



EOS privacy statement for children of EOS members (aged 12+)

Why does EOS know stuff about me?

When your parent or guardian signed up as a member of EOS we asked them for information about you and your eczema. We can only try to help you and the rest of your family manage your eczema if we know what is going on. For example we would only make suggestions about how to deal with the itch at night if we know that this is a particular problem for you.

It is EOS's job to make sure that any information we have about you and your family is kept safe and we are registered with the Information Commissioner's Office under registration number ZA 131266

What exactly does EOS know about me?

We know **your name, your birth date and your sex**. This makes it easier to talk to your parent/guardian or you directly about your eczema. We need to know your birth date so that we can send stuff to you that is best for your age (for example if you are 14 years old you would probably rather have information about other teenagers with eczema than a picture book about a dinosaur with eczema)

We ask your parent/guardian to tell us what **treatments** you have had for your eczema. We are not trying to be nosy, but knowing this information makes it easier for us to help. Different things might be helpful to you if you are on tablets that act on your immune system compared to another young person mainly having to moisturise.

Your parent/guardian might also have told us **other things strictly relating to your eczema**, for example we might have talked about it if you are finding it impossible to sleep because of a flare or if your school is not being helpful at all about your eczema. When we know this information we can try to help by making suggestions to your parents about different things to try to calm the flare down, or what it might be best to say to the school.

We only talk about things that have to do with your eczema or anything that might make your eczema worse or better.

If you are over 13 you might have joined the **Instagram group**. Any information you post there is yours and you can delete it. We don't copy it or put it anywhere else.

You might have downloaded the **EOS app**. Any communication you post in there you can also delete. No information is transferred outside the app.

Do you have pictures of me?

No. Unless you have specifically given us permission to take and keep photos if maybe you came to an event or you have helped us by telling your story to a newspaper.

Who else do you talk to about me?

Other than your parent or guardian who signed up as a member we don't talk to anyone else about you or give any information out about you unless we have agreed it with you first.

If your school were to do some eczema training with EOS we might mention that we know there are young people with eczema in the school, but we would never single you out or pass on any information you wouldn't want the school to know. We would only talk about your specific situation with the school if you had agreed to it.

Who can see information about me?

The information is stored in the cloud, but only people who work for EOS can see your information, no one else has access to it. We work very hard to keep it safe so that hopefully it can't be stolen or shared.

Will this information about me stay with EOS forever?

No.

When you turn 18 your parent/guardian is no longer able to be a member of EOS (unless you also have a younger brother or sister with eczema, then the membership can last until they turn 18). That means your parent/guardian will become an ex-member. 3 years after someone has become an ex-member, we delete all personal information about them and their children from our system.

Your parent can also tell us before you turn 18 that they no longer want to be a member, and they would become an ex-member straight away.

What if I don't want EOS to have my information?

If you are unhappy that EOS knows about you and your eczema then you have certain rights, such as:

- The right to ask for a copy of all information we have about you, (although sometimes we might have to ask for money from you to do this). This means that you can send us a letter or an email telling us what information you would like a copy of. We might also have to ask for ID. We then have to send you this information within one month or explain to you why we can't give you the information.
- The right to object. This means that you can send us a letter or an email asking us to remove the information from our database. We may not be able to remove your information straight away, but we will talk to you about the information that we have, answer any questions you might have about it and decide what to do.
- the right to request rectification and restriction of processing of your personal data. This means you can tell us if we have the wrong details about you and we then have to correct the information.

Any letter should be sent to Eczema Outreach Support, Tam Dalyell House, 93 High Street, Linlithgow, EH49 7EZ or email info@eos.org.uk.

You can find more information about your data and your rights from the website of the Information Commissioner's Office <https://ico.org.uk/your-data-matters/>