Amazing you! The slory so far...

Dear Sophie,

Mum and Dad want to tell you some more about your body.

We decided to write it down so you can look at it again whenever you want to!

How do you become 'you'?

Though we're all built to the same plan (i.e. egg meets sperm, baby grows inside mum's tum), we are also completely different from each other. We all follow a *different path* on that *same plan* to develop and grow.

There are hundreds of things that make you different from everyone else, from your taste in music, and your sense of humour to the sound of your voice and the shape of your face.

So how did you become unique?

Part of the answer lies in your genes. Mum and dad would have to have another

1,000,000,000,000,000

babies to stand a chance of having another gorgeous daughter with the same genes as you!

And part of the answer lies in the experiences that **shape** your personality as you grow up: being the first born daughter and the eldest sister, living where we do, the school you go to, the friends you have, the efforts of mum and dad to teach you about values: what is good and what is bad, the travelling we do, what that teaches you about other countries and their foods and flavours, the range of music dad listens to and how that introduces you to all sorts of other types of music (beyond One Direction!), etc.

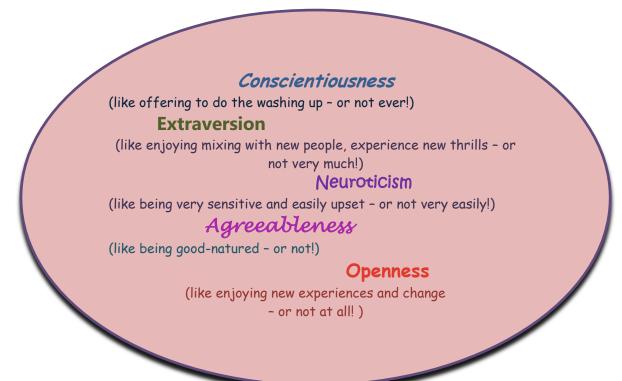
What else do you think shapes your personality...?

Who you are is an ever-changing and growing collection of behaviours, of tastes, of colours and interests – shaped by what **you** like and how **you** respond to all you see and hear and learn.

Remember the quizzes you like to do in teen magazines? They are often about personality! Want to do a quiz?

- Do you like doing things that are a little dangerous?
- If you don't like someone, are you afraid to tell them what you think of them?
- Are you good at remembering people's birthdays?
- Would you rather hang out with a large gang than just one or two friends?
- Are you sensitive to criticism?
- Do you enjoy talking to new people and getting to know them?
- Do you usually do your homework on time?
- Would other people describe you as shy?
- Do you keep your room neat and tidy?
- Would you consider yourself a bit of a rebel?
- Do you often get angry about quite small things?
- Does your taste in music and fashion keep changing?
- Do you ever offer to help with the washing up?

The answers you give break down your personality in different dimensions:



Everyone has a unique personality, with a combination of habits and quirks unlike anyone else's.

More than any other thing, it is your personality that makes you 4000



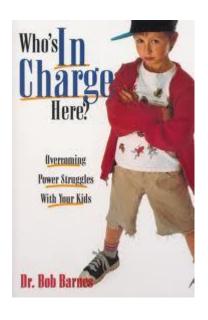
But this leaflet is not about your personality though!

It's is about a small part of your body, and about how your body developed when you were in mum's tum, and what it all means.

What have we already talked about?

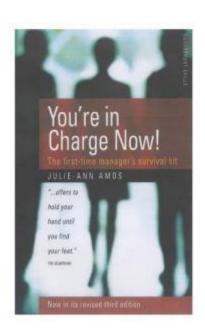
- ✓ We talked about not having periods and not growing babies in your tummy.
- ✓ We are doing blood tests to see and understand how your body will respond to the hormones that your body is beginning to produce as you go into puberty.
- ✓ We have talked about how your vagina is inside your body and that later you may decide to have surgery to create an opening, and that the vagina will need stretching.
- ✓ We also talked about how you will need to take medication at some point to keep your bones healthy and strong.

Whenever you want, we can meet up with other girls whose bodies, like our friend Marta's, developed in a similar way!

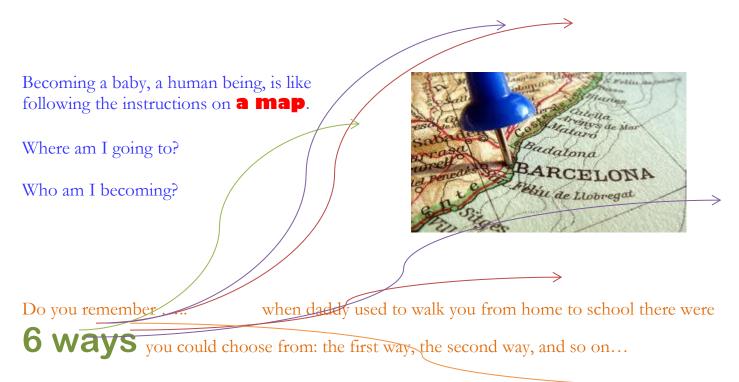


None of these things change the beautiful girl you are! It does not change your personality!

Talking about it now will make sure that you know as much as possible about your body, and that **you can be in charge** of it.



So how do our bodies develop?

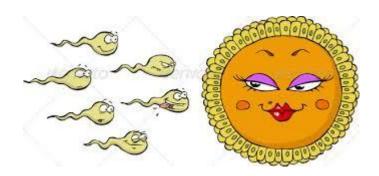


When you grow inside mum's tummy, it is a bit like that: there are different paths that a body can take to develop into a human.

The path that our bodies take is decided upon as soon as a little baby is conceived...

this means as soon as daddy's sperm meets mummy's egg....

and you became our first baby!



... Before birth....

Part 1 The Maps Latt 1 Le Maps

We are born with two maps, the chromosomes and the genes. These maps tell our body which path to take, and guide us along as we grow.

The first map is a very general one: it's called 'chromosomes'.

How do we get those chromosomes?

We get them from mum and dad.

Usually, we get 23 chromosomes from mum and 23 from dad (so we usually have 46 chromosomes).

2 of those are called 'sex chromosomes'

One comes from the egg (usually marked X) and the other from the sperm (usually marked as an X or a Y chromosome).



The chromosomal map is very small scale.

Like a map that has only motorways on it, showing no detail.

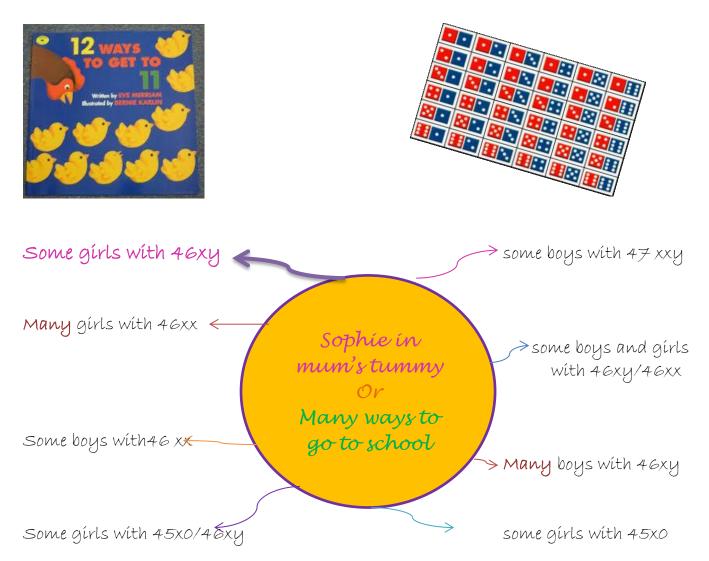


Or think of it like a wind vane: what direction am I going in?

Over there somewhere...

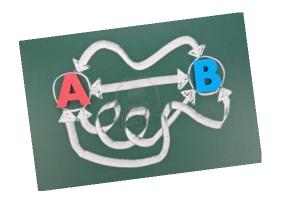


Like the many different ways to school, there are **different combinations of sex chromosomes**, each guiding the development of our body alongside different paths:



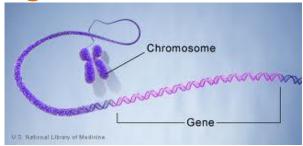
You are a girl with XY chromosomes.

In school, you usually only learn the general kind of stuff, what **many** have; that is why some people don't know that some girls and boys have these other combinations and that there are other paths our bodies can take to go from A to B!





The second map we are born with is the **map of our genes**.



Our genes have all the information (our DNA) on how our body is going to develop:

The **detail** on that map, on our genes, is **incredible**

Like when we go on big walks with the family and dad can read from the map that we have to go over a narrow bridge, and follow a muddy track just after a wooden rickety shed, and then walk till the signpost which has a funny face carved into it...and so on.



Or think of genes like a barcode, with all the details of how we will look like, what colour our hair and our eyes will be and how our body will develop!



For a few weeks whilst babies are in mum's tummy, a foetus is neither a boy nor a girl.

It has the possibility to become either...

This is because the foetus develops differently depending on the 'map', the 'barcode', the 'signposting' we get from our genes.

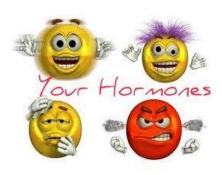


Hormones are important, because it is the map of the genes and the hormones **listening to each other** that make your body develop exactly how it is!



Hormones are produced to change something else in the body. They are special chemicals your body makes to help it do certain things - like grow up!

During puberty, you're loaded with hormones that tell your body that it's time to start changing.



Hormones don't just change your body, they can sometimes change how you feel

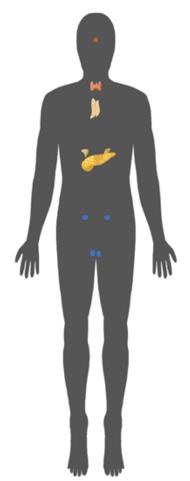
(Like when mum has her periods, she can get cross very quickly, and shouts a bit more (and louder than usual); she loves you really, but it's the hormones that make her do it!)



Various organs (see all the various colours in the picture) produce various different hormones

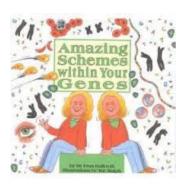
Inside our tummy we have organs called **gonads**, which is a word we use for both ovaries and testes (you learned about those in sex education).

In this picture, the gonads are in blue, they are in the tummy in girls and in the scrotum of the boys.





Let's look now at **two** of your about 24,000 genes!



Gene nr 1: SRY gene

When we have a SRY gene (which we usually get from the Y chromosome but can also sometimes be found on an X chromosome), **gonads develop like testes**.

As explained earlier, you are a girl with XY chromosomes. The gonads of **girls with XY chromosomes** also develop like testes.

You might think now: **But I am a girl: why do I have gonads like testes?**Even so that is **not such an extraordinary** thing.

It is just that **few people learn enough about biology, So it is not well**

known. Many times, school and even scientists' books skip that part, because they always concentrate on what MANY have. **Even your new top trump cards** on biology only talk about what many have (many boys with xy and many girls with xx).

I wonder what else those cards got wrong!

Gonads produce the hormones that develop good strong healthy bones, and they might be able to help you grow breasts, and **do lots of good things**.

Gonads that develop like testes produce **two** kinds of hormones:

Hormone T

(testosterone, also called androgens)
This hormore makes a clitoris grow; lots of T turns a clitoris into a penis.

Do you remember how in sex education the teacher explained that both the clitoris and the penis can become erect when you touch it?

They are very similar really!!

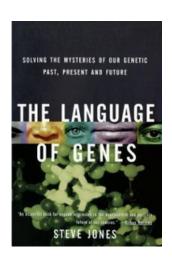
Hormone AMH

(this hormones stops the development of the womb, and the top part of the vagina)





For hormones to do what they are set out to do they need to be 'translated', we need to understand the message before we can use them, we need to read them.



Gene nr 2: Androgen Receptor gene (The translation gene)

This is the **gene** that is **responsible** for **'translating'**, for **'understanding'** the message of hormone T, the androgens.

Now, what happens if this gene is not listening, when it does not receive (receptor) the message, translate the message, read the message the hormones come with?

What if there is a variation in the gene so it does not understand the hormones?

Imagine when we go on holiday to France, or Italy or Spain...

And when we are there we can understand and speak a little bit of the language, like this:

pizza, and pasta, and ciao!

bonjour and merci!

Hola! and un helado por favor!



... And then there are so many other words we don't know how to say and which we don't understand.....

That is what happened with your body: this gene had a look at the hormone T., the androgens, that came its way... and **it understood a little bit**, a few words(which is why your clitoris is a bit bigger)... but the gene did not understand many of the hormone's words.

The message was *partially understood*, because the gene only partially understood what the hormones wanted to do.

(Some other girls have a similar variation on the Androgen Receptor gene that 'does not speak Italian or French or Spanish' at all... it is all gobbledygook, so the gene completely ignores the hormone T, it is completely insensitive to it).

Your map of genes did listen to the other hormone that the gonads produced, the hormone AMH.

And so the womb and the upper part of your vagina stopped developing.

And that is why your body developed a little differently –

some hormones were understood in a different way as they were following some hormones were nuderstood in a different way as they were following

the maps of your body...
...and you became our...

Who loves One Direction and Little Mix and Queen Whose new favourite brand is Hollister Who is a great Skier and Who has lots of lovely friends Snowboarder! Whose favourite city Sophie is Barcelona! Who thinks growing up is doing exactly the opposite to what mum wants her to do! Who is a total daddy's girl (and you're his girl!) Whose favourite colour is purple Who definitely does not like helping with the washing up! (and whose room is never neat and tidy!)

Who's happy to try new foods and flavours (but does not necessarily like them!) and is becoming quite a good baker!

Now that we know how you developed before birth...

What happens next?



Bloodtests....to understand how your body will 'translate' the Hormone T when you go into puberty, and how much of it your body will turn into another important hormone called Oestrogen, which is usually produced by ovaries.

Who helps us understand this? A doctor called an 'endocrinologist'.

What might happen? **We don't really know**. Mum nor dad nor doctors understand very well how the body responds to one hormone or how it translates it into another one...More research is needed.

We are presuming that as your body has grown up ignoring most of the hormone T, paying little attention to those androgens, it would be healthier if it keeps ignoring the androgens, and we might want to, indeed choose to help your body by removing your gonads.

The doctor who would do this is called an 'urologist'; and the endocrinologist would then give you medicines to keep your bones healthy and help your body develop like some of your friends, with breasts, and hips, etc.

So we will wait and see; it might be that your hormones simply will get your body to grow breasts all by themselves.

If this takes a little while, you could take some pills, some **top-up hormones**, sooner, and then your breasts will start to grow shortly after.











Soon some of your friends will start to have periods...and you might wonder when to tell some of them that you are not going to have periods.

You can choose who or when to tell; we can talk about it together, but you will know when is a good time.

Remember, there are many reasons why girls don't get periods: for you, it is the way your hormones are!

For other girls, it is about the path their body has taken!

Surgery/dilation...







18, 19, ...

When you are older, you will be meeting other doctors who will talk with you about surgery to make an opening to your vagina.

They will also talk about stretching the vagina, which is called dilation.

The doctor who knows all about this is called 'a **gynaecologist**'.



To dilate the vagina, to stretch the vagina, you might decide to use *a vibrator* (which is something that lots of women have for fun).

Or you might decide to use a dilator set, like this one with colours.

There is plenty of time to think about all that.

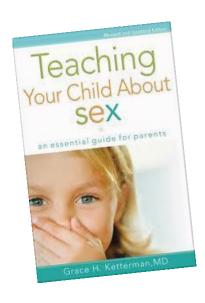


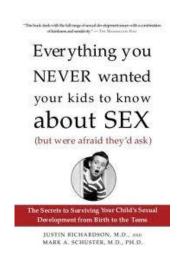
You might decide that you don't want to have surgery, and that is OK too.

When people talk about sex, and as you learned in sex education, they often only talk about a penis going inside a vagina, but there are many different and fun ways to enjoy sex

It's a bit like exercise: some people like to run, or cycle, or lift weights, or hike, or take a dance class, or row, or swim, or play football, or take a yoga class...there are many different ways to enjoy exercise, you might prefer one or you might like to try them all ...it's the same with sex.

Just remember:
Tenderness, and gentleness,
feeling good about your body and about who you are and what you want,
being with someone you love and who loves you,
respect and friendship,
are all basic ingredients of good sex.







Whenever you want, you can also meet someone called **a psychologist**, who can talk with you about how you feel, about your body, your friends, your emotions, and sometimes sex too...

She will know other girls who have followed the same map, the same 'way to school' as you have...and you can meet those other girls too.

And of course, mum and dad **will always make time** (honest!) to talk with you and answer any question you have, now or anytime.



With all our love, from mum and dad.

Post scriptum, by mum

This Visual Story on PAIS was written for 11 year old Sophie. I shared it with her cuddled up in 'mum and dad's big bed' on a bright Sunday morning in May.

Why then...?

It just felt right: Sophie had been ready for this for a while, asking increasingly more questions, and listening more carefully when I would talk with her. And now, I too - at last - was ready and prepared, knowing that with this colour-printed-story-in-one-hand and with my other hand holding her close, I could not get it wrong and all muddled-up...

The use of colours and visuals and personal stories kept Sophie interested and curious throughout.

She happily engaged with all of the content

('I always wanted to take the 6th way and my friends always wanted to take the 1st way!).

(when talking about sex: 'That's enough now mum'!)

Once downstairs, we told Dad (who had been keeping the little siblings out of our way) about having looked at the story, and how it was a lot to take in...He reminded Sophie how she can look at it again and again, ask any questions she has, anytime,

and how much he loved her.

In the afternoon, mum and Sophie went on a shopping trip planned earlier that week. Mum's legs were shaking most of the time as the enormity of what happened that morning sank in.

Something that had seemed so troublesome and scary 11 years ago had been turned into a positive experience.

For Sophie, of course, this is just the start. The doors to learning more and understanding better are completely open. At least once a week since that day in May, we've been having further conversations revisiting and exploring further the story she has been told, responding to anything she might have learned or heard about that day: 'Do you remember how I mentioned...', 'do you remember when I explained...'...

With her ever increasing knowledge and understanding about how her body developed, with the support and love from mum and dad, with a medical team that places Sophie's well-being at the heart of her care, and most importantly - with her lovely personality and enthusiastic nature...we are very optimistic about the future.

Go on, darling! Go and spread your wings.

Produced by

Magritte, Ellie (dsdfamilies.org) and Achermann, John (Paediatric Endocrinologist, Institute for Child Health, UCL, London), **Amazing you! - Sophie, PAIS**, 2013,

with input from:

'Dad', Elizabeth, and Joanne (parents of children with a DSD), Miriam, Sara and Marta (adults living with a DSD), and from

Lih-Mei Liao (Psychologist, UCLH London) and Katy Auckland (Psychiatrist, Sick Kids Hospital, Edinburgh). www.dsdfamilies.org