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# CHANGE AD TOGETHER

A guide for parents, guardians and caregivers of children with atopic dermatitis (AD), a type of eczema.



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## HOW TO USE THIS GUIDE

**We're here to make things a little easier for you and your child.**

While a lot of the information is for you, we've also added some content specifically for the child in your care.



When you see our **caregiver icon**, that means the information is **for you**.



When you see our **child icon**, that means you can share the information **with your child**.

Looking after a child with atopic dermatitis (AD) can be time intensive and emotionally demanding. Sometimes, you might need support too and it might help to know that you're not alone.

In fact, AD is the most common form of eczema, affecting 15-20% of children worldwide.<sup>1,12</sup>

# TOGETHER, YOU CAN CHANGE AD





# UNDERSTANDING ATOPIC DERMATITIS

**When caring for a child with AD, it can feel like you need to become an expert in the subject. Naturally, as a parent or caregiver, you'll likely spend a lot of time trying to find the right advice and information to help ease your child's discomfort. Late night online searches, texts to your family and friends, anything you can think of to make sure you're doing the right thing for them.**

This section of the guide will help you better understand AD and what causes it. You'll be able to have more confident discussions with the child you care for, as well as with their doctor. **So, let's break down the science of AD.**

## The fundamentals of AD

AD is just one of several different types of eczema.<sup>2</sup> It is characterised by intense itch, dry skin and a negative impact on quality of life.<sup>3,4</sup>

AD can be a chronic (long-lasting) condition, which means while some children may grow out of it, others might have it for life.<sup>6,12</sup> In some cases, especially if your child's AD is severe, it helps to talk to your doctor about options to achieve long-term control,<sup>4</sup> so you and your family can live the life you want and deserve.

Most patients with AD have only mild disease. For those with moderate-to-severe illness, however AD can disrupt far more than the surface of the skin, taking a toll on daily activities, sleep, mental health and beyond.<sup>4</sup> But that disruption isn't limited to just the person with AD. As you know, it can affect your life in many ways too.



## Inside the body

Both genetics and the immune system play a role in AD.<sup>5</sup> An imbalance in the immune system causes persistent underlying inflammation throughout the body, meaning that even though your child's skin may appear clear at times, there is still inflammation beneath the surface, which is why unpredictable AD flares can keep occurring.<sup>6,7</sup> So even if your child is having a good day, week or month with AD, it's important to know that AD may still be there – along with that underlying inflammation.

### Okay, but what actually is inflammation?

Inflammation is one of your body's processes of fighting against things that could harm it.<sup>8</sup> When something recognised as harmful is present, your body releases chemicals that trigger a response from your immune system.<sup>8</sup> For people with AD, there may be constant inflammation within the immune system, even if you can't always see the visible signs on the surface.<sup>9</sup>



## Outside the body

External factors in your environment also play a part in the way AD affects your child's life, sometimes triggering symptoms.<sup>5,10</sup> These triggers can vary from person to person, and the lag time between their exposure and symptoms can make triggers difficult to detect.<sup>10</sup> It can seem like you need to control every bit of their environment to improve their AD, but changing your lifestyle to avoid triggers won't address the underlying causes.<sup>10,11</sup>

### Where this leaves you

The truth is, neither of you should have to compromise your daily life when it comes to managing the condition. The good news is that the landscape is changing. We now understand more about the underlying causes of AD. And there are treatments out there that may make a meaningful difference. So, working with a dermatologist, there could be an opportunity to help your child live a life less impacted by AD.



## WHAT AD LOOKS LIKE IN CHILDREN

**Recognising the signs and symptoms of AD can help you understand what your child is going through, so that you can better support them.**

In infants under 6 months old, AD usually appears on the face, cheeks, chin, forehead and scalp.<sup>15</sup> However, it can spread to other areas of the body.<sup>15</sup>

In babies aged 6 months or older, AD typically appears on the face, or on the elbows and knees — places that are easy to scratch and rub as they crawl.<sup>15</sup> If the skin becomes infected, it may form a yellow crust or small bumps of pus.<sup>15</sup>

Once a toddler, your child's skin may start to look dry and scaly, becoming thicker if they scratch and itch too much — this is called lichenification.<sup>15</sup>

In children aged 5 years or older, AD usually appears in the folds of the elbows, hands, and knees.<sup>15</sup> Rashes and itchy patches behind your child's ears, or on their feet or scalp, may also be a sign of AD.<sup>14,15</sup>

It's important to remember that despite all this, the appearance of AD can differ from one child to the next.<sup>16</sup> Every child and their AD is unique.

So, whatever their AD symptoms appear, tell your doctor — because the clearer the picture they have, the better they can manage your child's AD.

### **Physical symptoms in children include:<sup>13–16</sup>**

- Itchy skin, exaggerated by scratching
- Trouble sleeping due to itchy skin
- Rashes, appearing more purple, brown, or grey in darker skin tones and red in lighter skin tones
- Skin that's very dry or scaly
- Open, crusted, or weepy sores

## HOW AD CAN MAKE YOUR CHILD FEEL

**The impact of AD isn't only physical — it can also affect their quality of life.<sup>4</sup>**

**These are just some of the ways your child could be affected:<sup>4</sup>**

- They might lose confidence in the way they look, or their self-esteem might take a knock
- Sometimes, spending time with friends or making spontaneous plans can become harder
- They might not feel happy and comfortable wearing the clothes they love
- Their sleep can be affected by their AD
- On bad days, they might find it hard to concentrate in lessons, or they might not be able to attend school

**What this means for you and your child.**

AD can take a toll on both of your lives, but you shouldn't have to compromise living well when it comes to managing AD. Though there isn't currently a cure for AD, our understanding of the condition is progressing, and there are treatments available that have been shown to improve patient quality of life. Speak to a doctor or dermatologist to find out more.

**Together with your doctor or dermatologist, you can get closer to finding the long-term control your child deserves.**

**HOW YOU FEEL  
MATTERS JUST  
AS MUCH AS  
HOW THEY FEEL**





## HOW THEIR AD AFFECTS YOU

We've spoken a bit about the impact AD has on the child in your care, but now it's time to focus on you. Every day you work incredibly hard to protect and support a child with AD, while also trying to keep your own life ticking along. So, don't feel guilty or worried that you're not doing enough.<sup>17</sup> We bet you're doing an amazing job.

If your child has moderate or severe AD, your life might have changed in a number of ways and it may have taken a toll on your physical and mental health.<sup>3,17</sup> It really is true that when you see your child suffering, you do too.

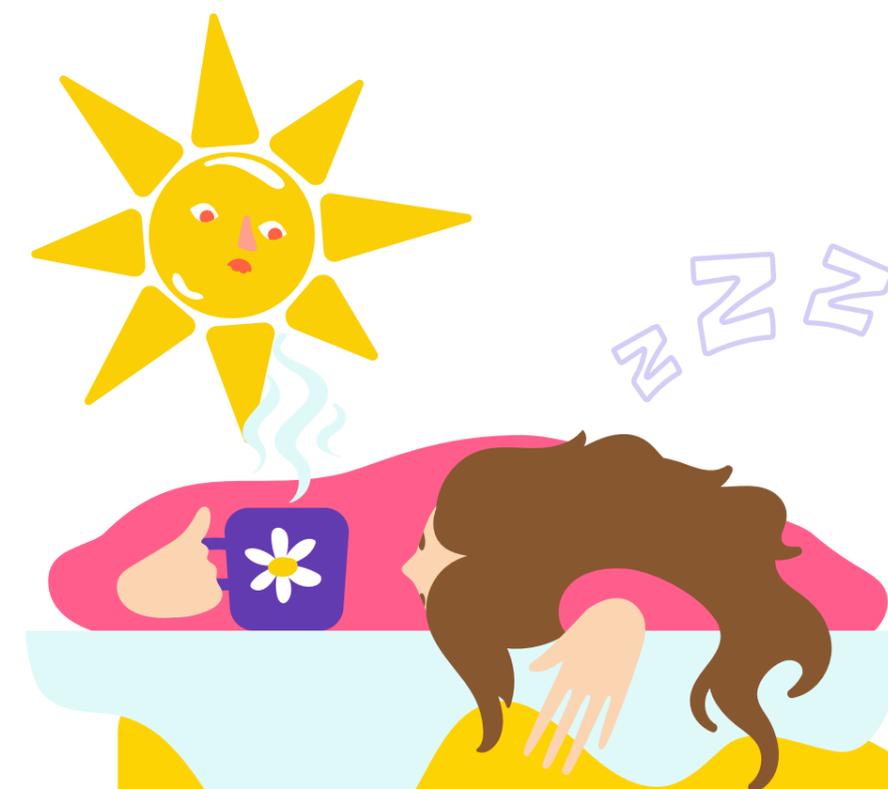
Maybe it's a lingering feeling of stress, or feeling like you have less energy to live your own life. The truth is, looking after a child with AD can really take it out of you.

You have so much to think about as a caregiver, but you can't pour from an empty cup. That's why finding a treatment that proactively manages your child's AD is so important – because ultimately, long-term control benefits you both. So keep talking to your dermatologist about long-term, proactive approaches to managing their AD.

### Ways that your life might be impacted:<sup>3,17,19</sup>

- A lack of sleep for both you and your child, which can really affect your mood
- Losing time to socialise or the ability to make plans in the spur of the moment
- Your productivity could be impacted
- Emotional upset, distress, guilt, exhaustion
- Strain on people around you, including your partner and family

A study found that **46% of caregivers have anxiety about their child's future with AD.**<sup>4</sup>



**In the same study it was found AD can affect around 67 nights of your sleep per year.**<sup>4</sup>

So, if you're feeling tired, we get it.



# TALKING TO YOUR CHILD ABOUT AD

**AD can be hard to wrap your head around as an adult, and to understand the science enough to explain AD to your child is even harder. So, we've simplified the science. You can read the next pages with them, or even let them read through in their own time. And hopefully, it'll make those sticky AD questions far easier for you to answer.**

## Let's talk itch

We know that tackling that constant, hallmark itch might be tiring for you and your child.<sup>6,14,19</sup> You might catch yourself saying 'stop scratching', and you might even hear medical professionals say the same. But we know it's not quite as simple as that. The intense itch that comes with AD is driven by underlying inflammation beneath the skin, and unfortunately it won't necessarily go away if you simply ignore it.<sup>6,7</sup>

## A new perspective

Our aim is to shift the child's view of their AD from 'harmful or angry' to 'protective and overactive' instead. This could help both you and your child to be a little kinder to yourselves, knowing that their immune system just works slightly differently to people without AD.

### Explaining AD to the child in your care could help them to:

- Grow up with a good understanding of their condition
- Understand that AD isn't their fault, or yours
- Navigate conversations about AD and explain their condition to other children and adults clearly
- Build confidence, allowing them to feel more comfortable when interacting with others or living their daily lives

**Instead of "don't scratch your skin", you could ask "is your AD bothering you? What can we do about it?"**





# AD EXPLAINERS

**Let's be honest – AD can be tricky for kids and teenagers to understand.**

So this section is a chance to help them see how it actually works.

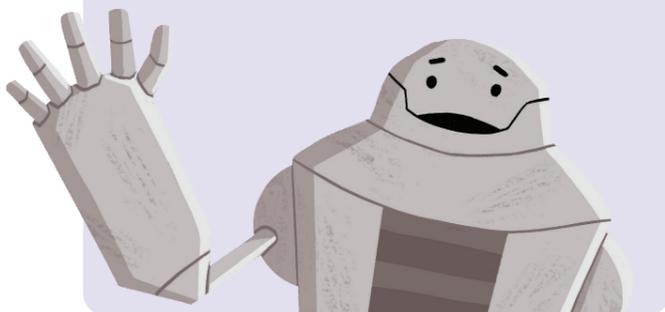
We've created two mini-stories that gently guide them through the science of AD. When you get a quiet moment, why not sit down together and go through them. Hopefully, it'll help change the way they see AD.

**For kids (6 – 11 years old)**

Pages 18-23

**For teens (12 – 17 years old)**

Pages 24-27



## Hi, I'm Flo, nice to meet you!

Someone told me that you have eczema too, just like me. I've had it for a little while now, and the itching and irritation can make my life a bit harder sometimes. It helps to know why my eczema is happening. So, I'll share with you what I know, and hopefully it'll help you too.

A few things can cause your eczema, and one of them is your immune system.<sup>5</sup> Everyone has an immune system, and its job is to protect us from germs.<sup>8</sup>

I think of my immune system as a personal guardian, just like this robot. It's always there and its job is to protect me, but sometimes it can be over-active.<sup>8</sup>



I need to pack my bag for school, but sometimes my eczema makes it hard for me to do things.

You see, eczema happens because your immune system is trying to protect you from harm, but in our case, it gets sensitive and thinks that things might hurt you.<sup>9</sup>

Sometimes my eczema gets quite bad, which is called a flare.<sup>14</sup>

It makes the itchy patches on my skin worse and I start scratching even more.<sup>13</sup> Flares happen because our immune systems are over-active.<sup>9</sup>

The itch can be really distracting,  
and it can make me lose focus when I'm  
trying to paint or do my schoolwork.



Sometimes, I feel like I'm the only kid in the world with AD.

**But that's not true!**

All around the world there are other children like you and me who also have eczema.<sup>1</sup> There might even be some at your school.



When I get home from school, I make sure that I've used my eczema treatments.

It's important to take my medicine, even if it means I have to wait to do my painting, because it can help my eczema to get better.<sup>11</sup>



Some days, I feel okay about my eczema.

**But sometimes,** it can make me feel sad. A lot of people ask me about my skin, or tell me to stop scratching, which makes me annoyed because I can't just stop.

If you ever feel the same, you should talk to someone in your family, I'm sure they'll be able to help too. Now, I've got to go and finish my painting, I reckon it's going to be the best one yet.

It was nice to meet you!

# WHAT IS AD?

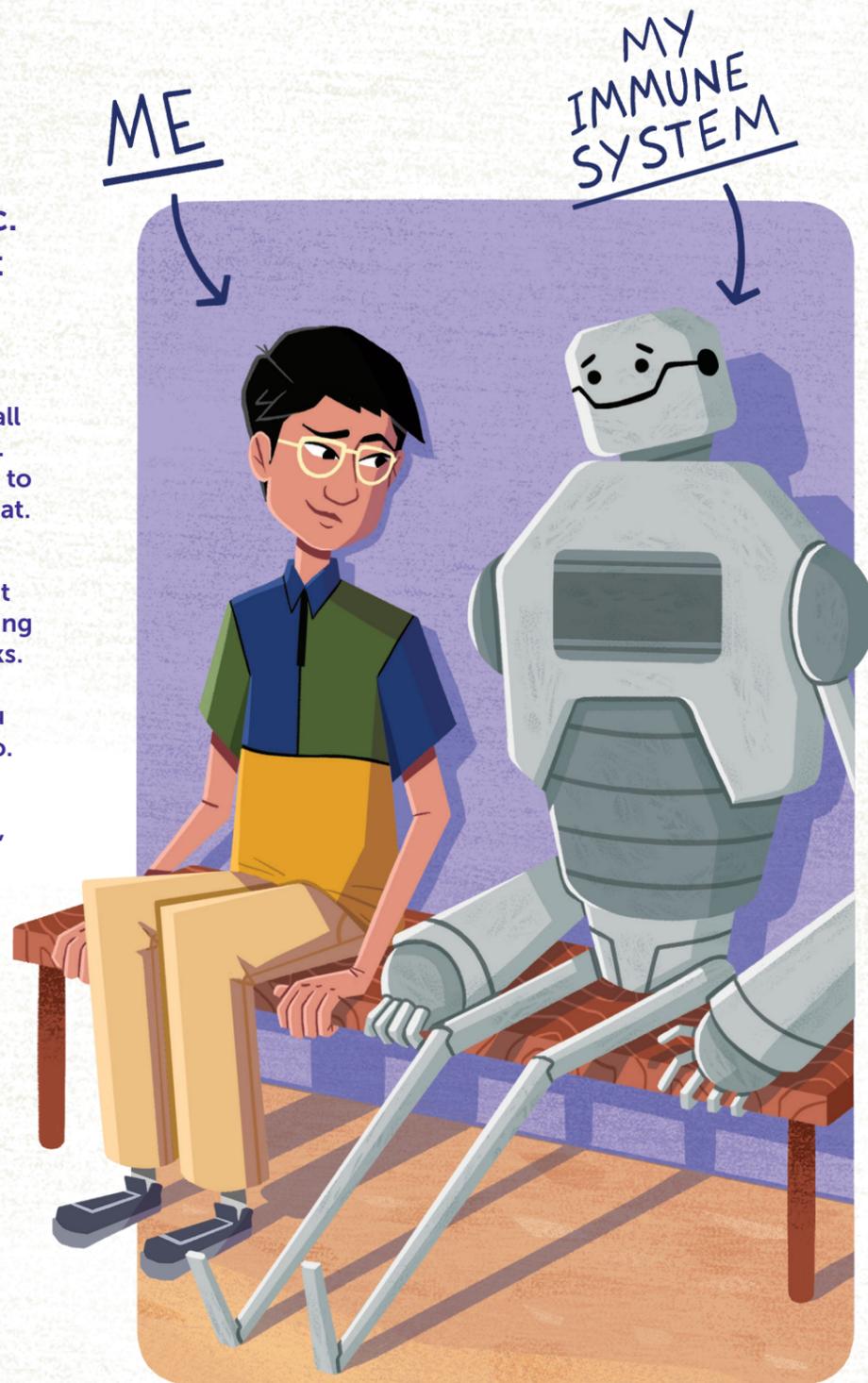
Hey there, I'm Eric. I heard you've got atopic dermatitis, just like me.

You might hear people call it eczema but I call it 'AD'. Whatever word you want to use, we're in the same boat.

I've had AD for as long as I can remember, and I just turned 14, so I know a thing or two about how it works. Plus, I'm really good at science, so I can help you learn the basics of AD too.

AD is actually the most common type of eczema, and it's caused by a few things.<sup>1,16</sup> That includes the environment, our genetics, and our immune system.<sup>5</sup>

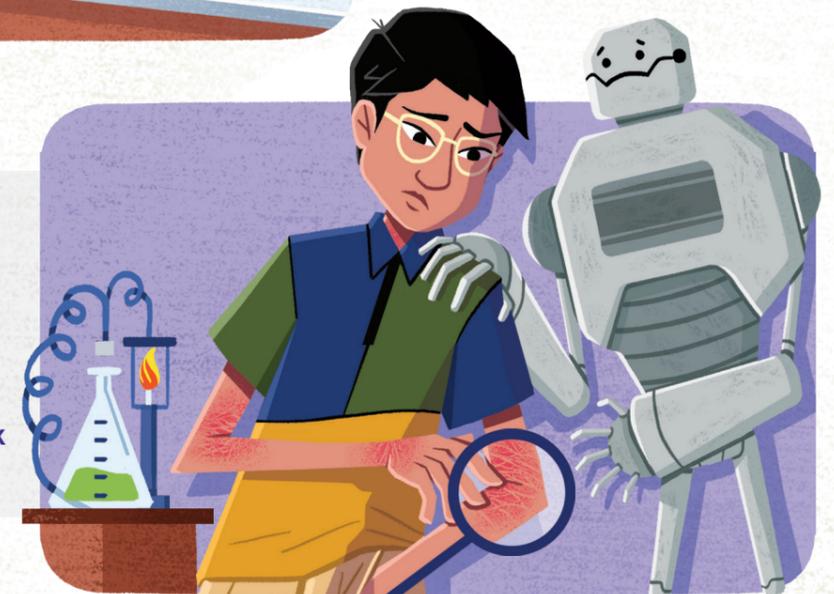
To make things simple, I think of my immune system as a personal guardian, just like this robot.



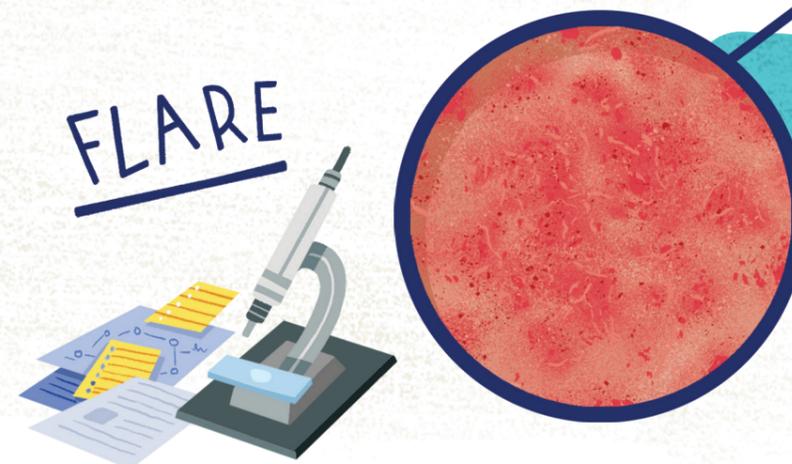
Everyone has an immune system that's supposed to protect us from viruses and bacteria.<sup>8</sup> But in people with AD, the immune system works a little differently.

Ours can be over-active towards certain things.<sup>9</sup> Thanks to AD, our skin can look a little different.<sup>9,14</sup> It might make you feel self-conscious, I get that too.<sup>4</sup> But we shouldn't have to feel ashamed about the way our skin looks.

AD damages your skin, making it feel dry and itchy, with red or purple rashes.<sup>14</sup> That itchiness distracts me at times, which really gets on my nerves, especially when I'm trying to get stuck into my science lessons.



FLARE



Some people can live with AD for a long time.<sup>6,12</sup> But some people's AD can get better as they get older.<sup>6,11,12</sup> Finding the right treatment with your doctor can really help, so that AD doesn't take up too much of your life.<sup>11</sup>



Let's take a closer look at what AD looks and feels like.



Your skin probably feels dry and itchy, so naturally you scratch it.<sup>14</sup> This can create patches (technically called lesions) of skin that can bleed and even ooze (this sounds intense, but it's just moisture escaping).<sup>11,14,16</sup>

These patches can harden and make you want to scratch even more.<sup>11,13</sup> That's why I get so frustrated when people tell me to 'just stop scratching'.

Sometimes I also have flares, which are times where your symptoms are more severe, thanks to inflammation going on inside your body.<sup>9,14</sup>

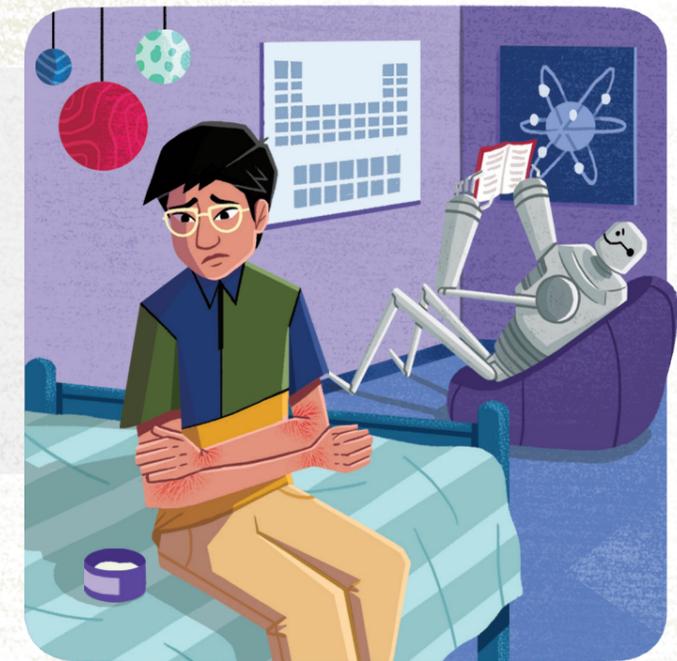
Inflammation happens when your body is trying to fight against harmful things, to try and heal itself.<sup>9</sup> When a potential threat enters your immune system, like an infection, your body releases chemicals.<sup>8</sup> These chemicals trigger a response from your immune system, and that response is inflammation.<sup>8</sup> As a person with AD, you have more of this inflammation in your body.<sup>9</sup>



Having AD can really get me down. Sometimes, I feel like I'm on my own, and you might feel that too.<sup>4</sup> But we aren't.

1 in 5 children have AD.<sup>1</sup> That means, in a school with 1000 students, there's roughly 200 children who also have AD.<sup>1</sup> So chances are you'll know someone with AD, just like I do.

When I get home, I make sure I treat my AD. Even though I want to chill and play guitar, I know it's important to keep on top of treating my AD, otherwise my flares will keep coming back.<sup>11,14</sup> I make sure to keep an eye on whether my treatment is helping my AD or not, so I can let my dad and doctor know.



AD can really take a toll on me sometimes. I find that it really helps to talk to my dad or my friends about how I feel. If AD is stopping you from doing the things you want to do, or if it's getting you down, you should speak up. Your family, friends and doctor are all there to help you live a life beyond AD.



# MANAGING YOUR CHILD'S AD

**You're already spinning a lot of plates when it comes to managing your child's AD. Their mental welfare, their appointments, avoiding triggers, applying treatments. But the one thing that may help to lighten the load is finding the right treatment for your child.**

You might be used to helping them apply moisturisers every single day. And while this helps, we know that treating AD only at a surface level does not target the underlying causes. So, they might not fully prevent flares from happening in the future. But you shouldn't have to settle for only temporary relief.

If your child's current treatment isn't effectively managing their AD symptoms, you should speak to a dermatologist about finding a treatment approach that gives you and your child long-term control of the itch.

But managing AD isn't just down to you. It's a team effort. So keep working closely with your dermatologist to get to where you want to go. After all, while you know everything about your child, your dermatologist knows how best to treat them. By working together, you can try to manage your child's underlying, overactive immune system, to keep their AD under control in the long-term.



## Let's get talking

But how do you know if it's time to consider a different treatment? Well, talking to your child is a great starting point. You can ask them simple questions like 'how well did you sleep?' or 'does your skin feel itchy today?' to get a better understanding.



## Atopic Dermatitis Control Tool

If you want a quick way of seeing how controlled or uncontrolled their AD is, use the Atopic Dermatitis Control Tool (ADCT) on the next page. It asks some simple questions that you and the child in your care can answer together. The ADCT gives you a score which you can take to their doctor. They'll use this score to assess how well controlled your child's AD is, and better understand your child's treatment needs.

# CHANGE YOUR UNDERSTANDING CHANGE YOUR MINDSET CHANGE AD



### Understanding your atopic dermatitis using ADCT

Atopic dermatitis (AD) is a chronic form of eczema. It is a common and treatable disease, but it is not always easy to manage, and it may impact your quality of life in more than one way.

Measuring disease control across all areas of life affected by your AD – including visible skin signs, symptoms such as itch and pain, or overall quality of life – can help your doctor monitor treatment response, guide conversations about

optimal care that is right for you, and set achievable treatment goals.

Atopic Dermatitis Control Tool (ADCT) is a tool developed to assist patients and their doctors in comprehensively and efficiently understanding their disease. To self-assess how well controlled your AD is, please answer the following questions. Your responses to ADCT will help your doctor or nurse better understand your treatment needs.

### Step 1: Complete six brief questions about your AD

Please complete the questions below. To use ADCT correctly, you must answer all six questions.

### Atopic Dermatitis Control Tool

Please answer the following questions thinking about your experiences with eczema, sometimes called “atopic dermatitis”

- Over the last week, how would you rate your eczema-related symptoms (for example, itching, dry skin, skin rash)?  
 None       Mild       Moderate       Severe       Very Severe
- Over the last week, how many days did you have intense episodes of itching because of your eczema?  
 Not at all       1-2 days       3-4 days       5-6 days       Every day
- Over the last week, how bothered have you been by your eczema?  
 Not at all       A little       Moderately       Very       Extremely
- Over the last week, how many nights did you have trouble falling or staying asleep because of your eczema?  
 No nights       1-2 nights       3-4 nights       5-6 nights       Every night
- Over the last week, how much did your eczema affect your daily activities?  
 Not at all       A little       Moderately       A lot       Extremely
- Over the last week, how much did your eczema affect your mood or emotions?  
 Not at all       A little       Moderately       A lot       Extremely

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ADCT – US/English

To learn how to calculate your ADCT total score, please turn over to reverse side.

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The Atopic Dermatitis Control Tool (ADCT) was developed to facilitate patient-physician discussion on control of atopic dermatitis. The ADCT is not intended to replace the physician's medical judgment in diagnosing and treating the patient. The ADCT has been scientifically validated to assess atopic dermatitis control status in adult and adolescent patients (12 years and older).

**Step 2: Calculate your ADCT total score**

After you have answered all six questions, use the ADCT table below to calculate your ADCT total score.

- **For each question, your answer is scored between 0 points and 4 points.**  
Fill in the **grey** boxes in the right-hand column of the ADCT table below with the points you scored for each question.
- **The sum of points for your answers to the six ADCT questions is your ADCT total score.**  
Calculate the sum of your points in the grey boxes and write it into the **purple** box at the bottom. Your ADCT total score will be between 0 and 24.
- Note down today's date in the box on the top left. You might want to refer back to the time you recorded your ADCT total score when you speak to your doctor about your AD.

Today's date:	<input type="text"/>					Note your points for each question in the grey boxes
1. Over the last week, how would you rate your eczema-related symptoms?	(None) 0 points	(Mild) 1 point	(Moderate) 2 points	(Severe) 3 points	(Very Severe) 4 points	
2. Over the last week, how many days did you have intense episodes of itching because of your eczema?	(Not at all) 0 points	(1-2 days) 1 point	(3-4 days) 2 points	(5-6 days) 3 points	(Every day) 4 points	
3. Over the last week, how bothered have you been by your eczema?	(Not at all) 0 points	(A little) 1 point	(Moderately) 2 points	(Very) 3 points	(Extremely) 4 points	
4. Over the last week, how many nights did you have trouble falling or staying asleep because of your eczema?	(No nights) 0 points	(1-2 nights) 1 point	(3-4 nights) 2 points	(5-6 nights) 3 points	(Every night) 4 points	
5. Over the last week, how much did your eczema affect your daily activities?	(Not at all) 0 points	(A little) 1 point	(Moderately) 2 points	(A lot) 3 points	(Extremely) 4 points	
6. Over the last week, how much did your eczema affect your mood or emotions?	(Not at all) 0 points	(A little) 1 point	(Moderately) 2 points	(A lot) 3 points	(Extremely) 4 points	
Sum of your points = <b>Your ADCT total score:</b>						

**Step 3: Speak to your doctor about how your AD affects your day-to-day life**

Your AD may not be well controlled if:

- **Your ADCT total score is at least 7 points**  
OR
  - **Your ADCT total score has increased by 5 points or more since you last used ADCT**
- ✓ If you are concerned that your AD may not be well controlled, you should seek medical advice
  - ✓ Bring your completed ADCT with you for your next scheduled consultation
  - ✓ Speak to your doctor about your responses to the ADCT questions and how your AD is affecting you

# IT'S TIME TO GET MORE FROM YOUR APPOINTMENTS



# MAKING THE MOST OF EVERY MOMENT WITH YOUR DOCTOR

**Appointments.** They're one of the most crucial parts of your child's AD journey. But they can be pretty short and it can be tricky to know what to say to get the most out of them. Don't worry, this section is here to help you. If you're feeling overwhelmed, or just want a helping hand, we've got the tips you need.



## Before your appointment

First things first, there's never a wrong time to book an appointment. If AD is affecting their sleep regularly or is stopping them doing the things they love – or if their current treatment just isn't managing their symptoms – you should see a dermatologist. They can help address these challenges and help your child achieve long-term control.

## What to think about

So, what exactly are you going to tell your doctor? It can be hard to know where to start – especially if it's been a while since your last visit. Here are a few questions to think about. It may help to sit down with your child and talk about these questions together.

- How has your AD made your child feel since you last saw the doctor?
- How does AD impact their life every day? Does it impact school? Seeing friends? Sleep?
- Where does AD appear on their body? Has this changed recently?
- How are they getting on with their current treatment?
- What are their hopes with AD?

## Set an objective

Armed with these questions, you'll be in the best position to make an objective for your child's next appointment. This could be discussing treatments or symptoms, but whatever it is, have something to work towards so you can get the answers you need.

## Come prepared

The signs and symptoms of AD can change like the tide, and flares can be unpredictable. Sometimes, your appointment might fall when your child's symptoms are more severe in the middle of a flare-up, but other times the signs of AD may not be visible.

To make sure your dermatologist is getting an accurate look at how AD is impacting your child, it's best to keep track of it. Why not try writing in a journal and bring your notes with you to the appointment.

You could also complete the **Atopic Dermatitis Control Tool** questionnaire and discuss your child's score with the doctor.



## During your appointment

Be honest and open. Your doctor is there to help you and your child manage their AD better, so speaking up when something is going wrong (or right) is incredibly important. They need to know the full impact that AD is having, whether it's physical or emotional, so that they can help.

### Questions

Ask lots of them. Remember, there's no such thing as a stupid question. Here are a few to get you thinking.

- **Can you tell me more about the underlying cause of AD and how that can be managed?**
- **How can we stop AD affecting my child's sleep/mental health/social life?**
- **My child keeps having flares, is there any way we can prevent them long-term?** *(Don't be afraid to ask your doctor about different treatment plans, it helps to know what options are out there.)*
- **Does my child need to be referred to a specialist?**  
*If you have only seen a General Practitioner (GP) about their AD, or haven't seen a specialist in some time, asking for a referral may help.*

## After your appointment

Sometimes appointments can feel like a bit of a blur so it's important to consider how it went, what you covered, and what the next steps are.

### Reflect

Take a moment after the appointment to sit down with your child and talk about it. Are you both happy with how it went? Are you clear with what's happening next?

### Make notes

This is so important. It can be easy to forget what you've discussed, so make notes and keep them safe. Keeping a record of each appointment not only means you have something to refer back to for your next appointment, but it also gives you a wider view of how your child's AD is progressing overall.

We wish you every success with your child's AD journey. Remember, every successful appointment could be another step closer to getting your child's AD under control – for the long-term.

If you don't feel like you're getting the most out of your appointments, or with your dermatologist, don't panic. It's important to find the right fit for you and your child when it comes to their care. If you feel like you're struggling to achieve long-term control of AD with your current treatment or dermatologist, it might be time for a change.



**Ask your doctor to slow down explanations or request child-friendly language if you can see your child is confused.**

It's time to leave the stress of AD behind you. So, forget feeling like you don't have it all figured out. And forget blaming yourself. We bet you're doing a fantastic job. And, if you ever have a moment of doubt, we're right here. You can lean on Change AD for the information and advice you need, because you won't always have the answers — but we just might. Remember that your child's doctor could make a big impact for the both of you. They're the key to treatment, management, and the big one: finding long-term control of your child's AD.

Keep this guide handy for those all-important appointments and conversations with your child.

**Visit [changead.co.uk](https://changead.co.uk) for more tips, advice and information.**



# YOU'VE GOT THIS.