

Information for  
parents who are  
considering whether to  
talk about an extra Y  
chromosome  
with their son and  
family members.

# A Guide for Parents



# Introduction

Each cell in our bodies contains structures called chromosomes. Chromosomes are bundles of DNA that contain a 'blueprint' for building our bodies. Two chromosomes called X and Y differ in men and women; males usually have one X and one Y whereas females usually have two Xs. The X and Y chromosomes are commonly known as the sex chromosomes. Sex chromosome trisomies occur when there is an extra copy of one of these sex chromosomes. The term 'karyotype' is sometimes used to refer to the number of chromosomes an individual has. Boys with an extra copy of the Y chromosome have the karyotype 47,XYY; often referred to as just XYY. XYY is found in around 1 in 1000 boys. The 2011 Census shows that there are around 31 million males living in the UK; this means that there are over 31,000 boys and men in the UK with XYY. Many of these cases go undiagnosed, because the impact of the extra Y chromosome can be quite mild, with minimal or no symptoms.

XYY may be discovered when a mother undergoes prenatal screening (amniocentesis or CVS), or after birth if a child has their chromosomes tested as part of a medical investigation. When a sex chromosome trisomy is discovered, parents have to decide whether to tell their son about this, and if so how to go about this. We found that this was an issue that concerned many parents but very little was known about how parents decide to tell their child or the process through which they do this. Many parents were also concerned about whether to tell family members, or others such as teachers.

As part of a research project at Oxford University, we held a Study Day on XYY in collaboration with Unique, the rare chromosome disorder support group, during 2012. Some of the parents who attended agreed to take part in a series of focus groups. During these focus groups

we discussed how parents decided whether to tell their son about having XYY. For those who did tell their son, we explored the different strategies that they found useful in disclosing to their son, and also to other children or family members. In addition, we had a focus group for teenagers and young adults with XYY, and we also obtained information from other individuals who agreed to be interviewed by phone or by questionnaire.

It is clear that there are no right or wrong answers to the question “Should I tell my son about XYY and if so, how?” Different families have adopted different approaches, and the decisions they make will depend on personal circumstances. Nevertheless, we think it is helpful to describe a range of factors that need to be considered in making this decision. We hope that the information here will be useful for parents who are considering whether and how to disclose about XYY to their child, and to other family members and associated professionals.

One important note of caution: It is impossible to describe a ‘typical’ child with XYY, because they are so variable. In general, parents who are not worried about their son’s progress are less likely than other parents to be involved with support groups or get involved with research. This means that much of the information from our focus groups comes from families whose son is experiencing some problems. It is likely, too, that these parents will feel more reason to tell their son about XYY, as this can help explain developmental difficulties. We hope that parents reading this booklet will get an impression of the range of issues surrounding disclosure of a diagnosis, and may be able to relate to some of the examples we give of people’s experiences, but it should not be assumed that what is right for someone else will necessarily be right for your family.

# Disclosure of a diagnosis

Most parents who have a son with XYY will, at some point, think about telling their child about their genetic condition, and this may be something that you are currently thinking about. When we started working in this area, we found this issue was a source of concern to many parents, but there was little information or advice available to help parents like you in making these decisions.

The main questions that you will need to consider and that we will discuss in this guide are:

- Whether to tell your child.
- If so, how and when to tell your child.
- Whether to tell other people, such as family members or teachers.

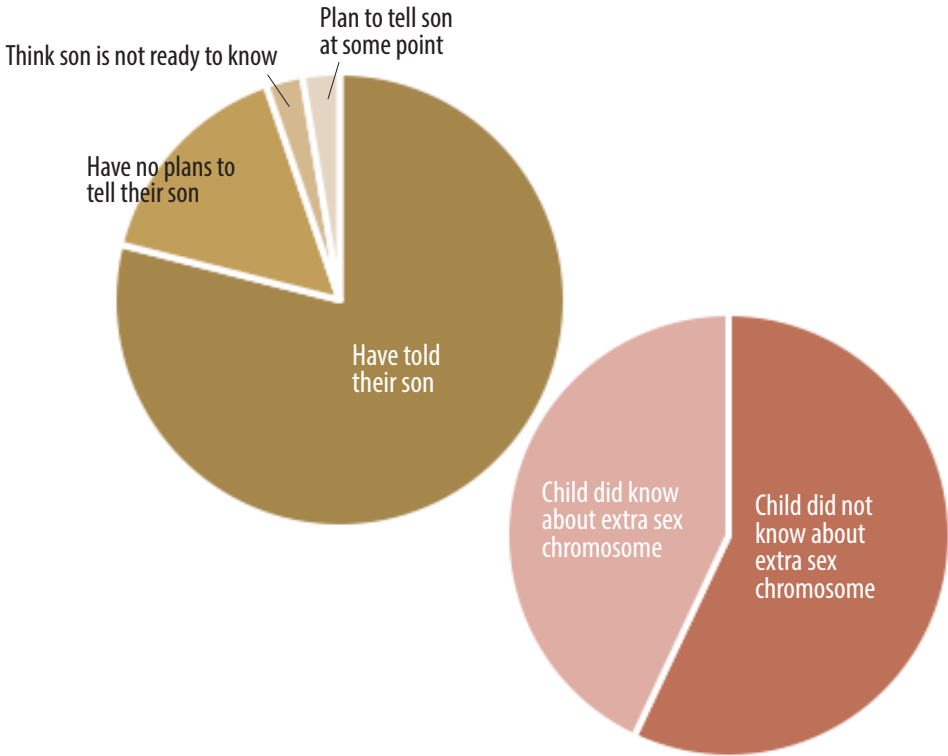
# Should I tell my child?

Parents typically face a dilemma in deciding whether or not to disclose an XYY diagnosis to their son. On the one hand, many argue that they feel the need to protect their child from any harm, stigma or undue stress that might be caused by their knowledge of their chromosomal condition; on the other hand, many families also feel that it is important to be open and be able to provide their child with information that may be relevant for future decisions, for instance about schooling.



In 2008 we carried out a study with parents who had a son or daughter with an extra sex chromosome. Of the 126 families who took part in our study, just under half of them (54 families) had told their child about their sex chromosome trisomy. In a more recent study with fewer families, we found a slightly higher number, 30 families out of 38 had told their son about XYY. Out of the 8 families who had not told, 6 families had no plans to tell their son about his XYY, and others planned to do so when he was older.

We summarise here the experiences and comments of parents who have a son with XYY, to help you to weigh up for yourself the pros and cons and come to an informed decision about whether or not to tell your son about his extra sex chromosome.



## Insights from parents discussing reasons against telling your child

### Disclosure may stir up problems and do more harm than good

As far as we know, having a sex chromosome trisomy does not affect a person's ability to have children, and there are no known cases of the trisomy being passed on to children. The impact of having XYY on development is incredibly variable. Some boys have no obvious difficulties, whereas others may have multiple problems affecting physical development or educational progress. If your son is progressing well, then it may seem particularly questionable whether disclosure would serve any useful purpose.

Some parents may decide that telling their son about XYY will only create needless upset and may leave him feeling stigmatised. As one parent explained, "It is, it's a label. And that's what I'm scared of – I don't want him to be labelled."

Lesley explains how she was told by her GP to not tell her son, particularly if he wasn't experiencing any difficulties; as her son, Dylan, has been coping fine, she hasn't yet told him about having XYY:

**“ I wouldn't say he has behavioural problems. We chose not to tell him from that... it's the same as when we went to genetic counsellors at [hospital] when I was pregnant, they said exactly the same. We told our GP who just said it's on his notes, it'll go back in the filing cabinet and you should just let him be treated as any other boy and if he has speech problems he'll get speech therapy and if he has behavioural problems then he'll be picked up just as other children who would have behavioural problems without chromosome abnormalities.”**

She continues by explaining that she has sought advice from friends and remains torn; on the one hand feeling that he has a right to know, but also not wanting to tell him when he is currently coping fine:

**“ Not many people know about Dylan, and I told a couple of friends more recently. One said, 'Yes I think you ought to tell him' and the other one said, 'Well he's got to where he is, he's got this far, does he ever really need to know? Because it's not going to affect him you know once he gets married and has children, it doesn't mean to say his children are going to be like that, you know and so with him growing up the way he has he sounds like a well-rounded boy anyway.' ”**

### **Concern that your son will use XYY as an excuse**

Even if your child is experiencing problems, you may still feel it is better not to disclose to them about their chromosome status. Several parents in our focus group expressed concern that awareness of a trisomy might provide their child with an excuse for behaving badly or simply not trying. Helen explains how she held off telling her son William until he was 15 as she was worried about him using XYY as an excuse while still at school:

**“ We'd got in our heads probably from 16 and we were in a bit of a trap because his behaviour was really bad at the time of school and we'd held off telling him because we didn't want to give him an excuse and although we'd already told the school, we always made it clear this is not an excuse for William's behaving badly; whatever he is he has to learn to conform and he has to learn to live with what he is but it's going to be more work for him because he's still got to become a well-balanced young man. That was why we were holding off because we thought if we say, 'You've got something wrong with you' he'll be like, 'oh well it doesn't matter, I can be horrible.' ”**



Other parents had similar concerns that telling their son would result in him ceasing to try and use his XYY as an excuse. Lesley continues by explaining that this is one of the reasons contributing to her not yet telling her son, Dylan:

**“ Our feeling was that we wanted to wait until he was 18 and he’d finished his education and the period before he went to university, if he was to go to university, because of the maturity and what you were saying about him understanding and you know I’m sure your sons, and even if they’re young, they probably will be like this, that when something goes wrong it’s never their fault, they’ll look to pass the blame because I think that’s all part of the disorder, so we just felt that Dylan would then say, ‘Oh it wasn’t my fault, it’s because I’ve got this extra chromosome’. So we wanted him to get to a level where he matured first.”**

### Lack of information or understanding

XYY can be hard to understand even if someone has a background in biology. Some parents may feel it is counterproductive to tell their son that they have a genetic condition, if they can’t explain what it means or answer questions about it. The fact that there is wide variation from child to child just makes matters worse: telling your son that he has XYY doesn’t allow you to say for certain whether or not he’ll have problems at school or home, and may just cause your son to feel anxious.

- As a parent, it may leave you feeling inadequate when trying to talk about the diagnosis.

Ian explains that he struggles to understand the genetics involved and so if he is to tell his son, he feels he will first need to gain a greater understanding to be able to answer his son, Nate’s, questions about XYY:

**“ Really in terms of knowledge I guess I think I have to do some research before I told him. If you think of kids’ questions, he’d probably bamboozle me pretty quickly in terms of ‘what does that mean?’ ‘what’s a chromosome?’ If I had something which kind of explained the genetics and chromosome in kind of layman’s terms then that would be great... I struggle now talking to my family thinking ‘what does it all mean?’ ”**

Other parents felt their knowledge about XYY was lacking, but Sinead explains that even though she felt like she was struggling to grasp the genetics, she still felt able to tell her son, Sean, when he asked:

**“ Chromosomes are such a weird thing for children to understand aren’t they? Even adults are struggling – it took me a while to digest how chromosomes work. And a lot of people just know as far as an extra**

*chromosome means Down's syndrome and that's as much as they know about it. So yes, it's quite a tricky one I guess. I think because [telling Sean] came out of the blue, I didn't have time to build myself up to that 'right, I'm going to tell him'. I just had to go with it when it happened really."*

## Feelings of guilt

A final consideration that might come up when deciding whether or not to disclose is related to guilt. Parents may be reluctant to open up a topic that they find incredibly stressful. Chris explains how he has struggled with feeling guilty about his son, Nathan, having XYY:

“ *My wife says it's more than likely from myself that he actually got these traits. She's probably just trying to make me feel guilty ... she's trying to tell me that 'it's more than likely that he's got XYY because of you'. I think it's very, very hard ... it would have been very hard for me if Nathan had been my first child, having it. Because I still sit back and blame my parenting skills and think ... well you do – I have moments when I think 'oh God, I'm really rubbish'. And it's how you feel looking at my daughter and go 'actually, she's turned out all right so maybe I'm not that bad'. But you do have moments ... because I was convinced it was me and then it's obviously not."*

Chris's experiences with feeling guilty about his son having XYY and feeling like a bad parent are not uncommon among other parents. However, it is very clear that that as a parent you are not to blame if your son is born with this condition. Sex chromosome trisomies can happen to anyone and accepting that you had no part in this is incredibly important and should not stand in the way of any decision to disclosure to your son. Although Sarah points out that she feels guilty that her son, William, has XYY, she explains that she has come to the conclusion that she isn't going to allow her feelings to get in the way of telling her son:

“ *You know I know that I will tell him and when I have this conversation it's like 'why do you want to tell him, look how well he's done', and you know he's as normal as anything now, but I certainly I feel he has a right to know and I feel you know I did think I want him to know because I don't want there to be a point in the future where he might have some blood test or something and they tell him and then he comes to me and says, 'Did you know? I've been told I've got this?' and for me to say, 'Yes' and that would be my guilt so I can't not tell him to protect my own guilt, I feel I need to."*

# Insights from parents discussing reasons to tell your child

So far, we have considered reasons why parents may decide against telling their son about XYY. We turn now to look at the question from the opposite viewpoint: that of parents who felt it has been beneficial to tell their child.

## An explanation for difficulties

If your son is experiencing difficulties at school or with his behaviour or emotions, then telling him can be positive in enabling him to understand why he might be struggling in comparison with his friends. Children may find a diagnosis empowering, as it allows them to feel that any difficulties they are experiencing are not their fault, and that they can make informed decisions based on solid facts.

Rachel explains that her son, Samuel, asked if there was something wrong with him and so she decided to tell him why he was struggling at school:

**66** *I told Samuel, I think he was about nine when I told him. He was having a really bad time at school – he’s got a teacher who was ... then he did need a lot of structure and she was a bit emotionally over the place and he doesn’t like that – he likes you to be really straightforward with him constantly. And he was having a lot of trouble at school and he just came home one day and he just said ‘is there something wrong with me mum, is there something different about me?’ And I just thought right, here we go, I’d better tell him now so I just said ‘actually Samuel, there’s actually just something very mild ...’ and I made very light of it, trying to explain it very basically, made light of it and he just went ‘oh okay’. He wasn’t bothered at all really. . He didn’t then think ‘oh that’s all right, I can carry on being naughty’ and running about in class or anything because there is something wrong. Because I said, ‘basically everybody’s got something wrong, like people have low self-esteem or they’re shy ...’ and I said what I thought I’ve got wrong with me and his dad ... and he was fine with it. He just took it like ‘ok that’s fine, it’s nothing major’. I know I did want to tell him but I was thinking I didn’t quite know when. I was thinking it might be when he’s a bit older than that actually but then when he came out with that, I thought it was an ideal opportunity to get it out then. And if I’d said then ‘no, there’s nothing wrong with you’ and then later on I told him, he’d have said ‘you lied to me back then’. So I had to really.”*

In Rachel's case, her son didn't use the diagnosis as an excuse. By explaining that we are all different to everybody else and pointing out ways that she and her husband were different, meant that Samuel didn't feel stigmatised. In fact, Rachel goes on to say that actually, it has since allowed him to feel as though he has an explanation, not only for his difficulties at school, but also for other aspects of XYY such as his height:

**“It also gave him a reason for some of his feelings, his behaviour and he's six foot eight, he's always been really tall and he's had growth spurts so at some points he'd be really tall compared to his peers. So it just sort of made it kind of fit into place a bit for him. Not that it made it any easier, but at least there was a reason.”**

That being told you have XYY could be a relief and an explanation for your behaviour, was also echoed by other parents. Sinead explains how her son, Sean, found it a relief to know why he always felt different to his peers:

**“If you knew at 16 when you left school that there was a reason you were a bit different would that not be more comforting to you? We present it as a positive thing, I think Sean finds it a reason, not an excuse, but a reason why he's the way he is.”**

Both Rachel and Sinead's experiences indicate that they feel that their sons felt relieved to know that they had XYY, and that it provided them with an explanation for either their difficulties at school or their behaviour. Sinead's son, Sean, explains how he is glad that he was told about having XYY as otherwise he would be worried by his own behaviour and not feel as though there was an explanation for it:

**“Up until I found out, I was questioning myself a lot. I had people coming up, like friends; close friends even asked me 'is there anything going on? Is there anything wrong?' And I was constantly saying to my mum and dad for about a month, 'what's going on?; 'have I got anything wrong with me?'; 'why am I so tall?; dad you are 6 ft 3, I was fifteen at the time, I am 6 ft 3, that doesn't make sense. If I didn't know today, there would be so many different things going on in my head, socially and college wise and... Because I know, I am not saying I behave badly because of it, but it's a factor, but if I didn't know I would be like, why am I behaving badly like that. And the whole thing like not remembering what I have done, it's like why is that happening? Because you think there is nothing wrong with you, you think you are kind of normal and it wouldn't make sense.”**

## Avoidance of secrecy

If your son is not demonstrating any noticeable problems then, as mentioned previously, you may feel this is a compelling reason to not tell them. However, it is important to consider that they may still appreciate being told and indeed may find out at some point in the future. In families where a child has found out later in their teenage years or in early adulthood, there is a possibility of resentment or disappointment at not being told.

Leah points out her dilemma in choosing when to tell her son, Joseph, as she feels that if she waits until he is older, he will resent her for not telling him earlier:

**“ This is the other thing I was worried about do we leave it for ages and then tell Joseph at a later stage and he'll get really annoyed, or is it easier for them to know slightly younger and get used to the idea as they grow and then it's not such a shock. Because you do get stressed yourself seeing your child being stressed in that way, so it is a natural, I think, where you've gone forward, 'sit down, this is what the problem is'. And obviously it's another way of, as you say, making light of it and the way you put it over is a good thing. But then, if you're at that age – say eleven or twelve years old – he's got access to the internet then ... then what we were told, to not look at the internet because there's quite a lot of troubled things on there – is he going to take heed of that? It's a strange thing. And then you think perhaps you should have said something earlier when he was say six or seven so he doesn't know how to use the computer properly so he won't get to know about it up until he's older and he wants to look at it.”**

Previous research on family communication about inherited genetic disorders has found that parents generally feel a responsibility to tell their children and provide them with adequate information about their condition<sup>1</sup>. Many parents reported that they felt they had a duty to promote openness and trust by communicating as a family which in turn enabled the family to be best placed to support each other and tackle any problems as they arose. This final point is highlighted by Sarah, who thinks that her son deserves to know:

**“ I always felt that I was one 100% going to tell William because I was like they're his chromosomes, it's his body and who am I to know something about him like that and not share that information with him?”**

<sup>1</sup> Metcalfe, A., Coad, J., Plumridge, G. M., Gill, P. & Farndon, P. Family communication between children and their parents about inherited genetic conditions: a meta-synthesis of the research. *European Journal of Human Genetics*, 16, 1193–200 (2008).

## Things to consider

### Should I tell my child?

#### Reasons for not telling your child

- The consequences of XYY can be mild or negligible.
- It can be stressful to be given diagnostic information that is hard even for adults to understand.
- Being told of the diagnosis could create anxiety and stigmatisation in the child.
- Could be used as an excuse for bad behaviour or not trying at school.

#### Reasons in favour of telling your child

- If your son is experiencing educational or emotional difficulties, it can be helpful to have an explanation.
- Awareness of XYY may empower your son, allow him to link up with others with the same condition and help him to make informed decisions in the future.
- It can be uncomfortable to keep a 'family secret', and your son may be upset if he does eventually find out that information has been kept from him.

# When and how to tell your child

If you do decide that telling your son is the right course of action for you, then the next big questions are 'When should I tell?' and 'How should I go about it?' The following sections provide insights from parents about both these questions.

## Insights from parents on when to tell your son

Knowing when to tell your child can be difficult. When boys are still young, their understanding may be more limited, but they may be more accepting. Older boys may be better able to understand the complexities of the condition, but may be upset to discover that information had been kept from them until now. Some parents suggest waiting until your son starts to ask questions – which may, of course, never happen.

Many parents argued in favour of telling their son when he was young, with some parents later introducing genetics concepts when they felt their son was better able to understand. Judy explains why she feels that, although she hasn't yet told her son, Harry, she believes that early disclosure is for the best:

**“ I don't think it's going to do anyone any good, shying away from it till the later years. I'll tell him as soon as he questions the fact of 'why', you'll say 'we'll best sit down and tell you this is why this is happening and this is why you feel like this'. I think that's the best time. I think it will do more damage to leave it till later years to tell somebody that they're different from everybody else. And especially at that transition age or before they go to high school ... if you told somebody then, I think that would be devastating to them. My friend likened it to adoption ... because I've had this playing in my mind for a while and she likened it to adoption and the fact that you hear so many cases where children aren't told until they're like mid/late teens and then they find that more catastrophic because they feel they've been misled. That made sense to me.”**

Several parents had felt similarly to Judy and made the decision to tell their sons at an early age. Sinead explains why she decided to tell Sean about his XYY when he was young:

**“ As for telling Sean I've always, always, told him right from the start. When he was little we called it 'his special thing' because you know ... Sean ended**

*up going in endless hospital visits to paediatricians and you know speech and language experts and OT [Occupational Therapy] people and all this sort of thing. And you know the rest of the school wasn't leaving at 11:00 to go and see the talking lady again. And so I decided ... I just call it 'his special thing'. And I go, 'Were just going to see what we can do about your special thing and how we can help you with it.' "*

Sinead goes on to explain that when she asked Sean if he was glad he knew, he said that otherwise he might have felt like a freak:

**“** *And we talked to Sean didn't we in the car on the way down and said, 'Would you want your son to know if they had it?' And he said, 'Yes because otherwise it would be really scary being really, really tall at eleven when everyone else isn't. And I'm glad I know why I was, I'd just think I was a bit stupid or a bit thick, or just a bit of a freak.'*

Like Sinead, Julie also decided to tell her son, Dominic when he was just 2 years old as she felt that he already knew he was different:

**“** *I told Dominic when he was two because we had ... again I've been lucky to have a lot of support. When I was pregnant we all went to antenatal and then we met up every single week for about two or three years so until they started school. And around two-ish they were starting, well about 18 months the first one was starting to speak. Then about two most of them were speaking and I was saying to Dominic, 'Well you can't speak just yet because you've got a special bit inside you that makes it a bit harder. You're going to speak soon and you just have to wait.' And as soon as I'd said that, that was the line I talked about because I felt like he was savvy enough to know that he was different to the others and I didn't want him stressing about it. So you know, I know it sounds a bit barking but I just felt that he was perceiving that."*

Both Sinead and Julie's experiences involve introducing a very basic concept about their son's being different. Telling your son when he is young allows you to build on his understanding year-on-year and introduce more complex explanations when you feel he is ready. In fact, some parents felt it was an advantage to start with explanations while the child was still very young, because it allowed understanding to develop gradually, with the child absorbing more as they grew older. This was the approach taken by Rebecca when deciding to tell her son Daniel about his XYY:

**“** *Throughout his childhood, I read about differences in people and not focusing on any one thing, and mentioning, you know oh yeah... really focusing on things like some people have genes for blond hair, some people have genes*



*for brown hair. So I introduced the idea of genetic difference pretty early on you know as a topic of conversation and... – Also I think the way that you tell them I think really makes a difference. When I told Daniel I'd been on this course... anyway the same week I sat down and told him 'you know you have an extra chromosome' and we can talk more about it and deal with our differences. Your differences might make you have problems with your behaviour but it also makes you lovely and tall. I think that's the other thing as well because I think you have to draw on their strengths all the time."*

Although she told her son early on, Sinead elaborated on the genetics side of Sean's XYY on the way to the Study Day as she decided it was the right time to tell him more about the condition:

**“** *Well funnily enough I did [tell him about the genetics] in the car on the way here [to the focus group]. Because it seemed relevant you see its good you know because otherwise it's a bit sort of weird going, 'Hi Sean I've got a bit of a quick genetics lesson, just while we in Sainsbury's.' So I said, 'This is why we're going and do you want to know a bit more about the actual science?' So I said, 'I'll tell you the scientific bit' and I just did it really simply you know, 23 pairs of chromosomes XX, XY, you have an extra chromosome and you know but I always, always have framed it positively."*

Other parents, however, left it until later to tell their sons about having XYY. Helen discusses that she felt she left it too late to tell her son but that she was following the advice she received when her son was initially diagnosed with XYY:

**“** *I think we told him too late because of the... exactly why you're here today, there was no knowledge, so we told him late because that's what we were advised."*

### Insights from parents on how to tell your son

Once you have made a decision about when to tell your son, the next decision to tackle is how to go about this. Even after committing yourself to telling your son about his trisomy, it can be very challenging to work out the best way to do so. Genetics is an exceptionally complex topic and many people find it confusing enough themselves, without having to work out how to explain it to a young child. Additionally, there is the underlying concern that if you do tell your son that he has an extra chromosome; he may start to feel like a freak.

As the experiences above demonstrate, some parents who chose to tell their son at a fairly young age approached the topic by simply telling them they were 'special' and not getting into the details about genes and chromosomes. As Trish explains, going into genetics when your child is younger is unnecessary and that you should tailor your explanation to their level of understanding:

**“ I couldn't sit down and talk about the genetics side of it because it would just blow my mind – it would just go over my head, in one ear and out the next. I believe in talking in real terms to kids and to my son, like myself. It's what they can understand isn't it? It's their understanding. Because every child is very, very different, it is their concept ... what they're able to understand and at what level – fluff it up for them so that it's nice ... explain to them at their level.”**

A couple of parents waited for their son to question if they were different before talking to them about it. Trish continues by explaining how she told her son, Matthew, when he asked about why he was different to his friends:

**“ I think we were chatting in the kitchen one night and he kept coming to us and saying, 'Why am I different?' and we just said we've got to tell him and we just took him to one side and made sure that Jacob was out or at a friend's or something like that and just sat him down and said, 'You know you've been asking, well this is why.' We didn't make a huge issue out of it, just sort of said... I think we were in a patch where he was really struggling with controlling his anger and it was very much him sort of 'why am I like this? Why can't I control my anger?' And you know that was what prompted him to really push it.”**

Waiting until your child questions why they are different can be useful in providing an opening to tell them about having XYY. Although Niamh waited for Adam to ask questions about why he was struggling with certain things, she raises an important point and goes to argue that as a parent you know when the right time is to tell and how to go about it:

**“ It was, I can't remember, but I think he was about eight or nine because he knew there was something different with him. He knew himself he was different. He used to get so frustrated that he couldn't do things like monkey puzzles and still can't do things like the climbing frames. He struggled with coordination and said, 'Why can't I do this, why can't I kick a ball?' You know, you'll come to that point and go right now is the right time to tell him.”**

## Things to consider

### Deciding when and how to tell your child

Your child's actual age is less crucial than his level of understanding.

#### Advantages of telling your child while still young

- Avoids a sudden shock in teenage years.
- Limited understanding means the child can gradually absorb information as his understanding grows.
- Can use picture-book to introduce the idea of being 'special'.

#### Advantages of telling your child when he is older

- He will have better ability to understand what he is being told.
- Allows parents to postpone decision to disclose diagnosis, especially if no problems encountered.

We have developed a booklet that can be used to help talk to your son about XYY, incorporating some of the experiences of parents who helped with our research.

### Using the “Things that make me special” picturebook

The picture book “Things that make me special” is intended for younger children. We have done pilot studies to check the level of understanding required, and found that most children with a language level of at least 6 years can understand most of the content. Many boys with XYY have immature language skills and social understanding, and so may need to be a bit older before they can comprehend the main messages. Nevertheless, following what several parents have told us, it is possible to use the book with younger children, even if they understand only parts of it.

In the picture book we do not attempt any detailed account of chromosomes or genetics. Even the simplified account that we provide may be over the heads of many young children. However, our aim is that the picture book should nevertheless be useful in talking about differences between people, and the idea that XYY is just one way in a boy can be different and 'special'. We also make it clear that, while some boys have associated difficulties, this varies a great deal from child to child.

As well as the main text, we have 'Talking Points' in coloured boxes, suggesting points that parents may wish to discuss with their son. This way, we hope it will be possible to personalise the way in which the picture book is used.

# Deciding whether to tell brothers and sisters and how to go about this

Deciding whether or not to tell brothers and sisters can also be a difficult decision. Every family will have their own unique set of circumstances that will contribute to their decision to tell their other children and there may be many factors involved in making that decision.

In the first instance you have to decide whether to tell them before you have told your affected child and this decision will largely come down to your children's ages and the age gaps between your children. When families have older children, particularly in the case of larger age gaps, telling the older children first might be the most appropriate course of action. David explains that he has told his son Harry's older siblings but, at the moment, he feels Harry is too young to understand:

**“***His siblings know. We haven't discussed [telling Harry] at all because he's still so young, we wouldn't even contemplate telling him because there's not really much point, you know, but they're 19, 17 and 12, you know so on the one hand we've not really talked about this in any detail, but we think it's a little bit unfair that his siblings know and he doesn't. But by the same token, you know putting that to one side, and I think probably all that's going to happen is that there will come a point when you know we just feel that's the right time either to tell them or not.”*

In deciding whether to tell any older children about their brother having XYY, you will also need to consider how your son might feel if he later realises that his siblings knew before he did. We've already noted how children with XYY can be resentful if they feel their parents have kept information from them: this can be made even worse if they find out that brothers and sisters have also been 'in on the secret'. Another aspect of disclosure to consider concerning telling siblings is the need for discretion in telling others. Although some parents may feel that it does not matter who knows about their child's XYY, many families would prefer that the information was not broadcast widely, because of the potential for stigmatisation of their child. But this means if another child in the family is told, they will need to be relied upon not to tell other people, and this need for secrecy can create a burden. For some parents, telling older siblings first might be most appropriate. In Trish's

case, despite her son Matthew having an older brother, Jacob, Trish explains that telling Matthew was her priority and she didn't consider whether or not to tell Jacob until afterwards:

**“ So Matthew’s got an older sibling, Jacob, who’s twelve and this wasn’t in our consideration around when and why to tell him, it almost sort of occurred to us afterwards. Actually what we found is we were growing up in a family where all of our friends and family were orientated around dealing with Matt and his issues. In telling him we are then able to tell Jacob and there is then an explanation of why Jacob’s got different boundaries to what Matthew’s had in terms of bringing them up, because we, rightly or wrongly, set different expectations in terms of their behaviour because of what we’ve dealt with. If we hadn’t told Matt we couldn’t have told Jacob and therefore he would continue to kind of think ‘well why am I being treated in with way?’; and those kind of things, so telling Jacob didn’t occur to us at the time of telling Matthew, this kind of occurred to us after.”**

Although Trish points out that Matthew’s older brother might have noticed that he was being treated differently to Matthew, she decided that telling Matthew about his XYY first was more important.

Trish’s experience does highlight that siblings may have already noticed that their brother is not able to keep up with his peers at school, or that he has additional behavioural or emotional problems and they may in fact ask questions about this. Asking about their brother may provide an excellent opportunity to talk to them about their brother’s extra chromosome and why it might explain some of his behaviour. Leah explains that she has told her son, Joseph’s older siblings as they were asking questions about why he wasn’t able to do certain things:

**“ His siblings who are only four and six already know because they say, ‘Joe doesn’t talk, Joe doesn’t walk’ but they just accept it as he’s their brother.”**

By not telling them, you risk leaving any siblings to make incorrect assumptions about their brother’s behaviour perhaps thinking that he is acting out for attention. Trish continues that once Jacob knew about his brother having XYY, it made it easier for him to understand why Matthew sometimes gets more attention:

**“ Jacob’s very much lived in Matthew’s shadow and an awful lot of our time and energy is spent on Matt; you know meetings at school and Matt’s temper, Matt’s anger, and always Matt, Matt, Matt. If you talk to Jacob he’s like, ‘it’s all about Matthew’, you know, and sometimes for long periods of time it is all about Matthew, so to actually have been open and to then have a reason and have Jacob understand why it has to sometimes be about Matt, actually helps.”**

Telling siblings can provide them with an explanation for their brother's behaviour. Siblings can often be mean to each other, though if a sibling is on the receiving end of particularly bad behaviour or emotional outbursts from their brother that may be due to his XYY, then by telling his siblings, they at least know that their brother may be acting this way because of his XYY and can be more understanding. By knowing that there might be a reason for their brother's behaviour, they may be able to deal with any poor behaviour better. Colette describes how her youngest son, Ben, often complained that his brother, Luke, got much more attention at home. In Colette's case, Ben found out about Luke having XYY by accident, but can now better understand why his brother has difficulties:

**“***My youngest son is exactly the same, he's just fourteen months younger and he has often said to me that Luke gets attention and I'll explain to him that attention can often be negative compared to the attention that he gets and he has said to me 'But it's still attention'. The GP wanted to investigate delayed puberty [in Luke] and twelve months ago we were with a consultant at Kings College Hospital sitting in the consulting room and my husband said something about Luke being very tall, you know and he knew why it was, and this consultant sat there in front of Ben and said, 'Oh well that's because of [Luke's] extra chromosome'. And Ben is a bright little spark and I very quickly changed the subject and then I drove him home and we got all the way back, put the car in the garage and he said, 'Mum what did that doctor mean about Luke having an extra chromosome?! And because he's the other way from Luke, incredibly emotionally mature for his age, I just thought I can't just pass it on and we sat in the car for about an hour and I told him about it. And he ... it's been very difficult for him, I know Luke's the one with the chromosome but for him having a brother with, you know, challenging behaviour and living with them it has been difficult for him and when I told him he just sat with tears coming down his face, and said, "Is that why Luke's had those problems at school mum? Is that why this has happened?" and it actually, I felt, I think Ben really benefited himself."*

As well as gaining an understanding of their brother's behaviour, being open with siblings, particularly when they are older siblings, can allow them the opportunity to provide help and support. Caroline describes how her eldest daughter, Sophie, has been really good with her brother, Nathan, since finding out that he has an extra chromosome:

**“***We've got an older daughter who's here as well today – she's nine-and-a-half – and we never had any difficulties with her at all. She's doing really well in school. So if I blame myself and think 'I'm not handling Nathan very well' then I think, 'well Sophie is actually okay'. And I could see that it's doing okay*

*for Nathan as well, having a sister around him because she's always putting things forward to him one at a time. So it's keeping him active."*

Caroline's experience of her daughter being very good with her younger brother is also echoed by Jennifer, who explains that her daughter, Charlotte, has not only been good with her son, Ethan, but is also explaining to others at her school about Ethan having XYY:

**“***My daughter – because Ethan used to come to school and so we did the school run with her – she knew he was clearly quite different to her friends' siblings. She's been very, very involved from about the age of six ... and she actually went into school and did the perfect presentation to her class on XYY and do you know what, the amount of her friends who came up and said 'that's really, really interesting' – and it also helped the other children because she had a little boy who's stated in her class and it helps other children.”*

## Things to consider

### Telling brothers and sisters

#### Reasons to tell brothers and sisters

- Other children might be able to provide support to your son with XYY and help him if he struggles with anything.
- Siblings might be more understanding and accepting of any poor behaviour.
- Siblings might provide an alternate place for your son to turn to for support.

#### Potential problems in telling brothers and sisters

- Children may find it a burden to keep a secret.
- Children with XYY may be upset if they realise others in the family have known information that was kept from them.

#### Factors affecting when to tell brothers and sisters

- The age between your children might determine who gets told first.
- Telling siblings at the same time can allow for their understanding to grow together.

#### Deciding how to tell brothers and sisters

- Think about whether you want to wait and see if they ask questions or find an opportunity to bring it up.



# Deciding whether to tell your son's school

Deciding whether or not to tell your son's school can be important, particularly if he is experiencing any difficulties and would benefit from support at school.

For most parents in our focus groups, a decision to tell the school was prompted by awareness that their son would benefit from extra support. Parents tended to avoid telling the school about XYY if they felt their son was coping OK, and that nothing would be gained by disclosing.

Rachel describes why she initially decided not to inform her son, Samuel's school about his XYY but decided to disclose when he started having difficulties:

**“ I didn't say anything and I thought I'd see how it went. Because he didn't look any different – he didn't really act very differently. So nobody really noticed anything. Nobody really knows. He was a bit emotionally immature - he would cry very easily but a lot of the stuff is what a lot of the kids do anyway so it was just accepted that 'Samuel is a little bit sensitive' ... but by the time he got to year two, he was starting to struggle with the work and then he would get frustrated and then he would cry a lot and want to leave the classroom and get away. So then I thought 'okay, they need to know now because he needs a bit of support here.' ”**

Other parents also decided to disclose when their son's problems began to affect their schooling. Sarah describes how she told her son, William's, school as soon as he started having problems and how she feels it has been incredibly valuable in getting her son help:

**“ William was diagnosed because he had behavioural and development issues and once we found out I told the school straight away. I wanted them to know because my opinion was if he needed the help although it's the school's job to do it it's my job as a parent to make sure that they're doing it. So I just thought the more people that knew the more beneficial it would be better for William. In the long run you don't want your child to suffer in any way and you want them to have the help they need to get them on in life to do what they want to do.”**

Where children are experiencing educational or emotional problems, there is a stronger motivation to tell the school. This is balanced, though, by a concern about possible stigmatisation and lowered academic expectations. In practice, parents' experiences were hugely variable, and the response from school staff ranged from very positive to totally negative. Rebecca explains that she is concerned about the school labelling her son, Daniel, if she tells them about his XYY:

**“ But if you go to a school where they know nothing about it [XYY] and you make too much a deal about it at the entrance and admission process, the school then label them and then all of a sudden he'll be in band five of five, he'll be in the lowest ability band, the lowest of low and that would be my concern.”**

Rebecca's concerns about labelling were realised by another parent, Sinead, who had a very negative experience with the Special Education Needs Co-ordinator (SENCo) at her son, Sean's, infant school, though this did ultimately result in her son getting the support he needed:

**“ The headmistress, who was the SENCo, kept on calling him 'that extra sexual child' and I had four years of hell and ended up reporting them to social services for the way they were treating him and labelling him and it was awful. But then that led to him going to a really good junior school and his results, I've just had his report and he's going to mainstream comprehensive with support. So it's all swings and roundabouts, it's a journey where you think, 'I wish I hadn't opened my mouth' and then 'Oh I'm glad I did.' It was really horrible but it's just something... I think it's part of the development in getting them the support they need.”**

In stark contrast, Steve explains how his son, Cameron's, school were very accommodating and that telling the school was a very positive experience:

**“ If we hadn't told the school I'm fairly certain he would have been expelled from senior school because of some of the behavioural issues and in telling the school they were a bit more ... they were actually fantastic the school, we're really been lucky with them. And if he'd gone to a different school or we hadn't told them and he'd been expelled, he would have had a very disruptive education.”**

Considering that different schools may react differently is important. Use your judgement to decide how you think the school would react to the news. For example, if the school have any other children with disabilities already in attendance this might be positive and you can be sure that the school are able to cope with children who are different, and that other children will already have an awareness of individual differences. Hannah explains that the school her son, Aaron, attends has other children with disabilities and that the school were proactive in highlighting that 'we are all different':

**“ In his school there’s been a child with Down’s and another child that had an undisclosed problem. No one ever did know what it was, it wasn’t a chromosome imbalance but he didn’t speak. So the school used them to say, ‘You know all children are different.’ They always explained that there are lots of children and some need more help than others and they’ve seen physical problems as well as other problems.”**

If your child is in need of support at school it is worth remembering that help might not always be easy to come by and that you might have to fight for it.

One point stressed by parents was that it was extremely unlikely that school staff would know anything about XYY, even if the school was familiar with other disabilities. If you do plan to tell the school, go prepared with material that explains the diagnosis, such as the Unique document “XYY”<sup>2</sup>. Julie explains that she has persisted in getting her son, Dominic’s school to understand about XYY:

**“ It all came down to communication with the school and that’s one thing I’ve been a lot more proactive with. I don’t know at what point I realised it’s me I’ve got to do all the work, but I got lovely information from [a researcher on XYY] sent through to social services, which helped me with the horrible school. Yeah and then we got all the help and backup from school and all the information from Unique which we give then to the school and they followed it through from school up to the high school where he still goes.”**

Although the medical-sounding label XYY may get your child’s problems taken more seriously than would otherwise be the case, the label alone does not really provide any guidance to the school as to how to help. Even if teachers read up about the condition, they will come away uncertain, because the educational profile varies so much from child to child. The diagnosis may help you get an assessment for your child, and will also indicate which areas of functioning are likely to pose problems, but on its own it is not very informative. Do not expect, therefore that the diagnosis alone will lead a school to recommend a particular type of support. It will be necessary to get an assessment by a professional such as an educational psychologist or speech and language therapist. This will allow school staff to characterise the child’s profile in terms of difficulties they are familiar with. XYY is a risk factor for developmental difficulties, especially those affecting language and social interaction, but your child’s personal profile of strengths and difficulties needs to be identified.

Niamh explains how her son receiving a diagnosis of autism spectrum disorder is much more likely to get him the help and support:

**“ Adam is 16 now and there is still no support. I think it’s through lack of**

2 <http://www.rarechromo.co.uk/html/DisorderGuides.asp>  
See also: Useful resources at end of booklet.

*awareness because you say 'autism' ... health professionals have treated my son completely different now he's got the autism label to XYY – everybody wants to know about him because they think they know what to do. 'Oh we don't know about XYY so we'll just ignore it'. They avoid it because they don't know what they're supposed to do."*

Niamh's experience mirrors that of many parents; with regard to XYY, although the school is aware, there may not be much they can do. An alternative is to tell the school only about your son's difficulties and not mention XYY as Lesley did. She explains that, although her son's school do not know about his XYY, he is still receiving support as he has been assessed for his learning difficulties:

**66** *Dylan got extra time on his GCSEs and I hadn't told the school. The school have never known about Dylan [having XYY] because I think he was just lucky that he had teachers who, various things, but you know he obviously performed quite well in the class doing things but when he actually came to write his thoughts down, and then they just realised that he was never finishing work, he was doing good quality work but he was never finishing it, and I think so they then decided to get him tested. And that's when they found that you know obviously he has difficulties with processing and handwriting."*

## Things to consider

### Telling the school

#### Deciding whether to tell the school

- If your son is not experiencing any difficulties, then telling the school about XYY may do more harm than good, by creating low expectations.
- If your son needs help and support at school, then a XYY diagnosis may be helpful in getting his needs taken more seriously. It's important to remember, however, that even after telling the school you may still need to fight for your son to get support.
- Schools that have a good track record with children with disabilities might be more understanding and more accommodating of any specific needs.

#### Deciding how to tell the school

- Print off some information about XYY and be prepared to explain a bit about it to the school.
- Discuss the specific difficulties that your son is experiencing, and ask for a professional assessment of his educational needs.

# Deciding whether to tell other family members and friends

Telling other members of your family or confiding in friends can provide a vital support network for your family, though there may be other concerns such as not wanting any pity or for your son to be pre-judged.

One of the most compelling reasons among most parents for telling other family members and friends was for support. David explains that his mother-in-law is very supportive and attends all the school meeting about his son, Brandon:

**“***Our family members know. The mother-in-law [travels to see us] and she attends these ... we have these meetings with all the so-called professionals around the table from all the schools ... we have these meetings maybe once every two months to discuss Brandon and the so-called plan of action. I haven't really got involved myself because I'm working away from home, but she does go – she's done the rounds at all these support groups.”*

If family or friends start to ask questions about your son, this could be a good opportunity to disclose about his XYY. Sarah explains how friends have begun to point out her son, William's, height and she is wondering whether this could provide the opening she needs to tell them about his XYY:

**“***When we go to parties now, a lot of the parents say 'your son is pretty big for four years'. Everyone says 'wow, he's big'. But for yourself, it grinds on you, doesn't it? Because they look at me and they think 'you're awful short, how is he so big?' and you think 'should I explain that situation?' ”*

Some parents were worried that by telling others, their child might be labelled or stigmatised. However, other people's ignorance of the condition can actually work in your favour. Rebecca explains that when other people haven't heard of XYY, they will only know what you tell them:

**“***Yeah it's not until recently that I've started telling friends. I think you just have to be prepared to go to friends with the little Unique booklet and just don't rely on anybody looking anything up and in fact tell them to not look at too much stuff on the internet as there is always false information. I just go and*

*print out from Unique - and that is quite succinct and the booklet, it's just constantly taking it with you and not expecting anybody to know anything off their own back and say 'this is it'."*

If your son isn't experiencing any difficulties, then friends and family may not notice anything is wrong and you may decide to not tell them. Jamie explains that although his son, Nate, is developmentally behind his sister, Naomi, only his Mum knows about Nate having XYY as he doesn't really have any obvious problems:

**“***I mean with Nate, there's not a lot of difference really ... because we've just had a little girl as well and she seems a lot more developed than he is. She's only just over one and she's doing things a lot faster than he was doing ... he's got the same about the speech, and things like that. But from my point of view, he seems quite a normal boy. Not all the family knows – my Mum knows but she's like 'it's nothing, he's right as rain', which 90% of the time he is.”*

David argues that instead of telling his family and friends for support, he finds it more useful to talk to other families who have a son with XYY as they are able to better understand what he is going through:

**“***It is good to be talking to people that are on the same level as yourself and seeking the same information as yourself. It's always chatting to somebody who knows nothing about it or it was a parent with a kid with XYY or other problems – it's pointless talking to somebody who doesn't show an interest in it themselves. I think it's really reassuring to speak to other parents.”*

In contrast, some parents felt that being open with others was the way forward. Sinead explains how she has been open with her family and friends and also how her son, Sean, is keen for her to tell other people about his XYY.

**“***Yes – probably most of our family know. Some of my close friends know as well. It's not made any difference or anything. [Sean]'s very, sort of, keen that people know about it and so (a) people don't treat him like he's some sort of weirdo and (b) so that people know how to appropriately handle it.”*

## Things to consider

### Telling family and friends

#### Deciding whether to tell family and friends

- Family and friends can be a great source of support and choosing to tell them can provide you with someone to help you through any difficulties.
- You may want to consider being wary of stigmatisation, although most people are ignorant of the condition, and so will only know what you tell them about XYY.

#### Deciding when to tell the family and friends

- Are friends and family asking questions? This may happen if your son is clearly having difficulties or not meeting milestones and this can provide an opportunity to let them know about the XYY.

#### Deciding how to tell the family and friends

- Think about telling others about the difficulties your son faces or going into more details about the genetics of the condition.
- If family and friends ask about your son, this could be an opening to tell them about his XYY.

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