

Top Tips for Talking

about differences of sex development

To Margaret Simmonds - in gratitude for more than 30 years of tireless service, and for showing us the way

J & E

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This booklet is for parents/carers of children with differences of sex development. These are a large range of conditions which have an impact on children and families in many different ways. They often affect how hormones work and/or how reproductive organs and genitals have developed.

We know it can be difficult to find a good time and a good way to talk about important things with our children. We have pulled together some tips and some examples to help you keep talking to your child

about this particular aspect of their precious life.

These tips are a starting point for your conversations with your child about how their body developed and how it will develop as your child grows. They are there to prompt you, to encourage you and to help you work out what is right for you and your child.

On the dsdfamilies website you will find further information and suggestions about talking to your child.



Doctors told us about tests, what they meant and what long term help our child would need. Lots of the information went in one ear and out the other.

The doctors then think 'we have discussed this' and move on. And yes, we have discussed it... but I still don't really understand.

- **Ellie**, Parent and Trustee dsdfamilies

As we left the hospital with our daughter one of our doctors advised us, 'Don't lie, never lie'. This was something that this doctor had learnt from past experiences. But for me it was the only thing I really understood, and I clung onto that advice with everything I had.

I thought: 'Don't lie' - I can do that.



Imagine your child as a young adult: able to find out anything and everything ever posted by or about people whose body is like theirs. What they see then should make sense to them at that time, perhaps just to see that their circumstances are different. It will make sense if you start now and help them learn more as they get older.

- **Julie Alderson**, Clinical Psychologist Bristol Royal Hospital for Children, Inaugural Chair of Trustees dsdfamilies

As they grow up we help our children learn about complicated things such as love and death and where rain comes from. We go over things again and again. The story starts simply and over time becomes more complicated.

You can do this about your child's body. Start simply. Start now.



1. Sow the seeds of knowledge

Use simple and accessible language and everyday situations to get your child used to the wide range of difference in many aspects of life. Start small and use everything around you: colour of eyes, people of all shapes and sizes and skin

colour, likes and dislikes of food and ice-cream flavours. We are all unique.

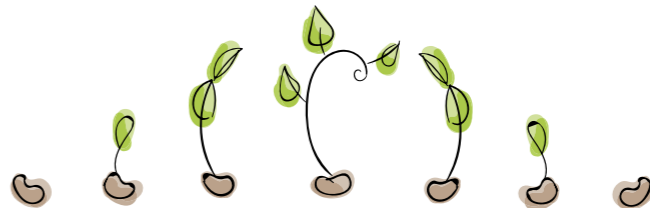
To explain difference and diversity, use words that help you to develop a story, like the ideas below.

No two bodies are exactly the same

Everybody is different in different ways

Many girls have... and some girls have...
Some boys have... and others have...

Sometimes... and other times...



2. Understand the story so far

When you understand your child's sex development it becomes easier to spot the opportunities in day to day life and in general conversations to explain and talk about it.

On the dsdfamilies website you will find the booklet *The Story of Sex Development* which can help you map out your child's development. Take a look and if there's anything you don't understand ask a

member of your healthcare team to go over it with you.

Build on earlier conversations by emphasising how we all develop differently. Keep it focused on how your child's body has developed to be able to do things well, rather than starting with 'it should have been like this – but yours didn't do that'.

Lots of people need help to grow grown-up bodies

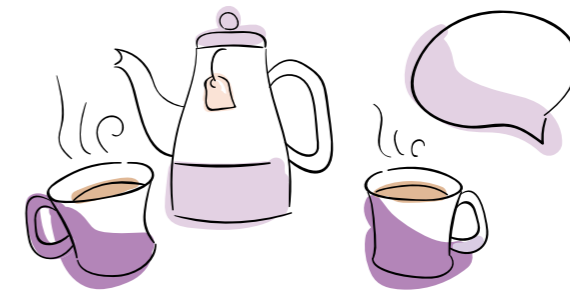
Not all parents can grow a baby in their tummy - some babies are adopted

Our bodies change in life, ready to do different things

3. Talk to a friend who can listen

Talking to a friend or someone who knows about development differences can help you manage your feelings and get things clear in your mind. You need someone you can trust to listen when you express your worst fears and someone who won't mind if you say things that sound wrong.

It is good for a child to see or know that a parent can talk about this with a friend or a relative, as it gives them a sense that they can be open too over time.



An example...

Family days

Support like this comes in many ways - a best friend or relative... or other parents and families who have a child born with a difference of sex development. Connecting with other families can happen in various ways: one-to-one, as part of a small email group or a larger online forum.

It can also happen face-to-face at family days co-hosted by your hospital team and dsdfamilies (or another family group). People may attend only one event, others will come back every time. Family days are a great opportunity for children to meet and make friends.



4. Prepare and plan

Take time to choose some words to use for the complicated parts of the things you want to tell your child about how their body has developed.

Write down as much or as little as you want - your healthcare team can help you.

You can say something like:

This is important to get right, so we have written it down to share with you



5. Follow your child's rhythm

Be ready for your child to have different concerns from yours. Children often focus on one aspect of an issue, not one that adults think is the most important part. This is either what matters to them right now or the only thing they can talk about at that moment. Go with it!

As children grow up they will ask lots of questions about the world around them and that can be a lot of fun.

If you are surprised by a question or if you are struggling to answer you can say,

'That's a great question, I need time to think about that'. Having thinking time is important since we don't have or may not know all the answers. You can also try some of the ideas below. Make sure to follow up when you can.

However difficult the question, praise your child for asking it! Children don't tend to ask difficult questions until at least the age of 3 or 4. You can revisit Tips 1 to 4 to further help you prepare and be ready to tackle them.

*I am not sure how to explain that,
let me ask someone who knows*

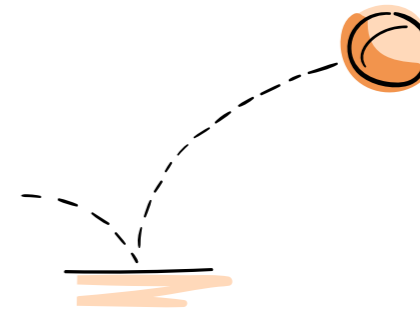
Let me double check...

Remember that question you asked...

6. Build resilience

Some things in life - for whatever reason - are upsetting or can make people feel they're missing out and this can hurt. We can't stop our children from feeling upset or hurt sometimes. But we can help them manage those feelings and focus on good things to help balance them out.

We cannot ensure our child's favourite cup never gets broken, but we can always help them pick up the pieces.



7. Balance openness and privacy

Your children will learn from you about openness and confiding relationships. They will also go their own way. You may have fears that they will tell their friends about private matters. You can begin to talk about personal matters with your child and you can tell them that when they are older they can share that information with their friends. You can add that you will help them think about how to explain it.

You can talk about genitals - using words that work for your family - and say that

the parts of our body that are covered by underwear are usually private.

Some parents want to tell their child not to share certain things. This can be very confusing for a child. It can make the issue more of a talking point if it is not clear why some information shouldn't be shared. Use examples to help your child understand there are things we don't discuss with everyone because they're private, not because they're secret.

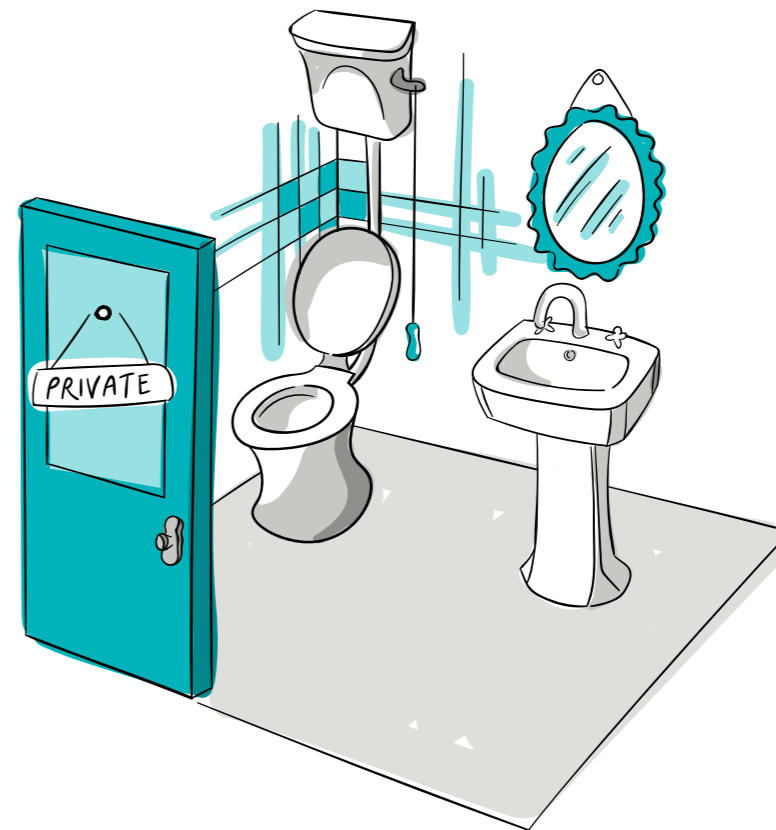


An example...

Closing the bathroom door

It might help to think about something you do as part of life but that you don't usually talk about. So...you could ask your child the question: why do we close the

door when we use the bathroom? Because it's private what we do in there! Same with genital difference or other aspects of body development. It's not secret, just private.





8. Empower your child

The more open you can be the sooner your child can actively take part in questions around growing up and support they might need. That can be really scary for a parent, but it is really positive for a child.

When you are uncertain about when to talk and what to say - or when you realise you are avoiding talking to your child about their development - be guided by the fact that it is actually their body and

their information. You are looking after that information until your child is ready to join you in facing some of the hard questions. In time, with love and support, they will find their own answers.

If you feel stuck and don't know where to begin, ask a member of your healthcare team for advice. Read the *Timeline for Talking* on the dsdfamilies website to understand what you are aiming for.

9. Keep it open

Show your child that you are happy to talk about things at any time however silly or 'rude' or complicated they may be. It doesn't always have to be a BIG talk. Don't leave these discussions until the last moment or on the way to hospital appointments.

So be open about it whenever it makes sense, like dipping in and out of an open box. Just keep talking.



10.

This space is for you to write down a top tip you heard from another parent, healthcare professional, friend or an adult living with a difference of sex development.

You could start to write your own tips as your confidence grows and you find what works for you.

Let us know about it so we can share it with other families.

A note about dsdfamilies

dsdfamilies provides educational, practical and peer support to children, young people and families living with differences of sex development*.

**including Androgen Insensitivity, CAH, penoscrotal Hypospadias, Swyers, 5-Ard, some forms of Turner, Klinefelter's, Gonadal Dysgenesis, Ovotestes, 13-Beta, 17-Beta, SF1, Frasier and many others*

We work to ensure that the experiences of children, young people and their families inform best-care practice and professional training. We do this in collaboration with health care providers and peer support networks for adults and families.

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