

Turning a corner – or about the time when I explained to my 8 3/4 year old daughter that she would not be growing babies in her tummy

Since the birth and diagnosis of my baby with PAIS I have often felt like there was a big cloud hanging over me. I have recognised it in other parents too. I don't think doctors know about this cloud, yet they have a word for what causes it: they call it 'disclosure'.

When my daughter was 8, I read about how a doctor suggested that we should not talk about 'disclosing' the condition to one's child, as if we are revealing a secret. Instead we should think of it as 'explaining' the condition to one's child' (Ref: Charmian Quigley, 'When to tell the patient', see 'Other things you may find useful', Parents pages, dsdfamilies.org).

I cannot say that the cloud hanging over me was lifted by that, but it moved quite a bit: I can do explaining. That is not so scary. That does not sound like I have only one shot at this and I have to get all the words right at the first go (and with no-one telling me what the exact words are either!). Explaining is what I had done before, when, at the age of four, I told my daughter while she was playing with her dollies, that not all mummies grow babies in their tummy and that some adopt.

What I really, desperately, wanted to learn about though was how other parents were explaining to their xy daughters that they would not be growing babies in their tummy? How did their daughters react? What questions did they ask? How did other parents know when was the right time to tell?

What follows is a compilation of emails I sent and was sent around the time I explained some of these things to my lovely daughter. It is her story – it is no one else's. It cannot be recreated, as every parent and child's circumstances are different. But I hope some parents can imagine from it what it might be like, and that it will help them not to be scared when their time comes to explain some more things to their own child.

With love and thanks to Marta and Ana.

From Gill, 38, mum of an 8 year old girl with PAIS, writing to her friend Marta, Oct 2010:

[...]

PS: these days are really special for me - my daughter knows she is 'different' and every day she asks me a bit more questions about it... I constantly have to be aware of this and see if I can tell a bit more without hurting her... But I think that within weeks now she will know: no babies, no periods, no vagina, need to take hormones, etc.....we need to go and see a doctor - this will be her first examination since she was 5. The doctor has proposed to do this under anaesthetic not to upset her. But either way, she needs to understand why she is going to the doctor.

Response from Marta, 36, CAIS, Oct 2010

[...]

About your daughter, I'd just like to say that I'm sure it will be ok. I think you have the right approach, honestly (even if there are, maybe, several different right approaches, depending on personal characters in each family).

Anyway, I think you have the right approach, you have a lot of information, you have been preparing yourself for years, you have spoken and exchanged experiences with other parents. You are very aware of your daughter needs, questions, and requests, and this will surely help her.

I have no children, but I think that if you have created the space for her to ask questions, and if you follow the rhythm of her questions and requests, the information will arrive when she will be ready. Afterwards, there is still a long way to go.

Ana, mum of an 11 year old girl with PAIS, joins the conversation a few weeks later, Nov 2010:

I have one daughter with PAIS, she is eleven years old, twelve in a few months.

We are at an important time with our daughter, because she is starting to ask a lot of questions about her body, like... "when will I get my periods, when will I grow breasts..." and it is likely that in March she must begin to take HRT [Hormone Replacement Therapy].

We must give her more information. I have told her already that she has some hormones that don't do their work well, and that she will need medicines to develop healthily, and she knows that when she was a baby, she had surgery. But for the moment, I haven't told her anything more. Sometimes, I don't know how to say more things...it is very complicated.....

Gill replies, Nov 2011:

Ana, my daughter will be 9 soon.

What follows is the story of 'telling my daughter'...it is a private story which I will rewrite sometime soon, but first the experience needs to settle a bit more. However, I wanted to share this with you....

I was telling Marta in our emails during October how I have been explaining more details on PAIS to my daughter. The reason why I thought it was the time to tell her was that she was asking me lots of questions: her clitoris is different from her little sister, why? When does pubic hair start growing (she has a friend in her class who already has pubic hair). She had also noticed her vagina is different from her little sister, etc.

I have always tried to give her truthful answers (way beyond kids of her age would usually get to hear), but I was really struggling with the idea of how to tell about babies. I also wanted to tell her about not having periods before it became the 'must-have accessory' in the playground....

I had also asked her whether she would come with me to a special doctor (because of her enlarged clitoris she knows already she is a bit different).

I had told my daughter quite a few times in the last months that I really wanted to have chat with her about her 'difference' and when would be a good time... at first, she really did not want to, and got angry. Then I suggested 'we can have a chat when you like to', she said OK, but not now (the X-factor was about to start!!)...and then one day I showed her a book (Hair in Funny Places) and asked her if she thought we could have a chat about that when I put her to bed that night... she said yes....

I knew she had been keen for a while to learn about how the body develops, both girls and boys bodies, and I thought that with all the questions she had asked, with increasing frequency and detail, and with her interest in this book I might try to explain things that evening.

The book tells and shows what happens to the body of a young girl and boy when hormones start kicking in.

When we were reading about girls starting to bleed (getting periods) and how that signifies you might be able to grow a baby in your tummy, I told her that I could not read any further and had to explain here how this was connected to her difference.

I explained that she would not be bleeding. And then she asked me 'does that mean I won't grow babies in my tummy'. I told her that yes that was what it meant. She cried, of course, and I held her tight. There is nothing you can say at that point... I felt awful, how could I do this to her – surely she was much too young to be able to cope with this information.

After a while I said I was sorry that I had to tell her this at the start of reading this book she was so interested in, but that I could not ever tell or explain her something that was not true, that I would never lie to her (and I think it is really important that you get that across)...She cried quietly and really just wanted me to hold her...

I told her how the next day she needn't go to school and how we would spend the whole day together, just the two of us, and that she could ask me any questions then or anytime. But that we would do some nice things, things that sometimes I don't always have the time for (because of school or because of my other children). That really cheered her up, and we started to talk a bit more, also about adoption. We talked about a dear friend of ours, an adoptive mum and her beautiful family. We also spoke about friends close to our family who decided against having children, and other friends who would have dearly loved to have biological children, but could not have them.

I also explained her that later she would be taking medicines to help her develop and grow up healthily. And then she asked where her vagina was. I explained it was hidden inside her and that doctors will help her create an opening to the vagina when she is older. She then asked me if her vagina needed stretching...? I could not help smiling and asked her 'where did you learn about that?' My laughter helped her relax, and she told me how an 8 year old friend had explained to her that babies come out of the vagina and that the vagina 'stretches' to let the baby come out. I told her that I did think her vagina would need stretching, but that we would be talking to the doctors about this and they would make everything clear to us when she was older.

She then asked me: 'Am I a boy mummy?' I did not know how to answer that question; I was not prepared for it. I was quite sure the question was related to the absence of the vagina and the enlarged clitoris, rather than how she felt about her own gender. Years of answering all sorts of questions in simple, child friendly ways helped me to explain it as truthfully as I could: 'Do you remember when I explained to you that all babies start off exactly the same way, in a mummy's tummy, and only after a little while do they become little boys and little girls? Well, when you were in my tummy some 'stuff', like the hormones in this book, were sent your way because there was

some confusion...but you said: 'Hey! I am not going to be a boy, I want to be a girl'. You are who you decided to become.' She thought about that, and just nodded her head. [Perhaps in hindsight I could have done this better. Let her explain why she asked me that question, reinforce the similarities of the sexes rather than differences, reinforce that it is OK to ask these questions etc.]

We then decided that I would finish reading the book, but that I wouldn't talk about her condition - just read the book....

I also told my daughter that later she can tell her friends about the news I told her but that for now I preferred it if it we could just talk about it a bit more within our family, so we all get used to this new information. I asked her that if she wants to tell a friend, could she first have a chat with me so we could see how best to do this.

I told her that the next day she could perhaps make her very first adoption - the zoo here is very big, and you can actually 'adopt' one of the animals. My daughter loves animals, we often have been going to the zoo and I would always point out the 'adoption sign' that hangs near the viewing points of some of the animals. I always used it in a 'let's do that sometime' way. I also told her we could look at some websites of organisations through which you can 'sponsor a child or a community' (e.g. Plan International) so that we know a little bit more about how that works, it is something i have often looked at with her, but never acted upon. She thought that was a great idea, and I could tell how she had calmed down...

Then, and just to show you how kids can take these things much better than we fear... she says 'Mummy, can we also go to Toys-R-Us tomorrow because I feel a bit sad....' I told her that going to Toys-R-Us was not going to take away or change what I had told her (I know mummy, she said)... and added with a big smile that yes, if she thought it would make her feel a bit better... we could go... We then went downstairs so she could get a big hug from her daddy (who was anxiously waiting downstairs; we had decided I would do this chat on my own, as she had always addressed her questions re: her body to me). I explained to him briefly what we had been talking about (he knew I was going to have this conversation, but it was a good way to say this out loud again, and make sure my daughter would know that she can always turn to both mum and dad).

He gave her his biggest hug and told her how very much he loved her... we spent some time watching television, she was sitting in between us, ... And then I went upstairs with her, and stayed with her until she fell asleep...

Now that I have told her, I can see how 'knowing *when* to explain the condition to your child is a bit like giving birth to your first child. Throughout pregnancy you keep wondering how you will know when you are in labour, how you will possibly know it is time to go to the hospital, but when it happens ... it is pretty clear when you have to go...: If your daughter keeps asking questions, I think the time has come for you to explain the condition....Marta told me: give her space, and follow her rhythm - I think that is wonderful advice.

The other thing I have come to realise is that what doctors call 'disclosure', this 'big event' when you tell your child bits of information re: their condition is not an 'event', but it is a long process. And I think doctors should explain it more as a long process whereby the way you start to explain things

(anything!) to a child early on will help you find words more easily when you come to explain a more complex matter. I can now see how much of the things I have done in the last few years helped to make this whole process easier; it's like peeling away at an onion, layer by layer...

The next morning... before breakfast, she had made her very first adoption (dolphins from WWF). We had a lovely day together -I spoilt her in time and love, and got a few treats for her - but nothing much. And when we ran into a friend of mine, I blatantly told a white lie ('she is not well'). Afterwards I told my daughter that it was OK to tell a white lie when sometimes you want to keep some information private, or need to get used to something (and then I insisted she still cannot tell any other lies!)

For me, the worst moment was when the day after, she left for school and she shouted with her young voice 'bye mum' - I felt awful. How could I let her go, what if she realises or remembers what I have said in the middle of the day and I am not there to hug her,... I cried a lot that day and my heart felt heavy for her... the next days I tried to understand if she was anxious in any way, or withdrawn... I really wished a psychologist had told me what to keep an eye out for...

This is now nearly a month ago, and she seems well. When she mentions breasts, I will say something about her having breasts soon enough (I want to reassure her that some of the things her friends will have she will have too); and when she tells about how a girl and a boy in her class 'fancy each other', I say something about how her turn will come soon enough, and that they are all still a bit too young for fancying each other anyway.

And finally, to give you the extra confidence to take the time now and speak with your daughter... let me tell you something else: she told a friend of ours that she knew who Santa Claus really was. I asked her about this and she said some friends had told her but she did not want to tell us because of her little brother and sister.

A few days later, she told me at bedtime 'I really regret knowing.... who Santa is... it was more fun beforehand.....'

Ever since I gave birth to her, I feared the moment she would say 'I regret knowing...' ...but Santa was what really mattered.

I have written all of this quite quickly, and am sorry for my spelling mistakes, but I must stop now as I have a big headache! But I hope that by providing this detail you will feel encouraged and inspired that you can find the words too...

Perhaps one last thing: I always thought that telling her would provide such a relief...that that would be it. I realised though that this was only the start: as if we had only just turned the corner and still have a long way to go....

Marta replies:

Thank you very much for sharing with us your story, your feelings, your experience, your strategies... everything. Thank you. I think it will be very useful for other parents too.

As you say, things need time to settle. Both for you and for your daughter.

Now, she knows a little more. She is beginning to understand, and the syndrome starts to be part of her life (in her mind, I mean). But, of course, and fortunately, she continues to think about things of her age (such as who is really Santa Claus...).

Ana replies:

Thank you very much for your words.

I think the right time to tell the girls more or less things about the syndrome depends largely on the maturity of each. Some girls at 9-10 years are already very mature, some at 12 aren't. My daughter is just in the second situation, she is like a little girl so I have only told her a few things even though she will be 12 soon. But I think as we go to see the doctors in a few months, more questions will surely come and it's time....

Gill replies

[...]

The point you made about maturity is a very valid one. And I think there is not only variety between children; I think there is also variety between cultures/societies. E.g. I think kids (all kids) here in the UK know much more about sex.

The other thing also is that I think the sooner you tell a child (like say age 8) the more often you will gently need to remind them/repeat the messages. When I read of parents who have started to tell even earlier about not having babies, my first reaction was, oh dear, I have left it too late, I should have said something sooner... But then these parents will go on to say that they are not sure how much their child has absorbed, has really understood....

Marta replies:

About how and when to give information, I think you are right, there are differences between cultures and societies.

In my opinion, the sooner you give some pieces of information, the sooner it's incorporated into their lives. Of course, they will not understand the subject like an adult, but they start to "internalise" it, and as you say, you can repeat it again afterwards, and the door is open to give more details when they ask questions.

I think that a lot of us (affected women) knew somehow that we were different (because of visits to doctors, or genitals, hernias, or whatever); it is better to have answers (age-adapted answers), even if when we are very young, we don't understand everything.

In my case, I never asked questions, because I didn't dare. It's because of the relationship between my parents and me. It was not bad, but it belonged to another time, (and maybe, I noticed that it was not a subject to ask questions about...).

But, it doesn't mean that giving information is easy. I understand that it's difficult.

I imagine that first parents have come to terms with the condition of their child to be able afterwards to explain it.

EPILOGUE - 18 months later

Marta and her husband are in the process of adopting their first child.

Ana's daughter is very happy. She started to take hormones and is now growing breasts just like her friends. She is planning how to handle the absence of periods socially.

Gill: As the day that I took my daughter out of school was a specific day in the school calendar, she remembered when a year had passed. And so it was that one Thursday afternoon in November 2011, in a cramped changing cabin at the swimming pool, my eldest daughter (with my youngest daughter also getting changed in the same cabin) said to me 'Mum, tomorrow it is a year ago you took me out of school so the two of us could have a special day together'.

I smiled and said 'That's right sweetheart'.

Then she said: 'Can we do that again?'

I gulped invisibly and asked her: 'Do you remember why I took you out of school?' 'Yeah', she said. 'Okay then', we can do that again' I responded, feeling quite strange but also happy at this turn of events...

I had every intention this time to say to school that I was taking her out to spend a nice day together with mum— no lies...but in the end my daughter asked if I could just say she was unwell; she did not want to stand out that much.

Off we went for a lovely morning of shopping, and in the afternoon, Daddy joined us and we went to the theatre to see the musical 'We will rock you'.

It's a tradition now – my daughter does not know this yet, but she can count on a very special day with mum and dad next November too.

She has had sex education at school (how are babies made, how are babies born, what happens in puberty). I had explained to her that it is difficult for primary school teachers to explain how complicated life is, and had reminded her that some things would be different for her and that she could ask us any questions at any time. I was quite sad a few weeks later to see in one of her jotters an 'exercise' they had to do, summing up what happens in puberty. She had to write: 'I will have my periods'. I asked her whether it had been difficult to write that. She shrugged her shoulders and told me 'I just did what the teacher wanted me to do, I did not think about it'. All I could do was hold her and tell her I loved her very much. Overall however, sex education was helpful in that it boosted her knowledge and created lots of opportunities for her to ask questions.

I am now (May 2012) preparing myself with the help of a psychologist to explain her about gonads and gonadectomy (she has PAIS), and about xy chromosomes. My husband is not sure about telling her about the chromosomes ('how can she begin to understand? I don't really understand it'), but I am sure it is the right thing to do – once the door is open, she can ask questions...and together we will learn. That has to be better than giving it undue significance by leaving it as the last piece of this challenging puzzle.

I told my husband how different it feels to prepare for this conversation: where last time I felt I needed a script, have word for word written out what I needed to say...now it feels that all I need is a draft.

And so we continue our journey, navigating corners and clouds as we go along.