

Topical Steroid Withdrawal

Notes for Doctors

Topical Steroid Withdrawal (TSW), also known as Topical Steroid Addiction (TSA) and Red Skin Syndrome(RSS)N, is a debilitating condition that can arise from the use of topical steroid creams to treat a skin problem such as eczema. For further reading, please research The International Topical Steroid Addiction Network which is a nonprofit charity formed to raise awareness about a condition called Red Skin Syndrome, also known as Topical Steroid Addiction or Topical Steroid Withdrawal Syndrome. <https://www.itsan.org/> Also check <https://scratchthat.org.uk/> resources provided by a group of TSW survivors in the UK.

This is preventable. Please watch this documentary



<https://youtu.be/RMbtf3C8BZk>

Further reading

[Topical Steroid Withdrawal in Atopic dermatitis
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4207549/](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4207549/)

The TSW debate: Review the research and decide for yourself
<https://www.eczema.life.com/blogs/tsw/tsw-research>

National Eczema Society guidance on TSW - <https://eczema.org/wp-content/uploads/Topical-Steroid-Withdrawal-position-statement.pdf>

Dr Peter Lio talks about TSW

Please watch this video where Dr Lio talks about how to spot patients who can become resistant to steroids, why some people don't develop problems, how to spot the condition, how to treat and help people



Ask the Ecz-perts: How do you know if you're experiencing Topical Steroid Withdrawal (TSW)?

<https://youtu.be/PePru4C01mA>

Videos explaining what is going on with the skin, body and organs from Heba, TSW Atlas

[TSW Atlas - YouTube](#)

TSW Facts

- Withdrawal can take anything from months to years and in some cases 4-5 years
- It isn't easy to predict the length of time it takes to heal, it just takes time.
- NMT is No Moisture Treatment. Some people do this as well as withdrawing steroids. Medical advice should be explored before doing this.
- Treatments for TSW are not widely available and little research has been done into what works. But the following things may help
 - Epsom Salt baths
 - Regular exercise to promote sweating and raise the heart rate and body temperature, if it is possible
 - Mindfulness can help people deal with the pain, loss of self, helplessness. This will pass, they will heal, but a positive attitude can help speed up healing.
 - Ask if they help – how is their mental health? Many people feel extreme anxiety, desperation and suicidal thoughts
 - Social media can be very supportive. There are many people sharing their tips and experiences on Facebook and Instagram. This could help the patient feel less alone and reach out for support.
 - Sleep –rest aids healing... Suggest they use fans and cool packs to help cool the body.
 - Natural loose clothing is more comfortable.
 - There is currently no research being done into length of time to recover, symptoms and what helps. Ask them to Record symptoms daily and take photographs so you can track progress

TSW Symptoms

When someone who is addicted to Topical Steroids stops using them the following symptoms can cover the whole body within days of last application

- Oozing, weeping skin
- Skin that splits, cuts and sores
- Leathery skin that thickens
- Flares which cycle through burnt, swollen and red, through to dry, crusty and tight and then excessive flaking of whole areas with lots of skin flaking off.
- Sleeplessness, fatigue, exhaustion
- Sweating, extreme coldness and an inability to regulate temperature
- Skin cannot sweat
- Infections, eczema herpeticum can spread on TSW skin. Seek medical support if this happens

Topical steroids should only be used short term but with no other options available patients are using this topical drug for years. The result is red skin syndrome or topical steroid addiction. If you are treating patients with eczema, psoriasis and atopic dermatitis please make sure you are aware of TSW and the implications for the patient

Medical views on TSW

I have certainly seen Topical Steroid Withdrawal Syndrome, now multiple times. Generally, I find that these patients tend to have more widespread involvement on their body, but almost always have face and neck involved. Unlike eczema, it tends to be more red and flushing or blushing in appearance, although many patients will also have eczematous and scaly lesions at the same time.

Peter Lio, MD, Dermatologist and Partner at Medical Dermatology Associates of Chicago, US

Steroid addiction is a more subtle and more insidious type of side reaction. It is common but is not high in medical consciousness because it frequently goes unrecognized. Hence, it is underreported and not well characterized. Because it develops in stages, often slowly, both the physician and the patient may fail to incriminate the steroid.

Albert M. Kligman, MD, PhD, US, (Albert died 2010)

A dermatologist in California who named the illness 'red skin syndrome' says patients in the US — including some from the UK benefit from deciding to come off steroid creams. ... that one in eight adults diagnosed with eczema may, in fact, have TSW.

Dr Marvin Rappaport, US

Though the topic of topical steroid addiction (TSA) is troublesome for physicians, we should not postpone facing it. It is not a temporary tide, TSA is real. Please search articles in PubMed. At the minimum, warning of TSA as a side-effect of topical steroids must be added in the guidelines of all areas of atopic dermatitis treatment.

Mototsugu Fukaya MD, JDA, Tsurumai Kouen Clinic, Japan

Also blogs about TSA and TSW

<http://mototsugufukaya.blogspot.com/>

A GP based in the UK who has gone through topical steroid withdrawal and now manages her eczema naturally through gut health and mental health.

Dr Ruth Camish, Manchester, UK

Recognises TSW and sees patients to advise on tapering and treatments..

Dr Anthony Bewley, Whipps Cross Hospital, London

A petition for change, signed by many patients who feel they are going through TSW:

<https://www.change.org/p/secretary-for-health-matt-hancock-u-k-dermatologist-recognise-and-treat-topical-steroid-addiction-red-skin-syndrome>

Books you can recommend for patients of staff who want to understand more

Cara is a writer from London who suffered from eczema for most of her young life. It became severe in her teens, and in her twenties only seemed to be getting worse, until she found the answer that changed her life. She had developed Topical Steroid Addiction (TSA), a condition brought on by the use of topical steroids that were prescribed to treat her eczema, and the only way for her to get better was to stop using them completely.



She has since made a full recovery and is now an advocate for the relatively unknown condition which affects thousands of people worldwide.

In December 2017, she released the book, *Curing my Incurable Eczema*, about her battle with Topical Steroid Addiction which reached the top five in the dermatology book charts on Amazon

www.tswcara.blogspot.com

www.authorcaraward.blogspot.com

Instagram: @carasnextchapter

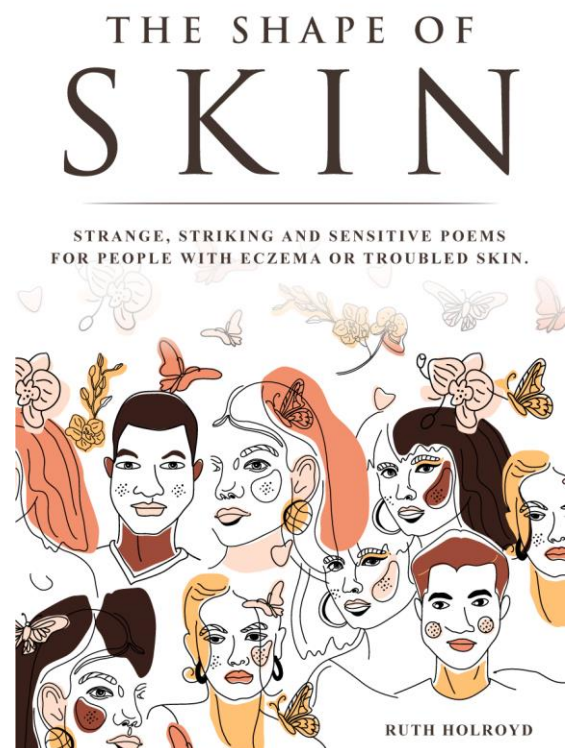
Twitter: @carawardwrites



Written by Claire Oxenham, from Australia who is currently healing from TSW, this book explains what to expect with illustrations and easy to understand bite sized information.

Available on Amazon as ebooks, kindle and Paperback.

Healing poetry about eczema and topical steroid withdrawal, aimed at helping those going through this condition feel less alone, and feel understood, listened to and seen. Something we all struggle with when it is so poorly recognised and accepted by the medical profession in general.



This is preventable



Created by Ruth Holroyd, www.whatallergy.com
ruth@whatallergy.com
Instagram <https://Instagram.com/whatallergy>