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WHAT YOUR PATIENT IS THINKING

Help me navigate life with atopic dermatitis

Yen-Hsiang Wang describes life with atopic dermatitis, and how he has learnt to explore and cope with different treatments

Yen-Hsiang Wang

I have suffered from atopic dermatitis for several years. Tissue, fluid, and blood exude from wounds all over my body. When I wake in the morning, I often find my bed full of bloodstains from where I have scratched unconsciously in my sleep. I need to apply oil all over my body to keep my skin moist, and the greasy feeling makes me uncomfortable.

Atopic dermatitis deeply affects my relationships with others. When travelling on public transport, I wonder if people are keeping their distance from me because of my scars and rash. My friends are curious as to why I won't go with them on an overnight trip, but I don't want to tell them the truth. I don't want to let them see me scratching at night or see me feeling embarrassed in the morning. This gives me physical and psychological pain.

Overwhelming side effects

One of the main treatments for atopic dermatitis is steroids. They are effective and bring great improvements to my skin, but the side effects are troublesome. I am more susceptible to infections, and the shape of my body has changed. These changes in body shape frustrate me the most. They make me feel awful about myself.

Unfortunately, when I started the steroids, my doctors did not clearly explain these potential side effects. When I first experienced them, I felt overwhelmed as I didn't know why my body had changed so much. I wish I had been better informed, as I think this would have made me feel calmer when the effects occurred.

Learning to be patient

After struggling with the steroids and creams I decided to try light therapy. This treatment exposes the skin to ultraviolet light at a certain wavelength and helps to regulate the immune response. I receive light therapy four to six times a month. At first I noticed little improvement in my condition. But after three months my symptoms reduced significantly, and—even better—I experienced few side effects. Light therapy can make the skin darker in colour, but for me this is an acceptable drawback.

I wish that my medical team had explained to me, even briefly, that I might see a delay before the therapy took effect. When I wasn't able to see positive results from the start, I had wanted to give up the treatment.

What you need to know

- Living with atopic dermatitis can make patients feel anxious about their appearance
- Explaining common side effects of treatments can help patients feel calmer if they do occur
- Sharing how long it can take for a patient to see improvements from their treatment is important to keep them motivated to continue

Education into practice

- How might you support someone who is feeling embarrassed about the effects of their condition?
- At what stage might you share with patients some of the common side effects of their treatments?

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