



It's  
good  
to talk

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**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'

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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](http://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

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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.



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