



## Topical Steroid Withdrawal Syndrome Awareness Fact Sheet

Topical Steroid Withdrawal Syndrome (TSWS), also known as Topical Steroid Addiction (TSA) or Red Skin Syndrome (RSS), is a debilitating condition that can arise from the use of topical steroids to treat a skin disease, such as eczema, psoriasis or alopecia areata. This condition can also arise from topical steroid use in individuals with no prior skin condition; such as with cosmetic use for skin bleaching or to treat acne, or in the case of caregivers who neglect to wash their hands after applying topical steroids on someone else.

Topical steroids are also called topical corticosteroids, glucocorticosteroids, and cortisone. They come in many different preparations including creams, ointments, oils, gels, and lotions. Some are sold over-the-counter; others require a doctor's prescription. The National Institute for Health and Care Excellence states, "Corticosteroids suppress the inflammatory reaction during use; they are not curative and on discontinuation a withdrawal reaction (rebound or flare) may occur. Withdrawal reactions are thought to occur after long-term continuous or inappropriate use of topical corticosteroids (particularly those of moderate to high potency)."<sup>1</sup>

Topical Steroid Withdrawal Syndrome is characterized by skin flushing, inflammation, diffuse spreading rashes, profuse skin flaking, burning and itching worse than the original condition that typically appear after use of topical steroid treatments, between treatments, or after discontinuing topical steroids. Topical steroids are effective for a period of time to treat the skin condition. As time passes, however, applying topical steroids results in less and less clearing. The original problem escalates as it spreads to other areas of the body. This "progression" is often mistaken for worsening eczema, contact dermatitis, an infection, or an allergic reaction. However, a cluster of non-skin related symptoms also emerge, constituting a syndrome — not solely a skin condition. These symptoms may range from hair loss, nerve pain, thermoregulation issues, and insomnia to depression, anxiety, and suicidal ideation. These severe secondary complications require multiple daily interventions for a protracted period of time. Many sufferers are bedridden and housebound for months to years before symptoms abate.

TSW Syndrome is an iatrogenic condition, which means it is a condition caused inadvertently by a medical treatment. Not everyone who uses topical steroids will develop TSWS. It is unclear why some individuals experience TSWS secondary to topical steroid therapy and why others do not.

Topical steroids have been the first-line treatment for eczema and many other acute and chronic skin conditions for over sixty years. While these medications, when judiciously prescribed and regularly monitored, have had enormous benefits for patients, some experience serious side effects, like topical steroid withdrawal from their use. Over the last decade, there has been a growing concern in the patient community over the safety of these drugs, especially when used to manage chronic skin conditions. This hesitancy has subsequently led to physicians' concerns over patient or parental undertreatment, non-compliance, and steroid phobia, which has in turn resulted in a breach between the patient/physician relationship and ultimately poor health outcomes.

To mitigate this breach of care, it is imperative that more research is conducted to define diagnostic criteria for TSWS; understand its causes, mechanics, and effects; develop appropriate treatment protocols; and educate providers and patients about TSWS and steroid stewardship.

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<sup>1</sup> National Institute for Health and Care Excellence, British National Formulary. Topical corticosteroids. 2022. <https://bnf.nice.org.uk/treatment-summary/topical-corticosteroids.html> (accessed 16 Dec 2022). Link to article: <https://onlinelibrary.wiley.com/doi/10.1111/bjd.21770>

In a British Journal of Dermatology Perspectives article, 'Topical steroid withdrawal syndrome: time to bridge the gap,' the authors state: 'Looking forwards, dermatologists can advocate and develop research to better understand the nature of TSW and what population it is prevalent in. Observational studies leading to consensus on a clearer disease definition can be followed by epidemiological studies and investigation of the underlying pathophysiology. We also need to review critically the long-term safety data on TCSs, clarify optimal usage in terms of potency, frequency, duration and area of TCS application, and communicate this information more clearly and consistently to patients and caregivers than is the case at present. Above all, we must be open minded and listen to patient voices, understand their concerns and learn from them.'<sup>2</sup>

What Physicians are saying:

*"There is much we still do not know when it comes to health and disease, and some degree of humility is required before learning can happen. TSW Syndrome represents a real challenge to dermatology: identification, diagnosis, treatment, and perhaps most importantly of all: PREVENTION. I remain optimistic that with a concerted effort in good faith, we will find answers together."*

Peter Lio, MD

Dermatology & Aesthetics of Wicker Park, Chicago, IL

Assistant Professor of Clinical Dermatology and Pediatrics, Northwestern University's Feinberg School of Medicine, Director, Northwestern University Eczema Care and Education Center

*"We are in a situation where thousands of people are convinced the topical steroids prescribed by their doctor have caused a debilitating rash, and to add insult to injury, none of their doctors believe the topical steroids are to blame. There is now convincing evidence published in top tier dermatology journals that this really is a distinct and unrecognized entity but clearly more research is needed to raise awareness in the medical community as well as to elucidate treatment and prevention strategies to mitigate the risk of TSW."*

Jeffrey Morris, DO

Board Certified Dermatologist and Eligible Mohs Surgeon

Alliant Dermatology and Vein Center, The Villages, FL

*"TSW symptoms can completely upend lives, often forcing patients to become bedridden thus impacting entire families financially and psychologically. Because TS usage is pervasive worldwide and TSW is not well understood or treated, rigorous research and broader public and practitioner awareness is needed to stop this seemingly preventable condition."*

Olivia Friedman, DACM, LAc

Chairperson of The American Society of Acupuncturists

Owner/Herbalist, Amethyst Holistic Skin Solutions, Chicago, IL

*"As a physician, we take an oath to "do no harm" to our patients. Though the harm is not always immediate, the medicines that we prescribe are capable of causing harm to our patients. Judicial use of these medicines and an understanding of the harm that they cause are of utmost importance to protect our patients. Topical steroids, for example, are a very commonly prescribed medication by dermatologists and can cause a debilitating condition in our patients called TSW. In order to further prevent harm to our patients, we need to be open minded, humble, and work to better understand this condition which is entirely iatrogenic."*

Kurt Ashack, MD, MHS

Dermatology Associates of West Michigan, Kentwood, MI

Assistant Professor, Michigan State University College of Human Medicine

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<sup>2</sup> Cotter, et al. "Topical Steroid Withdrawal Syndrome - Time to Bridge the Gap." British Journal of Dermatology, July 14, 2022. DOI: 10.1111/bjd.21770. Link to article: <https://onlinelibrary.wiley.com/doi/10.1111/bjd.21770>