NATIONAL ECZEMA SOCIETY

exchange

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FREE TO
MEMBERS

Managing lip eczema

How to talk about eczema

Immunosuppressant treatments

Eczema Care Online

It's personal – female genital eczema

NATIONAL ECZEMA SOCIETY MEMBERS' MAGAZINE

NATIONAL ECZEMA SOCIETY

Exchange is the National Eczema Society's quarterly magazine, produced to keep members up to date with the management and treatment of eczema and to provide a forum for an exchange of news, ideas and information. If you'd like to join us, go to www.eczema.org/become-a-member

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Contents

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Warning: Products, treatments or other forms of medication that suit one person may not suit another. It is advisable to test different skin products on a small patch before general use. If possible, you should also consult your doctor before changing eczema treatment and should also do this if in doubt regarding a treatment or proposed treatment. The Society cannot accept any responsibility for failure to take medical advice.

Policy: The Society's general approach is to encourage active partnership between patients and healthcare professionals and the discussion of all available options, in the interests of informed choice on the part of the patient.

New eczema care guidelines

The National Institute for Health and Care Excellence (NICE) has a hugely influential role in directing how healthcare professionals diagnose and treat people with eczema. Although focussed on England, NICE guidelines are often influential in shaping practice in other UK nations. NICE has announced an update to its eczema guidelines for children aged 12 and under, and is also developing new guidance for adults with eczema. It seems extraordinary that there are no NICE guidelines for adults already, which is one of the reasons why approaches to eczema care can vary so much across the country. The Society is contributing to the guideline development process and will promote opportunities for patients to participate. It is vital that patient views and preferences are considered and reflected in the new guidelines.

In this edition, Hannah Kunzlik talks about her experiences of living with eczema (pages 33-36) and how it affected her growing up. School life can be so challenging when you have eczema and have such an impact on how children feel about themselves. For Hannah, being referred for cognitive behavioural therapy (CBT) proved to be a turning point, and shows the importance of finding ways to support our emotional and psychological well-being.

Hannah brings her personal experience of eczema to her work as a Trustee of National Eczema Society. This is the same for all our Trustees and helps ensure the Society achieves the most it can to make life better for people with eczema and their families.

Talking about how eczema makes you feel can be awkward and difficult, even with close family and friends. Eczema is a visible and very personal condition and sometimes it's just easier to cope by keeping things to yourself. That's hard for you though and the people around you. Claire Mould has some tips for how to share your eczema journey (pages 14-17).

Elsewhere in this issue, Jing Husaini and Lucy Moorhead (pages 18-24) review the different types of immunosuppressant treatments for more severe eczema. People sometimes worry about taking these because they are powerful medicines and can have side effects, so it's important to understand how they work and are monitored.

Many thanks to members and donors who generously supported our Christmas fundraising appeal this year, raising £10,331 for vital eczema research. We want to start a new research programme to support the most promising scientists working in eczema research. It's important to build the research capacity in eczema, to give us the best chance of developing new treatments and ultimately find a cure for this painful and debilitating skin condition.

Best wishes,

Stephen

Stephen Pugh | CHAIR

Campaign builds for clearer potency labelling of topical steroids

Leading professional dermatology organisations have joined National Eczema Society in calling for clearer potency labelling of steroid creams and ointments. We are asking the UK medicines regulator, the MHRA, to require pharmaceutical manufacturers to include simple and clear potency labelling on topical steroid (TCS) tubes, packaging and patient information leaflets.

TCS are routinely prescribed to treat or prevent eczema flare-ups and it is important patients have enough information to use them safely to manage eczema well. TCS are effective treatments for eczema but, like many treatments, they can have side effects. People with eczema are understandably concerned about overusing TCS. We believe clearer potency labelling will help improve patient understanding and confidence in these medicines.

We need a standardised labelling scheme, so that patients and healthcare professionals become familiar with the way that potency is shown across all the many different topical steroid products and brands. The goal is to achieve a level of public understanding comparable to sunscreen strength using the Sun Factor Protection (SPF) labelling, which enables people to use sunscreens confidently and effectively.

This change has strong support from the eczema community. The Society conducted an online survey in January this year, to find out more about people's knowledge and understanding of steroid potency. We received 943 responses, from both adults with eczema and parents of children with eczema, and many thanks to all our members who took part.

Almost all respondents, some 98%, knew that TCS comes in different strengths (potencies). However, almost half said they did not know how many different strengths there were, and only 17% correctly answered '4'. Most people (70% of respondents) said they would look at information printed on the tube or product packaging to find out about potency. It seems a glaring omission that potency information is not routinely provided at the moment. Some 95% of respondents said they would like to see clear strength labelling on all steroid creams and ointments.

This initiative for clearer labelling has strong support from healthcare professionals too, with the following organisations endorsing our campaign:

- British Association of Dermatologists
- British Dermatological Nursing Group
- British Society for Paediatric and Adolescent Dermatology
- British Society for Allergy & Clinical Immunology
- Primary Care Dermatology Society
- Scottish Dermatological Society.

In a confidential survey, over 90% of delegates attending a dermatology course for consultants in late 2022 said they supported the idea of clearer TCS labelling. We are grateful too that the charity Eczema Outreach Support is endorsing the campaign.

NICE updates eczema care guidelines for children

The National Institute for Health and Care Excellence (NICE) is proposing to change its eczema care guidelines, to say that doctors should not prescribe bath emollients for children with atopic eczema. The Society believes children with eczema and their families will be disadvantaged and suffer as a result of the proposed changes, and has asked NICE to reconsider. NICE acknowledges that some children benefit medically from using bath emollients, but says parents should pay for them. This will penalise the poorest families and children with more severe eczema.

The proposals rely heavily on just one research study, called the BATHE trial, which NES believes did not reflect how families typically use bath emollients. Parents also tell us that dermatologists do recommend bath emollients, as part of wider skincare regime for their children, but these are not available on prescription from the GP.

Thank you!

Many thanks to all our members and other supporters who so generously donated to our Christmas fundraising appeal. We are very grateful for the ongoing support of our members, especially at this time when the cost-of-living pressures remain so challenging. The appeal raised an amazing **£10,331 plus Gift Aid**. Your donations will help fund a new National Eczema Society programme to support the most promising researchers working in eczema. We believe this is the most effective way we can one day find a cure to this painful and debilitating skin condition. We will share more information about this exciting research programme in future issues.

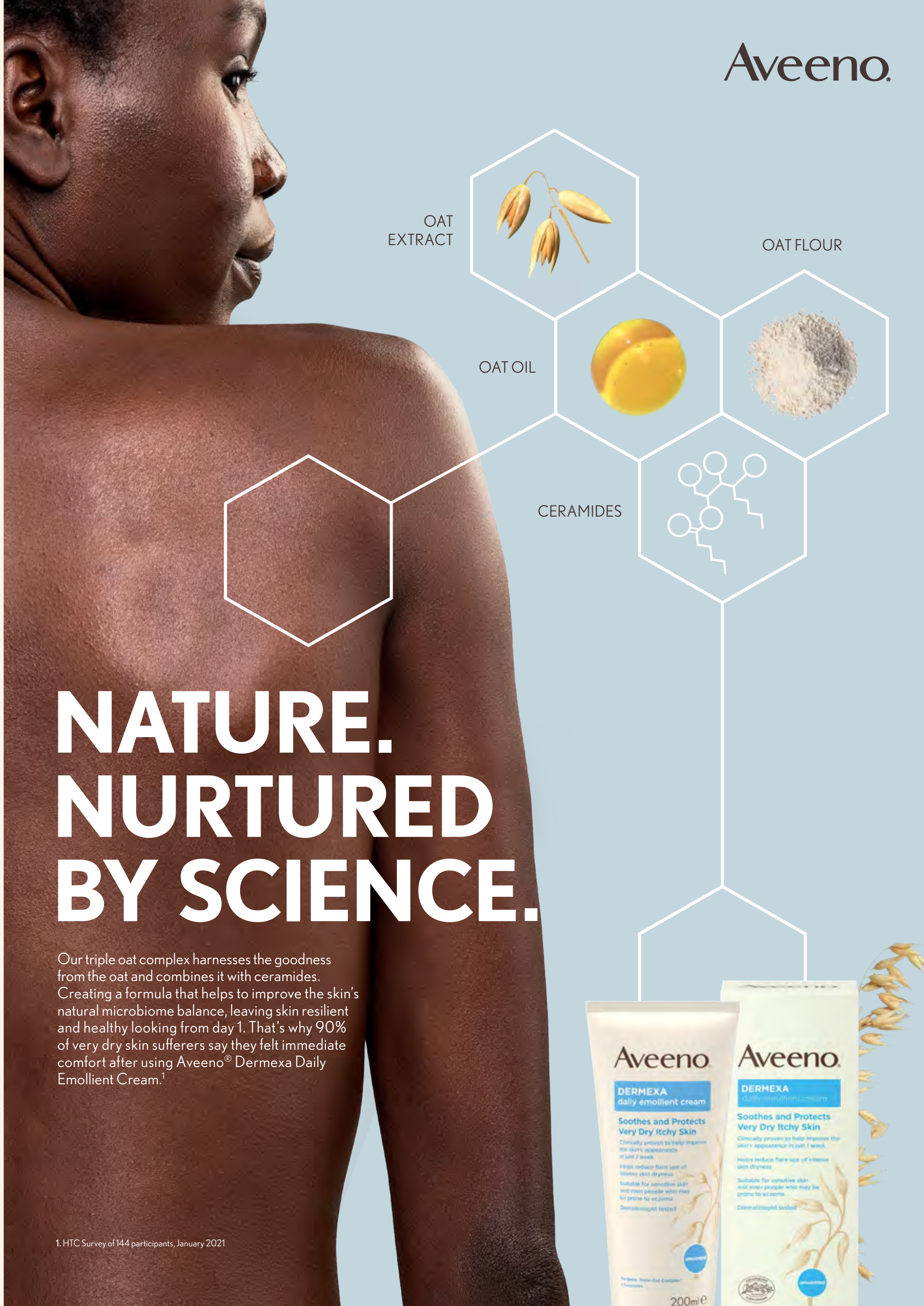
TALK: Does eczema have an impact on other health conditions?

Are you more likely to develop other health conditions because you also have eczema? This was the subject of a fascinating talk by Professor Sinéad Langan, organised by the Society's West Surrey and North East Hants Support Group in March.

The event was also livestreamed on Facebook, so people could watch remotely on their phone, tablet or other device. This was the first time the Society has livestreamed a talk and it was a great success.

You can still view on the Society's Facebook page here: **ww.facebook.com/100064692756603/videos/698944808621593**

Sinéad Langan is a Professor of Clinical Epidemiology at the London School of Hygiene and Tropical Medicine. She looked at what the research shows about the likely risk of developing other conditions when you have eczema. One study led by Professor Langan, examining the health records of more than three million adults, showed evidence of a link between atopic eczema and the risk of bone fractures.



Meet the Society's Medical Advisory Board

Day in the life

Dr Paula Beattie

Dr Paula Beattie is a consultant dermatologist in Glasgow, clinical lead for dermatology at Glasgow's Royal Hospital for Children, Chair of the British Skin Foundation small grants committee and a former committee member of the British Society of Paediatric and Adolescent Dermatology. She has a special interest in eczema.

7.00 My day starts with my husband bringing me coffee, and I do the Wordle while I wake up. I get my emollient on after a shower then have breakfast (usually yoghurt with some fruit and nuts) while it soaks in. My 12 year old (I have three boys) also has eczema, but hates creams so I try to get some ointment on him well before he puts his school uniform on – otherwise, he gets annoyed that it gets greasy.

8.00 The boys head off to school by train and I cycle to my clinic at the Children's Hospital. As a doctor who has eczema and a parent of a child with eczema, when kids with eczema come in, I can really empathise – with them and their parents. I have lots of experience with the burden of putting creams on and battles to get children in the shower or to put on steroids when it makes their skin sting.

12.00 I spend the afternoon answering emails and seeing patients on the wards. We used to get a lot more children admitted with acutely infected flares but we try to treat most as outpatients now. Like other hospitals, though, we are getting more people coming to A&E because they can't get GP appointments.

Patients' organisations such as the NES play an important role in providing reliable information for eczema sufferers and parents. I've been very involved in eczema education, giving talks and lectures to doctors and the public. I've also run an NES webinar on topical steroid treatments.

Dermatology is so interesting – it's always challenging. Rashes look different on different people and there are so many diagnoses. Also, you can make a real difference to people's quality of life because actually, living with skin conditions can be so miserable.

5.45 After I cycle home, I make dinner or do laundry while supervising my youngest doing his homework. After dinner, I might go for a walk or do a class at the gym if I'm not driving the children to rugby or hockey. Between work and family, I don't have much spare time during the week, but I meet up with friends at weekends.

8.00 I read my youngest a story and apply his ointments again. Then it's back to work – going through research emails and safety reports ready for my research clinic tomorrow. I enrol adults with eczema on clinical trials for new therapies for severe eczema. It's wonderful that we now have a number of new treatments for severe eczema so that if one treatment doesn't work, we have other options.

This month:
eczema treatments and
how to apply them

MYTH BUSTERS

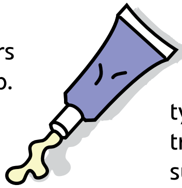
MYTH 1 EMOLLIENTS SHOULD BE APPLIED BEFORE ECZEMA TREATMENTS

In the past, it was said that there's no rule about whether you should apply the emollient or the topical steroids first. People said that the important principle was always to leave time between applying them, to avoid diluting the topical treatment with the emollient. But recent research has shown that applying an emollient before a topical steroid can reduce the amount of topical steroid that reaches the skin.

So, if your eczema is flaring and you use topical steroids, follow these steps:

1. If you've had a bath or shower, pat the skin dry.
2. Put on the topical steroid.
3. Wait for 20–30 minutes.
4. Apply the emollient.

If you use the topical calcineurin inhibitor Protopic, the manufacturers recommend leaving a two-hour gap.

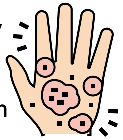


MYTH 2 USE TOPICAL STEROIDS 2–3 TIMES A DAY

Labelling on topical steroids can be confusing and is sometimes incorrect. One study 15 years ago concluded that **applying strong steroid cream once a day is as effective and safe as twice a day.** This was confirmed in a systematic Cochrane review in March 2022 combining data from 15 studies involving 1,821 people. Once-daily topical steroid application is considered most helpful, as it is more convenient than multiple applications.

MYTH 3 TOPICAL CALCINEURIN INHIBITORS INCREASE YOUR RISK OF CANCER

Topical calcineurin inhibitors (TCIs) include the non-steroidal tacrolimus (Protopic), and pimecrolimus (Elidel). When TCIs started being prescribed, more than 20 years ago, they had a 'black triangle' warning (meaning it is more closely monitored), as there were reviews suggesting a theoretical cancer risk. However, more recently, a huge systematic review looked at 3.4 million people with eczema worldwide who are treated with TCIs. This study provided clear evidence that there is no increased risk of cancer, for infants, children or adults.



MYTH 4 IF A TREATMENT STINGS, YOU ARE ALLERGIC TO IT

Stinging is not unusual for some treatments. For example, TCIs often cause burning and stinging for the first few days, but this sensation will typically subside. If you are allergic to a topical treatment, this is usually accompanied by sudden flares of skin redness or darker areas of skin and intense itching and burning.

Some emollients may cause stinging in some people, too, while being fine for others. At the same time, for people with sensitive skin – which includes anyone with eczema – some topical treatments may sting if applied to dry skin but are fine if the skin is moisturised. That's why it is so important to find an emollient that suits you and to moisturise with it every day, to repair the skin barrier and prevent dry skin.

Ask the expert

Welcome to our panel of experts

Helen Dennis

DERMATOLOGY NURSE ADVISER

Helen has worked as a dermatology nurse practitioner in the community and as a sister at St John's Institute of Dermatology. She is a keen educator of parents and healthcare professionals, and was coordinator for the Eczema Education Programme, a service training parents to self-manage their child's eczema. She is a dermatology nurse advisor to the National Eczema Society.

Julie Van Onselen

DERMATOLOGY NURSE ADVISER

Julie is an independent dermatology nurse with 25 years of clinical experience. She is passionate about improving care and support for people with skin conditions, and educating patients and healthcare professionals. She is a dermatology nurse adviser to the National Eczema Society and leader of the dermatology module in the School of Health and Sports Science at the University of Stirling.

George Moncrieff

GENERAL PRACTITIONER

George retired from his practice in 2017 after nearly 40 years in the NHS. Before retiring, he ran a busy community dermatology clinic receiving referrals from the local GPs. George chaired the Dermatology Council for England from 2014 to 2018. He helped set up, and was clinical lead for, a federation in South Birmingham and has appeared regularly as a skin-care expert on ITV's This Morning.

Infant eczema

Q My six-month old baby has been diagnosed with atopic eczema and I'm not sure how best to help her. I've seen the GP several times now, but it just seems to be getting worse. I'd really appreciate any advice on how to help. It breaks my heart to see her so uncomfortable.

Helen Dennis: To really help your daughter, it is worth spending some time reading up on eczema. Unfortunately, there is no quick fix or cure, but it is possible to manage it to a level that does not impede her quality of life. Eczema is a fluctuating, unpredictable condition and flare-ups can start quickly.

In babies, the range of active treatments that can be used to treat eczema is limited. But mild-potency topical corticosteroids can be prescribed to treat the inflammation if this is not controlled with emollients alone.

Daily bathing with emollients is vital for eczema skin, to help rehydrate it and control the bacterial levels on the skin. Avoid hot water and all soaps (even the ones labelled as suitable for babies or sensitive skins). Instead, use the emollient as a soap substitute and apply immediately after washing, before gently patting her skin dry.

Skin with eczema loses moisture easily, leading it to dry out quickly and crack. Emollients are key to restoring the skin's barrier function, by adding oil to the skin and reducing moisture loss. Apply emollients with every nappy change. To make it fun, try singing a song or rhyme or doing it underneath a baby mobile when applying it. Over time, it will simply become a normal part of the regular routine.

Night-times can be tricky too, and itchy eczema in children often leads to a sleep-deprived household. At six months, your daughter's developing motor skills will make her hands and feet increasingly effective tools to scratch with. However, this can exacerbate the problem over time, leading to the itch–scratch cycle.

There are some simple changes to her bedroom that may help with night-time itching. Keep the room cool (16–18°C) and use light layers of cotton bedding. A fan across the room from the cot may be helpful. Dry her bedding indoors to avoid pollen floating in the air and sticking to the bedding. Co-sleeping is likely to make the itching worse, as your body heat will act like a radiator beside your baby, so if you share a room, push the cot away from your bed. You can also buy gloves and sleep suits that cover the hands to prevent scratching in her sleep.

You will find lots of tips in *Exchange* magazine and on our website about how to support your daughter as she grows and develops. If you are worried about anything, contact our Eczema Helpline. Good luck and remember, we are here for you.

Staying on top of prescriptions

Q I have so many different creams, ointments and tablets for my eczema. The repeat prescriptions all seem to run out at different times and occasionally I need to get emergency prescriptions. Have you got any tips?

Julie Van Onselen says: It's good you have a repeat prescription so you have a well-stocked toolkit to help manage your eczema day to day. However, staying on top of things – especially if you have several prescription medications – can be overwhelming. There are various things you can do to keep on top of your prescriptions and ensure that you don't run out of treatments.

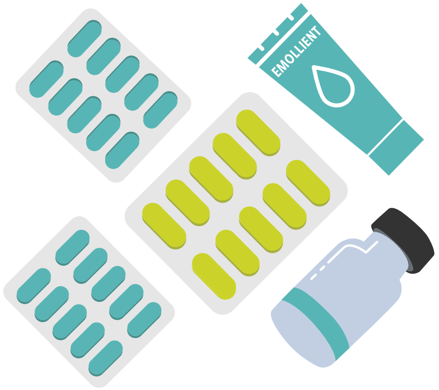
The first thing is to get in a routine of keeping track of everything you are prescribed. That way, you'll know exactly how many of each item you have, when it's due, and if you have enough to last you until your next refill. This is really important, as it will help you avoid running out – leading to health problems or the inconvenience of phoning the practice for emergency prescriptions and dashing around to late-night chemists.

To track your medication, you need to draw up a simple medication schedule showing when each medication is due for ordering. You can do this on a paper calendar or use one of many smartphone apps designed specifically for this purpose. Ideally, talk to your GP, pharmacist or healthcare professional and ask if your repeat medications can be streamlined and ordered on the same date. Bear in mind there may be different intervals. For example, you may need to order emollients weekly but antihistamines every four weeks.

If you have a smartphone, it's a good idea to register on the NHS App. Alternatively, many practices use NHS-approved websites, such as Patient Access. These list all your repeat medications and shows when they are due. You can then order at the touch of a button. You either collect it from your nominated pharmacy or can use one of the free medication delivery services (ordering through their own app or phone service). Just bear in mind that if a repeat prescription needs a GP review, these apps may not flag this.

If you're really struggling to keep up with your medication, ask a friend or family member for help or talk to your healthcare professional. The NHS App has an option for a friend or family member to order medication on your behalf. People other than yourself can collect medication from the chemist or receive deliveries from online pharmacy services. So, it's worth seeking advice: do ask your pharmacist.

If you're a working adult and pay for your prescriptions, you may make considerable savings with the NHS Prescription Prepayment Certificate (PCC), which covers all your NHS prescriptions for a set price. Find out more at: www.nhsbsa.nhs.uk



Lip eczema

Q My eczema mainly affects my face. I manage to control flares with occasional use of 1% hydrocortisone. My problem area is my lips, which are always chapped, sore and swollen. The 1% hydrocortisone doesn't seem to help and I am loath to try anything stronger. My facial moisturiser makes my lips sting too. Can you suggest any specific emollients and treatments? I'd love to wear lipstick again.

Dr George Moncrieff says: I fully appreciate how debilitating cracked, red, swollen lips can be – and they can develop deep fissures. The medical word for inflamed, sore lips is cheilitis and there are many causes for this, including eczema. It sounds as if this is what you have, but there could be other causes.

People with eczema are more likely than others to develop contact allergic dermatitis, too. This can be triggered by various substances that come into contact with the area. For the lips, this could include lipsticks, toothpastes (particularly ones that contain SLS that can cause irritant dermatitis), foods, fragrances and preservatives. It's worth keeping a diary to see whether you can recognise an obvious trigger, but you should have patch tests arranged to explore this in detail.

Saliva irritates eczema too, so licking your lips would aggravate things, as would picking at the lips and cold, dry weather.

Rarely, cheilitis can be caused by a deficiency in vitamin B12 or iron, so it would be worth having a simple blood test. Zinc supplements sometimes help. I would examine the entire lining of your mouth and lips, as occasionally, other conditions (such as lichen planus) can look like simple cheilitis.

Use a leave-on ointment, such as Aproderm or Vaseline. A more creamy ointment, such as Hydromol or Zeroderm would also be ideal and could be used as a soap substitute. (As always with eczema, avoiding detergents is key.) Better still would be a lip balm, such as Cicaplaste lips. This barrier-repairing lip baume is specially formulated to relieve dry, sore or cracked lips and can be used as often as you like throughout the day.

Eczema-related cheilitis often needs treatment with a moderately potent topical steroid – 1% hydrocortisone is very weak and unlikely to offer any benefit. I would recommend something like clobetasone butyrate ointment, once a day at bedtime. At first, apply this generously, but take care not to let it spread onto the surrounding skin as it could cause perioral dermatitis.

If you develop problems using a topical steroid in this area (such as perioral dermatitis), an ideal alternative would be a topical immune-modulator such as pimecrolimus cream or tacrolimus ointment. Tacrolimus is equivalent to a potent topical steroid and can be used long term as maintenance therapy for eczema.

It's good to talk

Sharing your eczema journey with those around you isn't easy – but it's so worthwhile, writes **Claire Moulds.**

You can never truly know what someone is going through unless they let you behind the façade they present to the world. But when you live with a highly visible and intensely personal condition, such as eczema, it's not easy to be open about the daily challenges you face and the feelings they generate. So, where do you start?

It takes two

First of all, it's important to recognise that sharing your eczema journey with others is a positive act that helps others, as well as yourself. It's easy to think that completely opening up places a burden on the people you care about most. If it was you, though, wouldn't you want to understand what your partner, family member or friend's life is really like – especially when so much of it is invisible to you?

But it is important for you, too. Carrying the weight of eczema around with you – physically, mentally and emotionally – is exhausting and being honest is one way to put some of that weight down.

For example, if you often cancel plans with friends at the last minute because of your eczema, having to hide the truth from them and make up an excuse only puts you under additional strain. Meanwhile, they're left in the dark wondering what the matter is or if they've done something wrong or thinking that you are unreliable or do not care.

By opening up, everybody then understands what's really going on. This replaces any misunderstandings and negativity with simple disappointment that you cannot join them.

Plan ahead

It's important to decide in advance where, when, how and with whom you want to share your story, so you feel in control of the situation.

Sharing something so intimate with others can feel overwhelming. You might get upset, so it's important to be comfortable with your surroundings when you are talking. Doing it in the afternoon gives you the morning to prepare and get in a good headspace. It also means you then have time afterwards to reflect on what's been said, rather than going straight to bed with your mind whirring.

Let everyone know what you want to talk about so they aren't caught out. Hearing first hand what someone you care about is going through can be hard for the listener too, so give them the opportunity to prepare for it.

You might want to let the conversation unfold naturally or you may prefer to prepare what you want to say in advance. Either way, it helps to have a list of points you definitely want to cover so you don't think afterwards 'I wish I'd said that'.

Be clear at the beginning if you're ok for people to ask questions as your story unfolds or whether you'd prefer to say everything you want to before they respond so you don't lose your thread.

Consider whether you're happy to answer questions. If you have any 'red lines' of topics you don't want to cover, share them beforehand. Not everyone may feel comfortable asking you questions, even if they're desperate to, so you can always direct people to the Society's website www.eczema.org if they want to learn more about the condition.

And, if it all feels too much, think about opening up to just one person initially, as that might give you the confidence and encouragement to then speak to a larger group.

Explain clearly what you need

When someone close to you shares the difficulties and challenges in their life, the natural response is to want to help. But anyone with eczema knows how frustrating it is to hear 'Have you tried…?' – however well meant. To prevent a potential onslaught of advice, product recommendations and 'helpful' suggestions, think in advance of positive, practical, empowering ways that people can support you.

Focus on things that are actually useful to you, and which also enable them to make a genuine difference to your life. For example:

- Often, the best thing someone can do is to provide a listening ear. But make it clear that you do not want to be 'Ali who has eczema', or for eczema to suddenly feature in every conversation you have. Perhaps you might need to occasionally offload for half an hour, or to scream in frustration for a minute, knowing someone will be standing there waiting and supportive when you've let it all out.

  Explain what your triggers are and how these affect where you can go and what you can do. There might be specific examples within the group that you can raise. For example, if your friend has lots of candles and diffusers in the house and fragrance is a trigger for you, explain that you only pop in briefly, as if you stay longer, your skin will start to react. Equally, if getting hot and sweaty makes your skin worse, explain that that's why you're never up for a spontaneous kickabout in the park.
- If something makes you uncomfortable, let people know. For example, do you prefer not to be in group pictures on social media because of how you feel when you look at them? Then ask if, from now on, they could check first whether you're happy with an image being uploaded.
- If there's anything in particular that is eating away at you, such as wondering how they feel when you leave a flurry of skin flakes on their sofa or in their car, and what they do once you've left, ask. Honest conversations about tricky issues will help everyone feel a lot more comfortable, rather than both sides pretending it's not happening.

You need me-time too

It's good to talk, but sometimes what you really need is time and space to process what's happened or is happening to you and to reflect on your own thoughts and feelings, without other people's input.

So, it's just as important to explain that sometimes, being alone is exactly what you need. If you aren't answering calls, responding to texts or active on social media, it doesn't necessarily mean that you're sinking and in need of an intervention.

Maybe appoint one or two people who you will definitely respond to if they check in with you because you've been quiet. Then they can let everyone else know that there's nothing to worry about and that you'll be back out in the world again as soon as you've had chance to regroup.

How to be a good listener when someone shares their story with you

- Use open body language. Uncross your arms and legs, have open palms, face them and make eye contact – to show you want to hear what they have to say.
- Give them your full attention. Don't check your phone, look around at what else is going on in the room or glance at your watch.
- Nod to show you understand what they're saying and encourage them to share more with you. A reassuring smile goes a long way, too.
- Resist the urge to interrupt them with questions, offer solutions or to fill any silences. Give them the chance to share their story in the way they want to.
- If they're struggling to find the right words, be patient.
- Avoid turning the conversation back to you with statements such as 'I know exactly what you mean as that happened to me…'
- Remember that often, all people need is to be heard and for their experience to be validated.

Immunosuppressant medicines

for treating eczema

Immunosuppressant medicines are now routinely offered to treat people with more severe atopic eczema. **Lucy Moorhead** and **Jing Husaini**, Dermatology Nurse Specialists at St Thomas' Hospital, look at the different types, what treatment involves, and how to take them safely.

Most people can treat their eczema successfully with emollients and topical creams or ointments. But if your eczema is severe, not well controlled and hugely affecting your life, you may be offered treatments that target your immune system. These treatments, called immunosuppressants, come in the form of tablets or injections that help calm down the parts of the immune system that overact with eczema.

There are four main medicines that work on the immune system to treat eczema:

- **methotrexate**
- **ciclosporin**
- **azathioprine**
- **mycophenolate mofetil.**

All four are treatments, not cures. They are usually prescribed by a doctor in a hospital dermatology department because some – although licensed for other medical conditions – are not licensed for eczema. People taking these treatments require close monitoring, as they can cause side-effects (see 'How does treatment work?', page 20). The table opposite shows the different treatments available. You can find more information in the individual factsheets for each drug at www.eczema.org.

Immunosuppressant eczema treatments

	Form	Dosage	How often do you take it?	Licensed for treating eczema	Other relevant information
Azathioprine	Tablet	Most start at 2mg per kg body weight. 25mg or 50mg tablets	Once a day	No	
Ciclosporin	Capsule or liquid	Most start at 3mg per kg body weight. 10, 25, 50 and 100mg capsules	Twice a day	Yes	Recommended not to switch brands without talking to your prescriber
Methotrexate	Tablet or injection	Maintenance dose normally 15mg but some start on a lower dose. Tablets normally provided at 2.5mg so a 15mg dose means taking six. Injections are provided	Once-weekly dosing	No	Users are prescribed folic acid to take alongside methotrexate on some or all days when not taking methotrexate
Mycophenolate mofetil	Tablets, gastro-resistant tablet, capsule, oral suspension	Most prescribed tablets, available as 500mg. Dose normally starts at 500mg then, if tolerated, increased in 500mg increments up to 3g per day	Twice daily	No	

Who are they for?

If you want to try immunosuppressants, you need to ask your GP for a referral to a specialist. GPs are generally advised to refer patients to hospitals in certain circumstances:

- if the GP is uncertain that it is eczema
- if the person's eczema often becomes infected
- if they are having more than two flares a month
- if they have facial eczema that does not respond to creams
- if eczema is affecting their life to a significant extent.

Some hospitals have a wait of more than 18 weeks so, if you have several in your area, ask about wait times at different hospitals.

Once you see a specialist, they may consider immunosuppressants if you have more severe eczema and are not responding to topical treatments, or if your eczema is significantly affecting your life. Which immunosuppressant treatment they suggest depends on any other medical conditions you have, as well as their hospital's local prescribing practices.

How does treatment work?

If you are prescribed an immunosuppressant, you will usually remain under the care of the hospital you were referred to, and will be reviewed regularly – either in person or virtually. Some hospitals may share this care with your GP, which may mean attending the hospital less often for blood tests.

Before you start any immunosuppressant medication, your healthcare team will take a comprehensive history from you. They will usually also do a physical examination, to assess what investigations are required. You will always need to do blood tests. You may also have a chest X-ray, depending on the drug being considered and your medical risk.

The person responsible for checking your progress – including reviewing blood results – is usually the professional who prescribed you the immunosuppressant drug. In the early stage of the treatment, this is probably your dermatologist.

Once your eczema has stabilised on the therapy (after at least three months), a shared care agreement can be arranged between your dermatologist and your GP. At this stage, your GP will also become your prescriber, and will be equally responsible for monitoring you.

What does monitoring involve?

Monitoring includes blood tests to check a full blood count and kidney and liver function. When you first start treatment and after any change in dose, these may be more frequent – possibly weekly.

> My skin was very bad before I started methotrexate and I really wanted help. I didn't worry about taking the tablet as I trusted that the doctors and nurses would make the right decision for me. Since starting treatment, my skin has really improved and I can't think of any side-effects that I've experienced. I didn't mind having the regular blood tests at the start of the treatment, as it reassured me my health was not deteriorating.
>
> **Kevin, patient who recently started once-weekly methotrexate**

After three months, if your eczema control is satisfactory and no clinically significant issues arise from the monitoring, blood tests usually reduce to every three months (and are usually done at the hospital when you go for your dermatology appointments).

If your blood tests highlight any issues, your healthcare professional will contact you. They may advise you to reduce or pause doses while they review the results. Very occasionally, they may refer you to another department for a review. If the issues that arise are severe, you may be asked to stop the treatment and your dermatology team will then discuss alternatives with you.

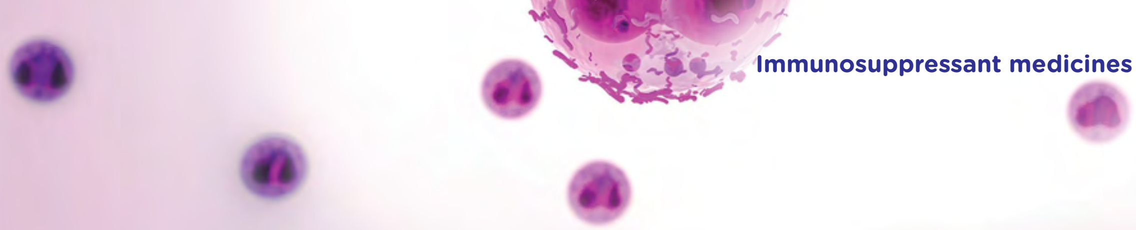
Infection

If you are taking immunosuppressants, you may become more susceptible to infections. For this reason, around the time you start treatment you may be advised to be vaccinated against common infections such as flu, pneumonia or Covid-19. These vaccines are inactivated (not 'live') and safe to have.

Live vaccines

Once you start immunosuppressant treatment, you will need to discuss with your team whether to take any live vaccinations, as this may require you to take a break in treatment. This is because live vaccines contain bacterial or viral infection in a much-reduced form. In someone whose immune system is weakened, the live vaccine could cause an actual infection of the illness you are trying to vaccinate against.

Vaccines that may be live include yellow fever, oral typhoid, BCG, chickenpox, and the measles, mumps and rubella (MMR) jab. Ideally, you should be offered any live vaccines at least 2–4 weeks before starting immunosuppressant treatment. If you are considering travel in the future, it's worth thinking about having the relevant travel vaccinations before starting immunosuppressive treatment.



Pregnancy

Let your team know if you are considering pregnancy or if you become pregnant. Azathioprine and ciclosporin are considered relatively safe during pregnancy and when breastfeeding babies who are full-term, healthy and with a normal immune system. But for now, information about risks is limited to case reports and registry data (information from patient records), so your healthcare team will consider your treatment options very carefully.

Methotrexate and mycophenolate mofetil (MMF) are teratogenic – meaning they could affect the development of the baby in the womb – and should not be used in pregnancy. Sexually active women should use at least two forms of contraception and have a negative pregnancy test before starting these medicines and for at least three months after stopping treatment.

Male fertility

For men taking methotrexate, the safety of fathering children is uncertain. For this reason, all men (including those who have had a vasectomy) should use condoms during methotrexate and MMF treatment and for at least 90 days after stopping treatment. This means waiting for three months after stopping methotrexate before conceiving a child.

Things to avoid

Some medicines, foods and supplements can change the drug levels in your blood, so you need to avoid them while taking immunosuppressant therapies. The common ones include:

- ✖ grapefruit or grapefruit juice
- ✖ St John's wort supplements
- ✖ non-steroidal anti-inflammatory drugs (for example, aspirin, ibuprofen and naproxen)
- ✖ common antibiotics
- ✖ anti-tuberculosis (TB) medicines
- ✖ anti-seizure medicines
- ✖ common blood-pressure medicines.

Always check with pharmacists and your treating doctor or specialist nurse before taking any prescribed or over-the-counter medication, vitamins or supplements while on immunosuppressants.

What are the side-effects?

One of the common side-effects of immunosuppressants is the increased risk of developing infections. Usually, these can be easily managed with standard antibiotic tablets.

If you have a fever above 38°C, burning when you pass urine or a cold or cough that will not go away, see your GP. Patients often report stomach upsets in the early stage of treatment, such as nausea, vomiting or diarrhoea. But these side-effects are usually mild enough for you to continue treatment. If you experience gastric side-effects, speak to your dermatologist or specialist nurse, who can help you manage them.

Throughout your treatment, the doctor or specialist nurse will arrange for you to have regular blood tests to monitor for side-effects. It is essential that you have these tests. Your dermatologist will give you details of where to report any troubling side-effects.

When will I see a change?

It may take up to 12 weeks from starting any immunosuppressant drug for you to notice a significant improvement in your eczema. But even if you don't see any changes at first, it's important to continue treatment. In general, don't stop taking immunosuppressant drugs without talking to your healthcare professional first.

All the immunosuppressants described here can be very effective in controlling your eczema – but they can't cure it. Some, such as methotrexate, can be taken for years if they are still effective at treating your eczema and not causing significant side-effects. Others, such as ciclosporin, can be taken safely only for a short period because long-term use can damage your body. Discuss with your doctor how long they might expect you to stay on your immunosuppressant treatment.

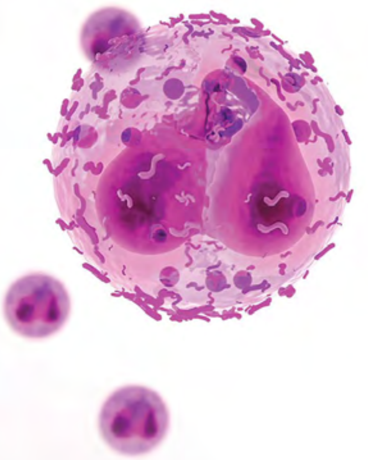
What happens when I stop treatment?

It is hard to predict what will happen when you stop taking immunosuppressant drugs. When you stop the treatment, your eczema may return. For some patients, this does not happen for a while (this is called remission), while others may suffer a flare soon after.

Stopping can happen in several ways. You may be asked to decrease your dose over a period of time rather than stopping abruptly. Alternatively, you may be asked to switch from one treatment to another. In this case, you may be asked to overlap both treatments for a while, or you may be asked to stop one, wait for a while and then start your new treatment. This is to make sure your immune system is not overloaded. Occasionally, patients take two immunosuppressants at once.

If you cannot take immunosuppressant drugs for medical reasons, or they were unsuccessful in treating your eczema, there are two new groups of treatments. Many dermatology teams can prescribe them as long as you meet the NHS prescribing criteria. They have only been licensed in the last five years:

- **Monoclonal antibodies (MABs)**
  There are currently two MABs licensed for treating more severe eczema – dupilumab and tralokinumab. They both work by targeting interleukins, which



are immune cells playing a key role in eczema inflammation. They are not available as tablets but are administered by subcutaneous injection (just under the skin) every two weeks after taking some initial loading (higher) doses.

- **Janus kinase inhibitors (JAKs)** There are currently three licensed JAKs – abrocitinib, baricitinib and upadacitinib. These work on enzymes in the immune system targeting a pathway called JAK-STAT, with the aim of reducing eczema inflammation. They are available only as tablets, which you normally take once a day.

Further eczema treatments are expected to be licensed in the next couple of years, but we do not yet know if – and how – we can use them in the NHS.

Jing Husaini

Advanced nurse practitioner, Adults' Medical Dermatology, Guy's and St Thomas' NHS Foundation Trust.

Jing has worked at St John's Institute of Dermatology at Guy's and St Thomas' NHS Foundation Trust since 2009 and was in the first cohort of nurses to be awarded the new Nightingale Award. With a background in general dermatology nursing, she is now part of the medical dermatology team leading eczema services. She is a non-medical prescriber and independently runs eczema clinics concentrating on immunosuppressant and biologic medication.

Lucy Moorhead

Nurse consultant in inflammatory skin disease, Guy's and St Thomas' NHS Foundation Trust.

Lucy has a BA (Hons) in Nursing and an MA in Medical Ethics and Law. She is on the steering committee for St John's DermAcademy and has published articles in periodicals including *Nursing Times, Nursing Standard* and *Dermatological Nursing*. She has won awards including Psoriasis Nurse of the Year Award, the Stone Achievement Award, and the Guy's and St Thomas' Patients' Choice Award. She is a trustee for the British Dermatological Nursing Group.

Introducing Eczema Care Online

People with eczema are often faced with confusing information about their condition. That's why researchers developed Eczema Care Online – a website about eczema and how to manage it. Here, the team talk about the research underpinning this new resource and how it helps people with eczema.

Too often, people receive unclear, and sometimes contradictory, information about what the best eczema treatments are and how to use them. We know from speaking with people with eczema, and 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**

Watch a two-minute video about Eczema Care Online at: tinyurl.com/eczemacareonline

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 up-to-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.

> 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 one-stop resource offering clear and reliable information for living well with eczema.

> 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.

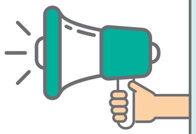
How has it helped people with eczema?

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.

UoN Online Eczema Research
@CebdNottm
@ECO_eczema
@eczema_study



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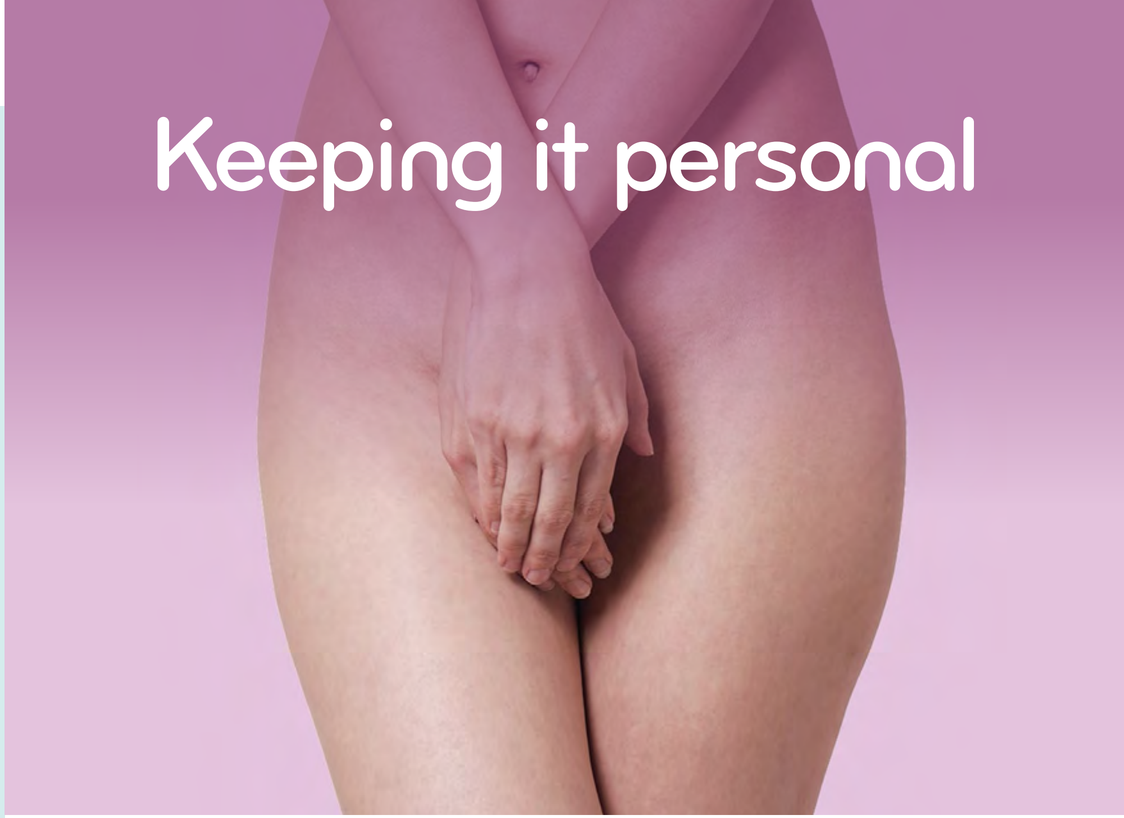
...help get control and keep control of eczema....



Keeping it personal

Privates, ladyparts, front bottom – whatever you call it, the area between the legs is not a fun place to have eczema, and many women feel embarrassed to seek help. Julie Van Onselen explains how to manage eczema in this sensitive area.

In women, genital eczema affects the vulva, vaginal entrance and the anal area, including the skin between the buttocks – and it's surprisingly common. Eczema in this delicate and intimate area can be uncomfortable, very itchy, and embarrassing. It can be distressing and affect relationships and sex lives. This article will cover eczema of the female anatomy in adults.

What is female genital eczema?

Genital eczema is often part of atopic eczema. It may affect adults who had childhood atopic eczema and can be triggered by a range of things, including soaps or bubble baths, personal products such as feminine wipes or deodorants, sweating or pee and poo (especially if someone has incontinence).

Occasionally, it may be due to contact dermatitis – a hypersensitive reaction to a certain ingredient in a product – perhaps something you use on your genitals or even on your hands (nail varnish can be a culprit), which becomes an allergic reaction. If contact allergic dermatitis is suspected, your healthcare

professional will refer you to dermatology for diagnosis by patch testing, to help you learn what to avoid.

If you think you have genital eczema, you need to see a healthcare professional. Do ask for a face-to-face appointment, as you will need a genital examination. It is important to confirm a diagnosis, as there are other conditions that can cause of genital itching, which you need to exclude or get treated.

Other causes

There are many causes of genital itching and reddened or darkened skin in the genital area. These include sexually transmitted diseases and common fungal yeast infections (such as candida, also known as thrush). Other less common skin conditions that specially affect the vulva include psoriasis, lichen planus and lichen sclerosis.

The menopause causes vaginal dryness, and this can irritate the vulva and anal areas too.

Your healthcare professional may refer you to a dermatology department that runs dedicated vulval clinics that may be run by female dermatologists and nurses. If your diagnosis is in question, a small punch biopsy of your skin may be taken.

Treating female genital eczema

If you are given a diagnosis of genital eczema, it is important to treat this delicate area appropriately and avoid irritant triggers.

Emollients

Moisturising is the first-line treatment to address dryness and itch. Choose an emollient formulation that you find most comfortable. Creams and ointments are available but many women prefer lotions or gels as they absorb well in hairy areas and can be kept in the fridge to cool irritated skin. You need to use emollients for washing, avoiding soap, cosmetic perfumed washes and bubble baths, and moisturise frequently. You can use the same emollient for both. Keep using your emollient every day, even when your eczema has settled.

Topical treatments

If genital eczema becomes sore, itchy and red or darkened, this is an eczema flare and needs treating with topical steroids. Topical steroids are safe to use in the genital area as long as they are the correct strength (generally, moderately potent, although if eczema is more severe a higher strength may be prescribed) and used correctly. The genital skin absorbs topical steroids more readily than other parts of the body, so they must be used carefully in this area.

Topical steroids are generally used once a day. Ointments are recommended, as they contain less preservatives, but you can use creams or lotions if you prefer. A short, two-week treatment burst is recommended (applying once a day for the first week and then every other day for the second). However, a two-week course is not always enough, and the eczema may return (which is normal). To gain control, you may need several courses over six months or more. As a guide, a 30g tube should normally last at least three months.

If you are prescribed topical steroids combined with antibiotics for infected eczema, use this for a maximum of 14 days, then return to using plain topical steroids if the eczema is still flaring.

An alternative to using topical steroids is to use one of the topical calcineurin inhibitors – Protopic ointment (tacrolimus) or Elidel cream (pimecrolimus). These are not as effective for a flare, but they can be useful as twice-weekly maintenance treatment. They do not have skin-thinning side effects, so are ideal for long-term use or prevention for more stubborn cases.

Do leave a gap between applying topical treatments and emollients. A 30-minute gap is recommended for topical steroids while for topical calcineurin inhibitors (Protopic only), the recommendation is two hours. Apply them once a day. If you are sexually active, apply them at the other end of the day to the time you usually have sex.

Personal care and practical tips to avoid triggers

There is lots you can do to help reduce your risk of genital eczema or to ease symptoms.

Itching

This is a hugely annoying and embarrassing symptom, which leads to scratching and rubbing, driving eczema flares and potential skin damage. The following emollients include anti-itch ingredients: Balneum Plus, Dermacool and Methoderm. Do avoid vaginal itch-relieving products, as they often contain local anaesthetics, which can cause additional problems in eczema.

Keeping emollients in the fridge helps, as well as cooling pads, which are particularly useful at night, as overheating causes itchiness.

Hygiene

It is important to keep the genital area clean, although washing too much may cause further irritation – especially if you use abrasive sponges or flannels. Wash with tepid water and always use your emollient as a soap substitute, avoiding any other wash products. Be careful with shampoo. You may need to wash hair separately, rather than in the shower or bath.

When you go to the loo, always wipe from front to back and don't use perfumed sanitary products such as wet wipes. Avoid hair removal in the genital area until your eczema has settled. Use your emollient rather than shaving gel and avoid waxing, which is harsh and can trigger eczema.

Underwear

Make sure your underwear is 100% natural fibre (such as cotton, bamboo or silk). Loose-fitting short-style pants can help prevent rubbing. Beware of seams – look for seamless underwear and avoid thongs. Try to reduce wearing tight trousers, jeans or tights, which cause irritation and friction. Wash your underwear on a good rinse cycle to remove washing detergent and avoid fabric conditioner.

Sex

Barrier contraceptives and spermicides can irritate genital eczema, so ask your family-planning healthcare professional to advise you on products suitable for eczema and sensitive skin. Emollients and topical steroid creams can damage condoms and diaphragms and make them less effective, and the cream can be transferred to your partner during sex. So, make sure you don't use topical steroids shortly before having sex.

Some women find lubricants help, as they reduce friction. If you use them, go to water-based options, which are less irritating than silicone based, and make sure they are unperfumed and do not irritate. Your emollient can also be used as a lubricant.

Piercings and tattoos

Body piercing does not cause eczema, but it can lead to problems. Nickel allergy is very common and this is greatly increased with body piercing and cheap metal jewellery. Having a tattoo close to, or on, the genitals increases the risk of developing contact allergic dermatitis to dyes, especially PPD (p-Phenylenediamine). This is particularly the case when black henna or dye is used. There is also a high risk of pierced and tattooed areas becoming infected.

Find out more

The NES has online factsheets on female and male genital eczema at: **https://eczema.org/information-and-advice/types-of-eczema/**

'Eczema **doesn't** define me'

Hannah Kunzlik (30) explains that chronic lifelong eczema is just one part of her story.

I've always known my limitations. That's not me being negative – far from it. It just means I know that backpacking around remote parts of Africa isn't compatible with my skin.

But eczema hasn't stopped me from building an incredibly full, varied and enjoyable life, designed around its needs and mine. After all, there's far more that I can do than I can't, and eczema doesn't define me as an individual.

First memory

Although I developed eczema at 18 months old, my first real memory is when I was five, when it suddenly took a major turn for the worse. I'd caught impetigo and was in a

really bad state. When my mum and dad called the GP, they were told 'Little kids make a big deal of nothing' – even though, by this point, I was complaining of double vision.

Next day, I woke up and the entire right side of my body was an open wound. A GP home visit prompted a rapid transfer to the hospital, where I was placed in an isolation ward. My skin was weeping, so my pyjamas stuck to it. I was crying and screaming, but the nurses seemed too scared to help. My parents had to step in, until a nurse made of slightly sterner stuff came in a few days later and took charge.

It's funny how children remember things differently. While I'm aware of all this, my abiding memories of the experience are that I got a TV all to myself (previously I'd had to share with my brother), everyone in my class sent me a card, and Santa visited and brought me a present!

False hope

Two years later, my eczema went into retreat, leaving me with dry, sensitive skin. It appeared that I'd 'grown out of it', as people said I would. However, aged 12, fuelled by puberty, it came back with a vengeance and hit me like a train. Wherever I had skin, I had eczema.

I understand why people want to give small children and parents hope that the condition will disappear as they get older – but for people like me, it sets you up for a huge fall when eczema sweeps back in again and takes over. It would be far kinder to offer a realistic assessment that it *might* go away, or it *might* go away for a time, only to come back later, or it *might* not go away at all.

Ultimately, it's much easier to factor eczema into your life plans from the start, rather than having to make major changes to accommodate it later.

Not the best days of my life

I don't know how I managed to go into school every day. I'd come home in tears, partly from the physical pain of horrendous eczema, but also because of what the other pupils had said.

I had a 'granny walk', as I couldn't move properly due to the skin splitting. I couldn't turn my neck, as the skin was so sore and tight. Classmates didn't want to come close as they viewed my eczema as 'gross'. I was literally a walking target. It wasn't one person, either. It was bullying on a massive scale – even kids in other years got involved.

Worse still, I got into a painful cycle where my skin had a huge impact on my mental health, which then had a negative impact on my skin, which then led to a further deterioration in my mental wellbeing.

Safe spaces

I wasn't completely alone, though. I had one friend in school and a couple outside of it. I'm still friends with all three. They've always seen eczema as just another part of me, and it was never an issue.

I was also a freakishly mature child and found it easy to befriend adults. I got on incredibly well with my piano and clarinet teachers and I found their lessons somewhere I could relax and have really good conversations. In truth, I never practised outside of lessons, but I always remember their rooms as safe spaces where I could be 'me'.

At 14, I joined Amnesty International and was the youngest there by decades. Everyone was lovely, though, and this became another safe space where I was 'Hannah', not 'Eczema Hannah'.

Game changers

I will always be grateful to the amazing dermatologist I met at this point, for really listening to me. On top of my emollients, topical steroids and antihistamines (to help me sleep), they prescribed phototherapy, which made a significant difference to my skin's appearance and condition.

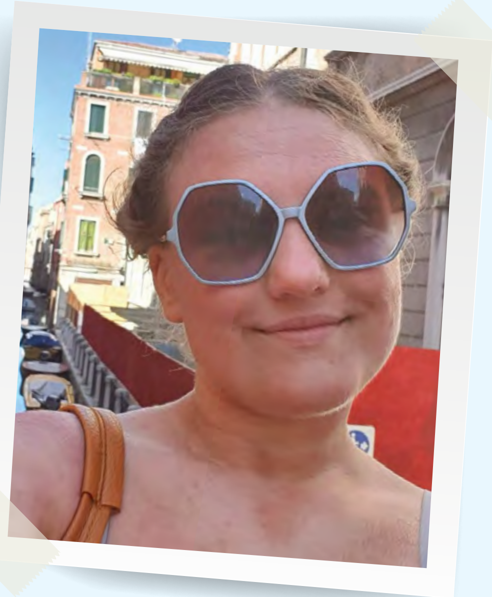
Crucially, they also referred me for cognitive behavioural therapy (CBT). It was supposed to help me with scratching but, once I met the psychologist and talked about the bullying and resulting panic attacks, they could see that I was suffering from anxiety and depression.

The sessions made an enormous difference to my life, and suddenly I had a bit more confidence. I was still having a really tough time, but now I had tools to help me.

Mindful visualisations, relaxation techniques and mantras were accompanied by exercises. For example, before, I'd automatically think I was going to be a target because of my skin. These techniques helped me reprogramme that thought process and see that this didn't have to be the outcome. I also learned tapping techniques to help turn off my stress response, which also helped me to feel in control. My life was literally transformed by these two specialists.

A whole new world

One of the best decisions I've ever made was to take a gap year between school and university. It gave my confidence another huge boost and really helped with the transition between the two. I took French classes, learnt to sew, pursued my love of



creative writing and spent one month in Brussels and another in Germany – with a suitcase crammed full of creams in tow!

Because of my experience at school, I headed off to university thinking I wouldn't make friends, so it was a surprise to me when I did. Although my eczema made my life very different to that of other students (especially the associated admin, like having to plan everything in advance and going home in between lectures to apply cream), they just accepted it, and me.

I was recently a bridesmaid for one of my university friends, and it meant the world when she went to great lengths to source 'team bride' pyjamas and dressing gowns in 100% cotton – which are almost impossible to find – not just for me, but for everyone. She did it without even mentioning it to me, because she knew I wouldn't be able to wear synthetic ones, and she wanted us all to have the same.

Never looked back

Since graduating, I've had good skin years and bad, but I've never gone back to the dark place I was in at school. I've moved around a lot, including abroad with work – which saw me based for six months in Washington DC – which has caused problems with continuity of care and health record transfers.

Eczema has shaped my career. I knew I'd never be able to take a field-based role and always accepted I'd be in an office in a city. I've loved every job I've had, though, and am still able to work in an area I'm passionate about.

Luckily, I've always had supportive employers, and working from home since Covid has been amazing. I can put on cream whenever I want, in comfort, without having to lock myself in an office toilet for an hour.

Giving back

Last year I became a trustee of National Eczema Society. My mum and my aunt – who also has severe eczema – have been members of the society for years, and it's a cause I really believe in.

I know first hand how it feels to be isolated because of this incurable condition. That's why I want to help make our organisation as accessible and as relevant as I can for the eczema community, so that nobody feels alone and unsupported and everyone feels represented.

Letters

Do you have ideas or experiences you'd like to share, a question you'd like to ask or an important point to make? Can you help answer questions that others have raised?

Our letters pages offer members the chance to share information. Please do get in touch if you'd like to join the conversation.

You can email us at **exchange@eczema.org**

Or write to: Editor, *Exchange* magazine, National Eczema Society, 11 Murray Street, London NW1 9RE.

The views expressed in the letters pages are not necessarily those of the Society. See our disclaimer on page 3.

Reader recommendations ☆☆☆

Thank you for your responses to Janet Wood's request for shampoo recommendations, Exchange September 2022.

Eczema-friendly shampoo

I suffer from seborrheic eczema and these two shampoos work for me:

- ✓ Sebclair to treat the problem; I find it calms the scalp, stops the itching and gets rid of the flakes, although that takes a few washes to work. The downside is that it costs about £15 for 100ml, and you need to use a reasonable amount, so it isn't cheap. I've only seen it available online.
- ✓ Sebamed as my everyday shampoo. It doesn't irritate my scalp at all and is inexpensive.

Bryan from Dennington

I use E45 Dermatological Dry Scalp Shampoo on my toddler, and for me too. It's also worth trying Skin Shop (**www.skinshop.co.uk**) products. I used these for years until I found the E45, which actually works even better than these!

Angela from East Sussex

Letters

Reader tips ☆☆☆

Eyebrow rescue

I have had eczema since childhood. I cope and have learnt things over the years that help me. One of my issues in later life has been night-time scratching while asleep in bed. I don't realise I am doing it, and as time has passed, my eyebrows have been rubbed away. I see it and it affects my self-esteem.

I have started to make a bandage like rugby players wear, using soft bandages and electrical insulating tape wrapped around the outside to fix it together. I can use the same one for several days and then replace with a new one. It fixes over the face, covering the eyebrows horizontally, all the way round the head, positioned so I can still see. I wear it when I go to bed, and it has to be tight enough to remain in place but not too tight to give me an unpleasant feeling.

Over the last weeks my eyebrows have recovered noticeably – not fully, but better than they were.

I know this will not suit everyone, but if it can help a few people that would be lovely.

John from Ludlow

Looking for recommendations ☆☆☆

Light emollients

I've had eczema all my life and my skin is always dry. It's worse in the colder, winter weather and especially as we move into spring. I need to use emollients three or four times a day, sometimes more when it's really bad, otherwise the itch is unbearable.

I use an emollient ointment when I'm at home and at night, when it doesn't matter as much what clothes I wear. I work, though, and need to look reasonably smart when I go into the office. The lighter emollient I have used for ages doesn't seem to work as well now, and I need to find another brand that soaks in easily and won't mess up my clothes. I'd appreciate any suggestions from members for lighter emollients and whether they are able to get these on NHS prescription, thanks.

David

LEGACIES AND IN MEMORIAM

♥

We are very grateful for the thoughtful legacy gifts received from the late Mr Anthony Hawley and the late Mrs Ena Reeve.

Legacies are such an important source of donations for the Society and are a wonderful way for supporters to make a lasting difference for future generations. Among other things, we need funds for research to find new treatments and ultimately a cure for eczema.

We also appreciate the generous donations made at funerals and at other in-memoriam events and anniversaries, in honour of National Eczema Society supporters who have passed away.

Many thanks to the family and friends of the following Society supporters for your support: Margaret Mayer, Mrs Janis Wallace, Mr Anthony Mercer, Mrs Betty Newbury, Mr Robert Kennedy, Mrs Marina Sibley, Mr Edward Jacyshyn and Lord Trevor David Oades.

A GIFT IN YOUR WILL

Leave a gift in your will and you'll make a significant contribution to improving the lives of people affected by eczema.

Over the years, National Eczema Society has often been remembered in the wills of members and supporters – on occasion, very generously. This money is crucial in helping to give us the financial stability we need to continue and grow the services and support we provide on behalf of the millions of people living with eczema.

We know from talking to our members and supporters that many more of you would like to continue to support National Eczema Society for future generations, in the form of a legacy. However, without a will in place, these kind intentions come to nothing.

Your gift – large or small – will bring help to people like Ryan's mum:

'Without the Eczema Helpline when Ryan was little, I don't know what I would have done.'

Will you consider including National Eczema Society among those you want to help?

Remembering us in your will would make a lasting impact, benefiting many people.

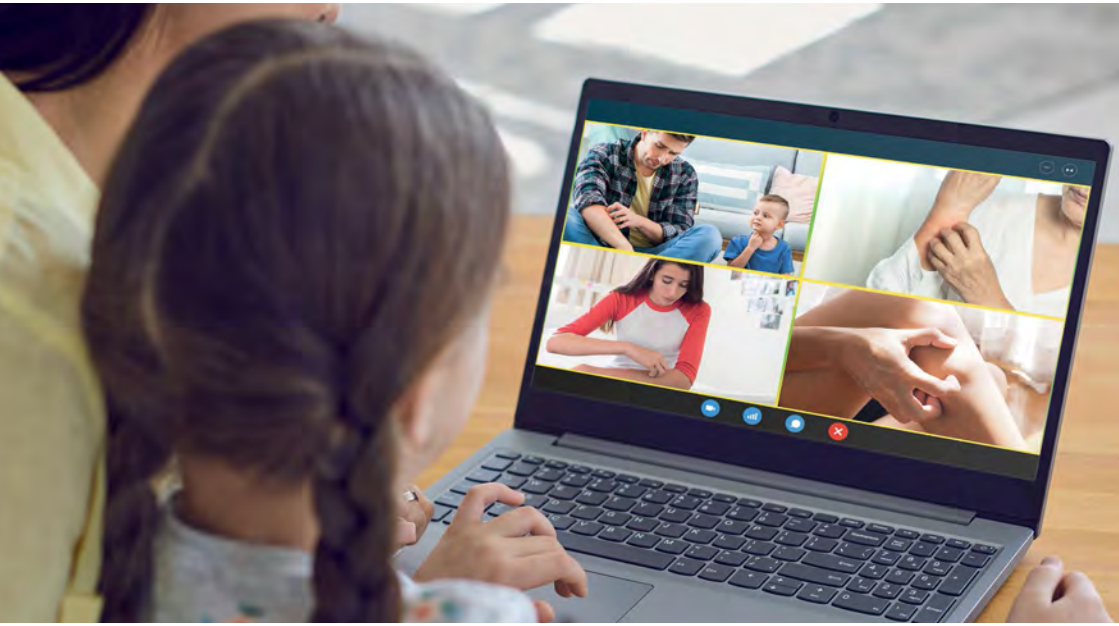
How to include a gift in your will

Including a legacy to National Eczema Society is straightforward.

- **Simply tell your solicitor** of your wish and our name, address and Charity Registration Number:

  National Eczema Society
  11 Murray Street, London NW1 9RE
  Charity Registration Number
  1009671 in England and Wales
- **Anyone can leave a legacy** and every bequest is important, no matter what its value.
- Legacies to charity are also **tax free**.
- If someone leaves **10% of their estate to charity**, any inheritance tax due on the rest of their estate is then charged at 36% instead of 40%.

When the eczema is itchy...



...it may be time for an emollient with added antimicrobials

- A type of bacteria (called *Staphylococcus aureus*), gathers on areas of eczema and often aggravates itch.
- The antimicrobials in **Dermol** reduce the amount of this bacteria on the skin.
- The emollient oils in **Dermol** soothe and rehydrate dry eczema skin.

Dermol®

A family of **antimicrobial** emollients

WASH SHOWER LOTION CREAM BATH

Specially formulated
for sensitive skin

Ask for 'Dermol' by name at your local pharmacy

Always read the label. Dermol is only available from pharmacies.

'Dermol' is a registered trademark. Date of preparation: September 2021. Further information is available from the Marketing Authorisation Holder: Dermal Laboratories, Tatmore Place, Gosmore, Hitchin, Herts, SG4 7QR.

Adverse events should be reported. Reporting forms and information can be found at www.mhra.gov.uk/yellowcard. Adverse events should also be reported to Dermal.

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