



**BRITISH ASSOCIATION
OF DERMATOLOGISTS**
HEALTHY SKIN FOR ALL



Topical Steroid Withdrawal

Joint statement by National Eczema Society, the British Dermatological Nursing Group, and the British Association of Dermatologists.

Produced February 2024.

Introduction

The aim of this document is to describe the various topical steroid withdrawal reactions reported by patients. Hopefully, this will make it easier for patients and healthcare professionals to discuss the condition.

Topical corticosteroids (described in this document as topical steroids) are often used to treat eczema and other skin conditions. For many people, they are a safe and effective treatment. Millions of people around the world have successfully benefitted from topical steroid treatment without any problems. Like other treatments, they can have side effects. In the UK, topical steroids are divided into four groups of increasing strength from mild to very potent (or very strong). Side effects are more common when using stronger steroids.

Most side effects of topical steroids are well-known. Often, this means that there is enough good research to understand and manage them. The group of side effects known as 'topical steroid withdrawal' (TSW) are generally less well understood. TSW is also sometimes called 'red skin syndrome' (RSS) and 'topical steroid addiction'.

Recently, there has been increased awareness of TSW, in part because people are sharing their experiences on social media. The Medicines and Healthcare products Regulatory Agency (MHRA), the UK regulator for medicines, reviewed topical steroid reactions in 2021. As a result of this review, all topical steroid products in the UK now include a warning about TSW.

Despite this, there remain many challenges to understanding and managing TSW. The term has been used to describe a range of issues, some of which are already recognised side effects of topical steroids. The problem is widely discussed on social media and '#TSW' has over 1.1 billion views on TikTok. However, the lack of a clear medical definition can make it difficult for healthcare professionals to communicate with people who are experiencing these reactions. It also means that some people who think they have TSW may be experiencing another condition.

Another problem is that there has been very little research on the topic. This means that information is based on patient reports and the opinions of healthcare professionals. These are important and useful but do not give us the full picture. More good quality research would make it easier to understand how common these problems are, what causes them and how to manage them.

Reported signs and symptoms of TSW

TSW is a term that has been used to describe a wide range of issues. Some of these are already recognised side effects of topical steroids whilst others need more research to fully understand them. TSW appears to include:

1. Skin inflammation which develops in previously unaffected areas.
2. Skin inflammation which extends beyond the area of the skin where the topical steroids were used.
3. Symptoms that get worse after stopping topical steroids.
4. The problem may take many months to resolve, and occasionally does not resolve fully.

These reactions have been described in various forms and sometimes different words are used to describe the same conditions:

Reactions that cause redness and swelling

In medical terms: erythemato-oedematous reactions.

Note: *'Redness' is often used to describe signs of skin disease. While it can be very noticeable in some skin tones, in others (often darker skin tones), the skin does not become red at all, but pink or purple instead. In some skin tones, the affected area of skin may become darker than the person's usual skin tone. We use the word 'redness' in this document repeatedly because it is one of the most reported signs of TSW.*

Redness and swelling are the most commonly reported TSW reactions and usually happen to people who have recently stopped using topical steroids.

MHRA describes it like this:

"Redness of the skin which can be a spectrum of pink to purple, or as darkening of the normal skin tone, depending on the skin tone of the individual. Other signs include burning or stinging, intense itching, peeling of the skin, or oozing open sores."

People with TSW also report 'elephant skin'. This is skin that has thickened and grown into folds. It can be caused by fluid retention (oedema) or by increased growth of skin cells. They also report the 'sleeve sign' and 'headlight sign'. The sleeve sign refers to the lack of redness and swelling people report on the palms compared to the surrounding skin. The headlight sign refers to the lack of redness and swelling around the mid-facial triangle, the area of skin from the top of the nose to the corners of the mouth.

TSW is also sometimes referred to as 'red skin syndrome' (RSS). Healthcare professionals do not use this term because there are so many different conditions that can cause the skin to become red.

RSS is sometimes used to describe reactions that can occur while still using topical steroid treatment. In these instances, patients describe patches of red, painful skin. This can happen on areas of skin where there has not previously been any eczema or topical steroid use. Healthcare

professionals understand that people with skin diseases, including eczema, can experience flares of eczema which are severe and produce widespread redness and swelling.

Other conditions relating to redness and swelling that should be considered:

People who have severe redness and swelling could also be experiencing a condition called erythroderma. This term describes widespread skin inflammation (more than 90% of the body surface). Like TSW, erythrodermic skin goes through phases of severe redness, swelling and oozing for a short period of time, followed by flaking. It is accompanied by swollen glands and problems with sleep, temperature control, blood pressure and fluid balance and can be followed by hair shedding. It can be caused by untreated eczema and other things. This can be a very serious condition which usually requires urgent treatment, often in hospital.

It is possible that the patches of painful red skin reported in RSS could be early erythroderma, which has been temporarily suppressed by topical steroids. This can erupt into full-blown erythroderma after stopping treatment.

Pimples, spots and bumps (sometimes filled with pus)

In medical terms: papulopustular lesions.

Papulopustular lesions are a way of describing pimples, spots, and bumps on the skin. While these issues are often described as part of a TSW reaction, they are recognised by healthcare professionals as a side effect of topical steroids in their own right.

Topical steroids can cause red bumps (papules) with pimples (pustules), particularly on the face. These are usually diagnosed as acne, rosacea or a condition called perioral/periorificial dermatitis.

These are all inflammatory conditions. Because steroids suppress inflammation, these conditions are likely to become worse immediately after stopping topical steroid treatment.

Topical steroid addiction

Healthcare professionals avoid the term topical steroid addiction because the word 'addiction' can have many different meanings. People sometimes use this term when their skin gets worse after stopping topical steroids, or if they no longer seem effective at treating their skin condition.

Healthcare professionals sometimes refer to this as tachyphylaxis, where a previously effective medicine suddenly, or gradually, becomes ineffective. Tachyphylaxis also occurs with many non-steroid-based medicines, such as some painkillers. This can occur with topical steroids but is not widely recognised by healthcare professionals.

On-going skin sensitivity

In medical terms: skin thinning and hypersensitivity.

People who have reported TSW reactions say that their skin problems may persist or recur for months or even years after stopping topical steroids. A common issue is that their skin is more sensitive than before, for example to sunlight or other environmental factors.

Topical steroids can cause skin thinning (atrophy). Mild degrees of thinning may not be noticeable when using topical steroids and, generally, the skin returns to normal in time. Stronger topical steroids and topical steroids used for a long time can make it harder for the skin to recover. This is usually most noticeable on the face and in skin creases. The thinning shows up as shiny skin with very fine wrinkles and visible small blood vessels (capillaries) or stretch marks or easy bruising.

Persisting physical weakness

People with severe TSW reactions may report feeling ill and weak, even unable to get up and walk around, occasionally for months after they stop using topical steroids. This is most often associated with severe erythematous-oedematous reactions. This can also happen in cases of erythroderma.

They may have low blood pressure, particularly when standing. This can cause dizziness and fainting.

Other conditions that could be the cause of persistent physical weakness:

Adrenal suppression, caused by too much steroid use, can be a cause of low blood pressure, dizziness and fainting. Adrenal suppression is a serious, potentially life-threatening condition that needs urgent hospital assessment and treatment.

Conditions that could be mistaken for TSW

While TSW is widely discussed on social media, it affects only a small proportion of patients seen by dermatologists. Some people who suspect they have experienced a TSW reaction may have another condition with similar symptoms. These include:

1. **Relapse of the original skin condition.** Eczema is a condition that tends to come and go. Many people have flares of eczema that are treated effectively with courses of topical steroids without experiencing side effects. If the skin condition returns after using topical steroids, it is not necessarily a sign of TSW or topical steroid addiction.
2. **Rebound redness (or erythema).** Topical steroids narrow blood vessels in the skin. When the treatment ends, the blood vessels expand again, causing redness and sometimes swelling. This usually settles down within days of stopping. In skin of colour, the redness may not be easily visible. There is also some evidence that eczema can appear after regular applying a very strong topical steroid. Unlike TSW, these effects occur only on areas of skin where topical steroids have been applied.
3. **Worsening of a different condition caused by the steroid.** Both topical and systemic steroids (e.g. steroids in tablet form) can cause conditions such as rosacea, acne or perioral dermatitis as described above. There are specific, non-steroidal treatments for these conditions, sometimes involving antibiotics.
4. **Skin infections.** Topical steroids treat skin conditions by suppressing inflammation, but they can also reduce the skin's response to infection. Bacterial, viral and fungal infections can appear on topical steroid-treated skin as pimples, papules, pustules or oozing skin which might be mistaken for TSW reactions.

5. **Contact dermatitis.** Allergic reactions on the skin, for example, to nickel, perfumes or preservatives, can occur for the first time in anyone at any age. People who already have eczema may be more prone to develop these reactions. When this reaction is due to something in contact with the skin it is called 'contact dermatitis'. Contact dermatitis can sometimes spread beyond the original contact site. In some cases, it can be caused by an allergy to one of the ingredients in a topical steroid treatment. This is hard to recognise because the topical steroid can both suppress the allergic reaction and cause it. If contact dermatitis is suspected, the patient usually needs a patch test to find the cause of the allergy.

In summary

National Eczema Society, the British Dermatological Nursing Group, and the British Association of Dermatologists and other professional bodies acknowledge TSW and the urgent need for high-quality research into this condition.

It is also important to emphasise that topical steroids can be used safely and effectively for eczema and many other skin conditions. For many people, topical steroids bring about major improvements in their quality of life and relief from suffering.

Concerns about TSW should not put people off using topical steroids when they can help. It is important to treat eczema effectively to avoid suffering, and if topical steroids do not help, alternative medications may be available.

Healthcare professionals should explain to people how to use topical steroids (considering the potency, amount, age of the patient, site on the skin of application and duration of use) and inform them of the risks if too much topical steroid is used.

Despite the lack of research on TSW, we would encourage healthcare professionals to be supportive of patients living with symptoms of TSW. Trying to find common ground and agree on practical plans for treatment will help patients who have concerns about the use of topical steroids. It is important to offer alternatives to topical steroids for people who would otherwise stop using them. People with eczema, who have concerns about topical steroids should speak to a healthcare professional before taking any action.

Please note that this document supersedes the earlier Position Statement on Topical Steroid Withdrawal produced jointly in January 2021 by National Eczema Society and the British Association of Dermatologists.



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