Introducing Eczema Care Online



EczemaCareOnline.org.uk

parents and carers of children with eczema, that the amount of information available can be overwhelming, with uncertainty about commercial interests only adding to the confusion.

To address this issue, our unique group of health professionals and researchers joined forces with people living with eczema to develop a new website. National Eczema Society participated in this research as a member of the project steering committee. Over the past five years, through close collaboration, we've created an evidence-based, user-friendly resource to help people better manage their eczema symptoms.

I thought I knew how to Look after my child's eczema, but I Learned so many new things from Eczema Care Online about how to keep eczema under control — things I would have never thought of.

Parent

Eczema Care Online has given me a Lot more confidence about my eczema and I'm now not as embarrassed about it. What I took away from it is that eczema shouldn't control you — you should control your eczema.

Young person



We launched the finished version of Eczema Care Online after two large clinical trials found that people who used the website experienced a significant improvement in their eczema symptoms. These results have been published in *The British Medical Journal*.

How did we develop Eczema Care Online?

In 2017, after winning funding from the National Institute for Health Research (part of the NHS), we ran a series of research studies to better understand effective eczema self-management and how to make this information easily accessible online.

We wanted to ensure our work was patient focused, so we started the process by talking to more than 150 people with eczema and their families about their experiences. This helped us understand the questions they needed answers to most.

Next, we wanted to ensure our guidance was grounded in scientific evidence. We evaluated and summarised research carried out in more than 100 studies, to answer patients' questions about flare-control creams (topical

steroids). We wanted to know how safe they were, which creams were best to use and how best to use them. We also collated the most upto-date advice about other important aspects of eczema care, such as bathing, diet, and the effects of weather.

Once we had evaluated and summarised all the relevant scientific evidence and advice, we looked at how best to present our findings online in a simple, engaging way. Web designers and people living with eczema helped us create an approachable, user-friendly website.

Eczema Care Online greets people with some core information about eczema before they arrive at the main menu, which offers a choice of topics. When you visit the website for the first time, you will be asked whether you are managing eczema for yourself or your child, so you are pointed to the most relevant guidance. Information is presented in either English or Welsh language.

What did we learn along the way?

Through developing the site alongside people with eczema, we have learned a lot about what works well. Most importantly,

effective eczema management involves proper use of two treatments:

Emollients (moisturisers)

are used to maintain control of eczema. Most people will need to use them every day. These creams help to

prevent eczema flare-ups by keeping out things that may irritate the skin, softening the skin by locking in water, and making the skin less itchy. Usually, they need to be used at least once a day, even when the skin is clear, to prevent flare-ups.

MOISTURISE

No one had properly explained to me what my two eczema treatments were for. Eczema Care Online helped me understand my creams much better.

Young person



Flare control creams (usually topical steroid creams) are used to get control of eczema flare-ups when the skin becomes more sore or itchy than normal. They are usually prescribed by healthcare professionals, and most people with eczema will need to use them at some point. They are most effective when used as soon as there is a flare-up and should be used for two days after the eczema is under control. Our studies show that these creams are safe and are usually used for just a few days or weeks at a time.

When these two treatments are used well, they will treat most eczema.

A one-stop shop

We wanted the website to provide a onestop resource offering clear and reliable information for living well with eczema.

EczemaCareOnline.org.uk

It was one of the best websites I've ever used. It was really easy to use and provided the answers to specific questions. I didn't have to read through Lots of stuff that wasn't relevant to me.

Parent

The broad range of advice has information on key topics including:

- using moisturisers to prevent flare-ups
- how to use flare control creams when flare-ups do occur
- managing sleep issues, stress, and controlling the urge to itch.

Eczema Care Online is aimed at adults, carers, parents of children with eczema, and young people who are starting to manage their eczema on their own. It includes information particularly relevant to younger people, such as how to manage eczema at school, university and work, along with advice about finances and cosmetics.

The information is provided without commercial influence and is not advertising any products.

How has it helped people with eczema?

To test the effectiveness of the website, we ran two research trials with more than 600 participants: one with young people managing their own eczema and one with parents or carers. Both groups found that after 12 months, people who used Eczema Care Online saw a sustained improvement in their eczema compared with people using their usual eczema care. (The quotes in this article are from people who took part in these studies.)

Get involved!

With the research showing that our website is having such a positive benefit, the next aim is to spread the word. We are partnering with GP practices and pharmacies and promoting it through social media, eczema support groups, and eczema societies. We'd love you to help us to get the message out there. Visit us on Facebook or Twitter, like our page, and share the link with anyone else who might find it useful.

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...find it... ..bookmark it... ...share it...

...help get control and keep control of eczema....