

# EVERYBODY'S DIFFERENT

How genes affect  
what we look like



by the ED Society

## Preface

Jack explains in this book how everybody is unique through the story of his genes. All children are different, and Jack shows us what makes us unique, how we can be kind and how we can help each other.

I founded the Ectodermal Dysplasia Society in 2001 to support children and their families in coping with Ectodermal Dysplasia (ED). My children have ED and I have always wanted to write a book to help explain children's differences to them and their friends.

I hope that this book increases awareness, understanding and support for every individual and family affected by ED.

*Diana Perry*

Diana Perry

The Ectodermal Dysplasia Society

The Ectodermal Dysplasia Society is a UK registered Charity (No. 1089135).

[www.edsociety.co.uk](http://www.edsociety.co.uk)

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European  
Reference  
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# Everybody's different.

Our **genes** are part of the reason why we are all different.

Genes are a set of instructions for your body, from your mum and dad, that decide what you look like.

They can even help decide what talents you might have or how you behave.

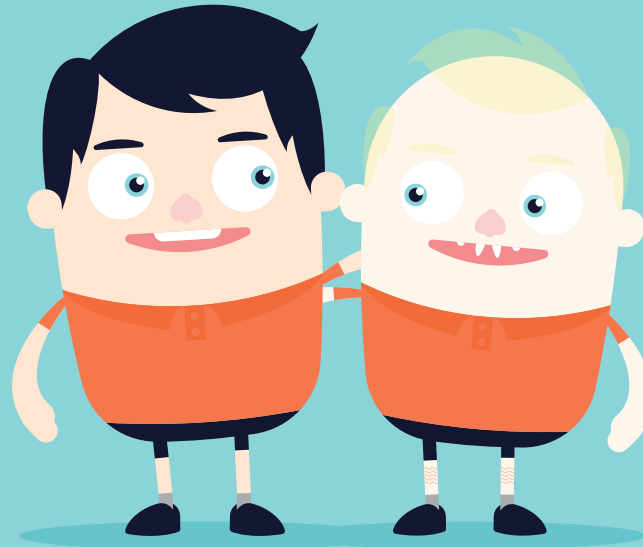
Our genes can help decide whether we are tall or short, the colour of our hair or the shape of our nose.

**Being different is great** and makes us who we are.



Think about what makes **you** different from your friends.

Henry



Jack



Henry and Jack are brothers and have very similar genes.

But Jack has a special gene that makes his body look and work differently to Henry and most of his friends.

Jack has something known as **Ectodermal Dysplasia** – let's call this '**ED**'.

There are almost **100** different types of ED. So far, scientists have discovered the genes for less than half of these.

# How ED can make children LOOK

# SYMP

Their **hair** can:

- Be thin or missing
- Grow slowly.

*They might not have eyebrows or eyelashes.*

Their **teeth** can:

- Be missing
- Be more pointed than normal
- Have big spaces in between.

*When their teeth are missing it can be difficult to eat or talk.*

Their **skin** can be:

- Very light and thin
- Wrinkly and darker (around the eyes, elbows, soles of the feet and palms of the hands)
- Dry, scaly and sore.

Their finger or toe **nails** can:

- Be small
- Be thicker or thinner than normal
- Be an unusual colour or have marks on them
- Get infected more easily than others.



They may also:

- Have had (or still have) a hole between their nose and mouth - this is called a **cleft lip**
- **Be smaller** than you
- Have a **bigger forehead**
- Have a nose that looks squashed - this is called a **'saddle' nose**.



## How ED can affect how the body WORKS



### Eyes

- Sometimes their eyes can't make tears, even when they're sad.
- Their eyes may feel sore.
- Sometimes their eyes hurt when they look at the light.

### Nose

- Their nose might be crusty inside and may bleed sometimes.
- Their nose may run or be stuffy.

### Ears

- Sometimes they may have hearing difficulties.

### Voice

- They may sound like they have a sore throat.

### Breathing

- They may cough a lot.
- They may have asthma and need to use an inhaler.

### Bowels

- Sometimes they may have problems going to the toilet.
- This can make them feel embarrassed and uncomfortable.



### Sweating

- Their body might not **sweat** properly or sweat at all. This means they can feel too hot and not be able to cool down.
- Their cheeks may be red, they might look pale, feel sick or have a headache.
- All of this can make it difficult to concentrate or make them feel grumpy.

**Rosa** needs **glasses** to help her read...



**Samir** needs a **wheelchair** to help him get about...



**Jay** needs **hearing aids** to help him hear...

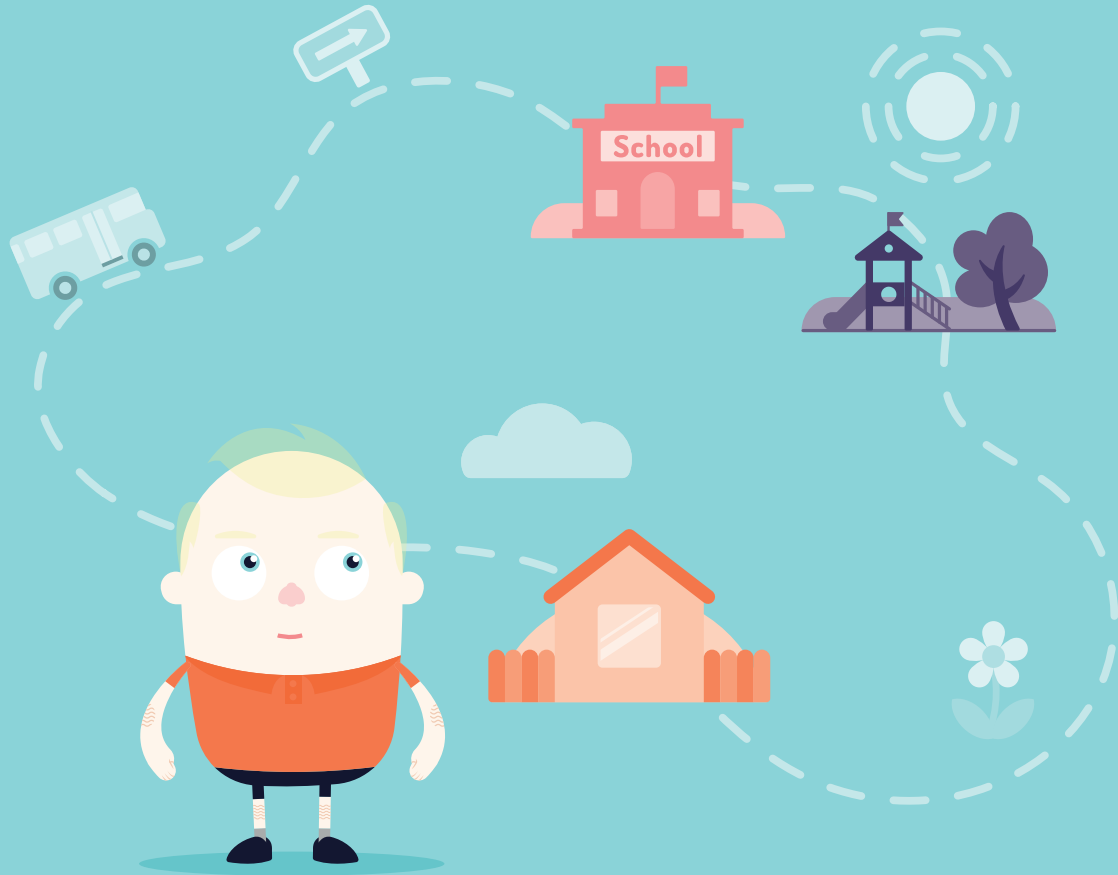


Everybody  
needs a little  
**help**  
sometimes...

**Kim** wears **braces** to straighten her teeth.







Somebody who has **ED** may need **extra help** now and then.

This might be in the classroom, in the playground or at home.



Think about the times **you** may have needed help.



Someone like Jack might need

## help in the classroom

“I need to drink **water** or my mouth gets dry and uncomfortable, and it helps to keep me cool.”



“Sometimes I may have problems with my **speech**, please be patient.”



“I can't really sit next to the **window** when the sun is shining as it makes me too hot.”

“A **fan** can help keep me cool, if I get too hot I get tired and distracted.”

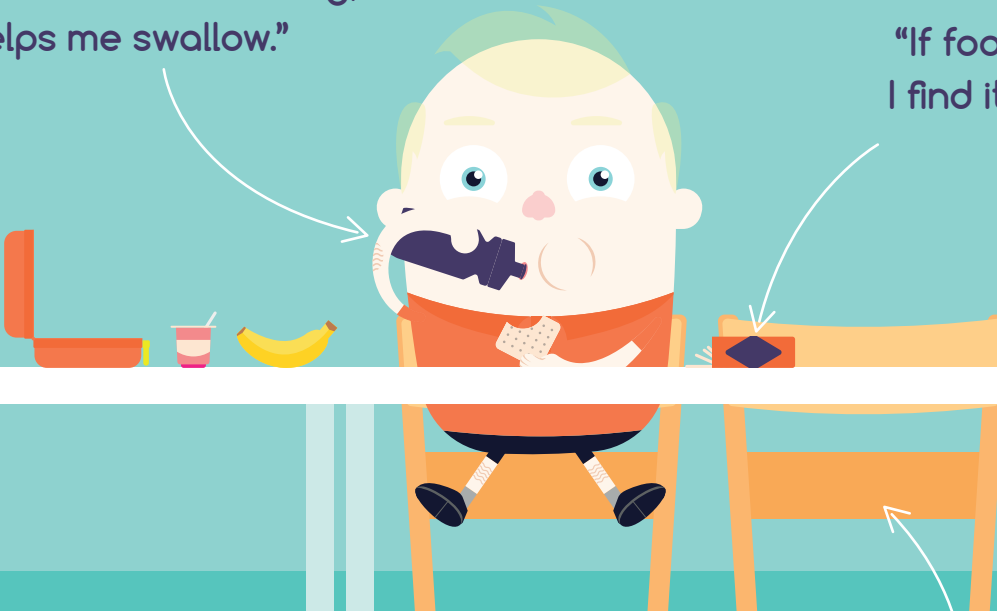
Someone like Jack might need

## help at lunch time ...

“My lunch might be **different** to yours, this is because I find some foods hard to eat.”

“I need to have a **drink** whenever I am eating, this helps me swallow.”

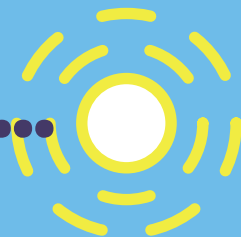
“If food is **too dry**, I find it hard to eat.”



“It might take me longer to eat my lunch, if I am on my own I would like you to **sit with me.**”

Someone like Jack might need

**help when playing ...**



**“I want to play with you,** please ask even if I couldn’t play last time.

I will join in as much and as often as I can”



“If we are outside and it is **hot**, I might have to wear **wet clothes** to keep me cool or **take a break**”



“If we are outside and it is **cold**, I might need to wear **warmer clothes**”



“I always need a drink of **water** nearby”

# Think about FEELINGS



The things we say and do can make other people feel happy, sad or even angry.

We can make someone who has ED feel happy if we say kind things or help him when he needs it.

If we say unkind things or tease him, this can make him feel sad or lonely.

Remember, we all look and behave differently, this is what makes us special.

Being kind to others means they will want to be kind to you.



Think about different ways you could be kind to someone like Jack...

Maybe you could offer to play inside with him on a hot day or sit with him while he has his lunch?

# Almost ANYTHING is possible!



Someone with ED can still do all the things everyone else can – he just needs a little help along the way.

Amazing things are possible with hard work and help from others.

"Everybody's Different was a slam dunk clear winner! It is inclusive, easy to use and written with great empathy ... The visuals are appealing and help the storytelling and, crucially, the science is accurate. It's easy to imagine this being used as a teaching aid in schools or with a parent. Simple but vivid explanations will help increase understanding and empathy among children's classmates, and potentially reduce bullying."

Judges of the Communique Awards 2019

"This resource is really very good, an introduction rather than trying to convey too much information ... The format almost makes it look like a bedside story which is thus a much less daunting format for children. It would not look out of place on a child's bookshelf."

Judges of the British Medical Association Patient Information Awards 2019

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