

Talking with your child about her diagnosis of Triple X syndrome



Many parents wonder how and when they should tell their daughter about her diagnosis of XXX syndrome. Some people also call this Triple X or Triplo-X or XXX. This guide offers some suggestions for talking with your daughter about XXX. As part of a research study, we asked adults and parents of children with X or Y chromosome variations about their experiences discussing the diagnosis. We also asked what advice they would give other parents who are planning to talk about the diagnosis with their daughter for the first time. This guide was developed from their responses, as well as from recommendations by healthcare professionals.

Why is talking about the diagnosis important?

There are many reasons why talking about the diagnosis is important for your daughter and your family:

- Children with Triple X often experience speech, learning or social challenges starting at a young age. They may feel different from their peers. Having information about the diagnosis can help your child to understand and accept her differences.
- Your child should hear the diagnosis from you, or from a support professional (like a doctor, therapist or genetic counselor) with you there. Your daughter can then address questions and concerns with you when she has them. Otherwise, your child may learn of her diagnosis incidentally. For example, she may overhear it in a conversation, or be told by a healthcare professional or teacher who assumes your child already knows. This may cause feelings of betrayal and misunderstanding.
- Children are intuitive and often aware when something is being kept secret. They may imagine something much worse than their diagnosis, like that they or a family member has a serious illness.
- Secrecy or reluctance to talk about the diagnosis may make your child feel that Triple X is shameful or embarrassing. If your child feels that you are uncomfortable talking about Triple X, she may avoid asking you questions. Instead, she may seek information from sources that could be unreliable or unsafe.

Common Parent Concerns

It is normal for parents to have concerns about telling their child about her diagnosis. You may be worried that:

- Your child will think that she is different or that there is something wrong with her, or that it will lower her self-esteem.
- You do not know enough about Triple X to explain it correctly, or to answer questions your child might ask.
- Your child will use her diagnosis as an excuse not to try when she faces a challenge.
- It will make your child feel upset, scared, or angry.
- Your child will not understand the information.
- Your own emotions will interfere with talking to your daughter about her diagnosis.
- Your child will not understand when it is and is not OK to tell other people about her diagnosis.

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How will my child respond?

Your child's maturity level, personality, and symptoms will affect the way she responds to the diagnosis. Keep in mind that your daughter's feelings towards the diagnosis may change over time. Your daughter may:

- Feel relieved
- Want to know who else knows, or when the diagnosis was made
- Need time to think about it
- Have a neutral reaction, seem disinterested, or act like it is "no big deal"
- Feel sad or angry
- Feel confused
- Feel special or think it is "cool"
- Wonder why it has happened to her
- Watch to see how you feel about it
- Ask questions about what the diagnosis means for her or how it will affect her future
- Show her emotional response through her behavior or actions, such as acting out or a change in appetite.
- Have a delayed reaction. For example, your child might seem disinterested at the time of disclosure, but distressed the next day. Or, she may ask more questions later.
- Have varied reactions to different aspects of the diagnosis. For example, your daughter might feel anxious about speech therapy, but relieved to know why she is struggling socially or in school.

Preparing for the conversation

- Become informed about Triple X before you talk with your child. Seek answers to your own questions from doctors, other parents, and reliable websites and books. This may help you to feel more confident when talking with your daughter.
- Children often pick up on their parent's emotions. Take the time you need to work through your own feelings about the diagnosis and about talking to your child. You may want to seek support from family members, friends, a professional therapist, support groups, or community groups of other parents of daughters with Triple X.

When is the right time?

Many parents wonder about the "right time" to bring up the diagnosis. Here are some considerations for when to begin the conversation about Triple X with your daughter. Remember, there is no specific "right" age, and every child is different.

- Keep in mind that there is not likely to be a "perfect moment" to bring up the diagnosis for the first time.
- For children diagnosed prenatally or in infancy, it can be appropriate to first mention the diagnosis around age 4 or 5. For girls diagnosed in childhood or adolescence, discussion may start at the time of diagnosis.
- Even if your daughter is young, it may be helpful to talk about Triple X a little at a time as relevant to her age and symptoms. For example, when going to speech therapy or if she is struggling with motor skills.
- Your daughter should be aware of her diagnosis before she enters adolescence.
- Rather than create an event, like going out to dinner or a special outing, try to find a casual time for the disclosure conversation.

Other opportunities to discuss Triple X include:

- If she experiences learning or social challenges
- When she brings it up
- Preparing for appointments (i.e. doctor, therapy, tutor)
- If she needs medications or treatments
- Triple X conferences or family meetings
- If she is learning about related concepts in school (i.e. chromosomes, human body, cells)
- Books, movies, or TV shows with related topics

- Consider talking to your child's doctor or therapist about your plans to disclose the diagnosis. He or she may have advice on age-appropriate ways to talk with your daughter. A healthcare professional can also help you to disclose the diagnosis to your child, or to talk to your child about specific aspects of her condition.
- If your child has more than one parent or caregiver, discuss together ahead of time how and when you will talk to your daughter about her diagnosis.

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What Should I Say?

Your daughter's unique needs and your family communication style will influence how you discuss your daughter's diagnosis with her. Some points to consider:

- Keep it simple - most children need minimal information at the start
- Be honest and direct. Do not give false or misleading information that may cause her to be confused.
- Keep a light, calm, and positive attitude.
- Encourage your child to ask questions and to share what she is feeling or thinking, acknowledging she may need time.
- Express support and reassurance. Offer to help your child get any help she may need for the challenges she may experience.
- Relate your daughter's condition to others' differences or challenges, with examples relevant to your child and your family. For example, others who required tutoring or therapies to help them.
- Consider using pictures or other visual aids when talking about complex topics like chromosomes.
- Identify your daughter's strengths and positive qualities. Also try to identify good things about the diagnosis (such as it may be part of why she is tall, artistic, or has made her more sensitive to others).
- Let your daughter know there are a lot of other girls and women with Triple X.
- It is ok if your child has questions that you are unable to answer. Become comfortable with telling your child, "I don't know, but we can find out together."
- Tell your daughter that it is always ok to ask about anything she may read, hear, or wonder about. Let her know that many things she reads or hears about Triple X may be wrong.
- Help your daughter identify appropriate places to seek information about her diagnosis, such as her doctor, safe websites or books. Encourage her to bring any questionable information to your attention.

Developmental Considerations

Remember that you do not need to talk about everything at once. The topics you discuss and the words that you use will depend on your child's age and experiences. These are some age-appropriate suggestions:

Preschool/Kindergarten:

- Explain that your daughter's body and brain are made a little differently than other children, and this means that she might need more help (i.e. speech therapy) or that some things may be harder for her than other children.

School age:

- Begin talking about chromosomes and genetics, providing more details as your daughter learns about these topics in school. Reiterate that some information she learns at school may be wrong, and to talk to you if she has questions.
- Reassure your child that Triple X is a condition they were born with. It is not a disease, and that it is not contagious or fatal.

Adolescence / Adulthood:

- Talk with your daughter about her feelings about sharing her diagnosis with friends and romantic partners.
- Let her know that she will need to talk with a genetic counselor before having babies. In most cases, fertility is normal and Trisomy X is not something that is passed along to her children. But, there is a small chance of having children with chromosome differences and she should discuss these risks before getting pregnant.
- Discuss ways that your daughter can become proactive and involved in her health care. Encourage her to ask her doctors questions.

Talking about privacy

- It is important to discuss with your child who is appropriate to tell about the diagnosis, and who may not be appropriate.
- Tell your child that sharing the diagnosis is a personal decision to be made by the child and her family. Most people will not understand what Triple X means.

Talking about genetics and chromosomes

- Chromosomes and genes may be explained as "instructions (or messages) for the body," or as "pages in an instruction book." Triple X is caused by "extra instructions" or "extra pages."
- It is important to emphasize that Triple X is something that "just happens" and that she was born with this; no one caused your daughter to have it. Avoid using the words "mistake," "accident," or "mutation" to describe this condition.
- Be careful when using the terms "sex chromosome" or "sex chromosome abnormality." Your daughter may confuse these terms with having a "sex abnormality."

Remember:

- Talking about the diagnosis is not a one-time event. It is a process that will happen gradually over time.
- Every child with Triple X is different with regard to her needs, comprehension, communication and coping skills. You know your child best.
- Consider seeking support for talking with your child about her diagnosis from your child's physician, therapist, or other healthcare professionals.

Sources for this guide include:

- Tartaglia, N., Howell, S., Sutherland, A., Wilson, R., Wilson, L. (2010). A review of trisomy X (47,XXX). *Orphanet Journal of Rare Diseases*, 5:8.
- Tartaglia, N., Howell, S., & Bornstein, A. How to talk to your child about his or her diagnosis. Presentation at KS&A Families Conference (2008).