help with the inflammatory process -therefore help with itch.

Putting creams in the fridge, or pjs in the fridge so they are nice and cool at night can help, as night-time can often be the most troublesome for patients.

We sometimes would use creams like Menthol in Aqueous (which can cool and soothe the skin).

Distractions, like fidget toys or knitting etc can help too.

Anti-histamines (which are sedating) might potentially help – however, I would speak to your GP or Dermatology team about this, as this might not be the right treatment for you and your situation.

Some patients also find talking therapies helpful – this might be something you wish to explore, depending on how much the itch impacts your life or mental health.

3. My Mum can't sleep. Do you have any suggestions?

See above.

4. What clothes can I wear to go out? Everything I wear irritates or causes blisters.

Garments – that are light and made of ideally natural fibres. Some areas, like in Scotland, you can get garments on prescription.

I usually suggest cotton (as this is a light fabric usually well tolerated), turned inside out so the seam doesn't irritate you!

Some patients also recommend bamboo garments, or silk garments – but these can be quite expensive.

5. Should I burst my blisters?

Take care when doing this!

I burst blisters when they impact on the patient's ability to do daily tasks or when I'm worried that it might burst (for example when walking) and therefore might increase risk of infection.

This is something hopefully I've covered in our talk today.

6. My feet are the worst. Any suggestions?

If your feet have flared despite treatment advice from your Dermatology team or GP – I would suggest getting back in contact with them, as it's possible they might need to change your treatment plan or increase medications.

Feet can be quite troublesome, particularly when healing, as they are furthest away from our circulation system, which brings all the nutrients and oxygen to the small blood vessels in the skin to promote healing!

I would suggest looking into the Leg Matters UK website, which has a range of resources available for patients, including leg exercises to promote lower-leg wound healing <https://legsmatter.org/information-and-support/treatment-options/movement/>

7. How long does Pem last

Depends on the type of PEM! I'd look at the British Association of Dermatologist leaflet <https://www.bad.org.uk/pils/pemphigoid/> or <https://www.bad.org.uk/pils/pemphigus-vulgaris/> for more in-depth information.

8. Does it (sometimes) return after going away?

Yes, again, depends on the type of PEM and the treatments you may have had or are on. See the BAD website for more info.

9. If so, how virulent is it 2nd time round

It depends on the type and whether you might be on treatments—some patients with PEM are on long-term treatments to prevent flare-ups.

Usually, your dermatology team will tell you what to look out for and what to do.

10. Effects of Pem on cognitive abilities?

PEM does not usually affect a person's cognitive ability. However, we know that it tends to affect older people more – who could have underlying conditions like Dementia.

As a nurse, I often see patients or carers struggle with the roller-coaster of emotions (fear, guilt, worry) that can occur through a person's journey with PEM. I think one of the main aspects we don't discuss enough is about how people are coping and the affects on their mental health – which can be different for every person – and different for the people looking after them.

Finding support, whether through a group like PEM friends, or via your GP can be helpful for some people, and is something I generally encourage patients to tap in and engage with to promote their wellbeing.

11. How long does Pemphigoid last and, if it does go away, will it (sometimes) come back, even after years/months.? If so can it effect internal organs?

Depends on the type, your treatments. We know it can affect the oral mucosa, and for some people it can affect deeper structures like the oesophagus. See the BAD resources linked.

12. Tips on dealing with mucous membrane lesions.

Have a great dentist and oral hygienist! Gentle toothbrush, and toothpaste that isn't super fancy flavoured and is SLS (sodium lauryl sulphate) free.

<https://www.bad.org.uk/pils/mucous-membrane-pemphigoid/> Has more information

13. I'm sure somebody will ask but I note that people often ask what they can use on their face so this I'm sure will be helpful.

Depends on the severity of symptoms.

Usually, we would use a weaker topical corticosteroid in combination with a light emollient.

I usually recommend that people look for a face cream with SPF (30SPF, with 3-4 stars on the bottle), as some treatments can increase light sensitivity – and this reduces the risk of UV related sun damage.

There are various sunscreens that are gentle/light on the skin, but might require some trial and error to find the right one for you.

I can't recommend brands – but bigger pharmacies or stores like Boots usually have staff that can help point you in a direction of reputable products/brands that are generally well tolerated by people with sensitive skin.

14. My wife, who is the person who has suffered from the blistering on her feet, has an appointment to see a dermatologist on 12th December so has not had a formal diagnosis yet. Perhaps my question might be whether the presence of inexplicable, very large, blisters on one's upper feet (3 on each) over a period of about nine weeks, could be BP or P? No new blisters for about two and a half weeks currently.

It would be challenging to say without a definitive diagnosis – or through examination and history, as different things could potentially cause blisters. Some people have a skin biopsy or blood-tests taken to help narrow down a diagnosis.

Hopefully, your Dermatologist will explain if further investigations are needed to ascertain the diagnosis – and plan about what might be needed to treat the blisters etc.

Just ensure to keep an eye out for potential infection – or if the skin becomes worse- to let your GP know as soon as possible so they can get prompt treatment if this needed.