

What is the best age to tell my daughter?

This is a very difficult question to answer. Only you can really answer this question because you know your daughter. You understand what information she will be able to handle at a specific age. It is really up to you to decide the best age to discuss the different aspects of the condition.

However, there are aspects of the condition that can be communicated at an early age e.g. the swelling of the feet, short stature but perhaps the fertility issues could be explained when she reaches the stage at which she may need to be preparing for pubertal induction.

What should I say?

This is difficult and some parents feel that they are ill-equipped to handle questions from their daughter and need time to adjust to the diagnosis before telling her. Explaining all the facts to the child can be perceived as just too hard.

Gauging just how much information to tell her can be difficult. This is a very personal matter and you will have to decide how to progress it. You may decide to tell her everything all at once, or you may just tell her about certain aspects as they arise. There is no right or wrong way to do this; it depends on you and your daughter. But remember, honesty is always the best policy.

If you have a problem explaining the condition to your child there are many avenues of help ranging from your health professional team to the Turner Syndrome Support Society who can all advise and support you in your particular situation.

Overall, disclosing this information must be done in a timely, caring, and sensitive manner.

What happens next?

When you have talked to your daughter you may find that you feel as if a weight has been lifted from your shoulders. Your daughter will trust what you are saying to her; she may not understand all of the information, but it will be a base from which you can all work together and move forwards. Encourage your daughter to be a positive person in all areas of her life and this will give her the confidence to accept her condition and maximise her potential.

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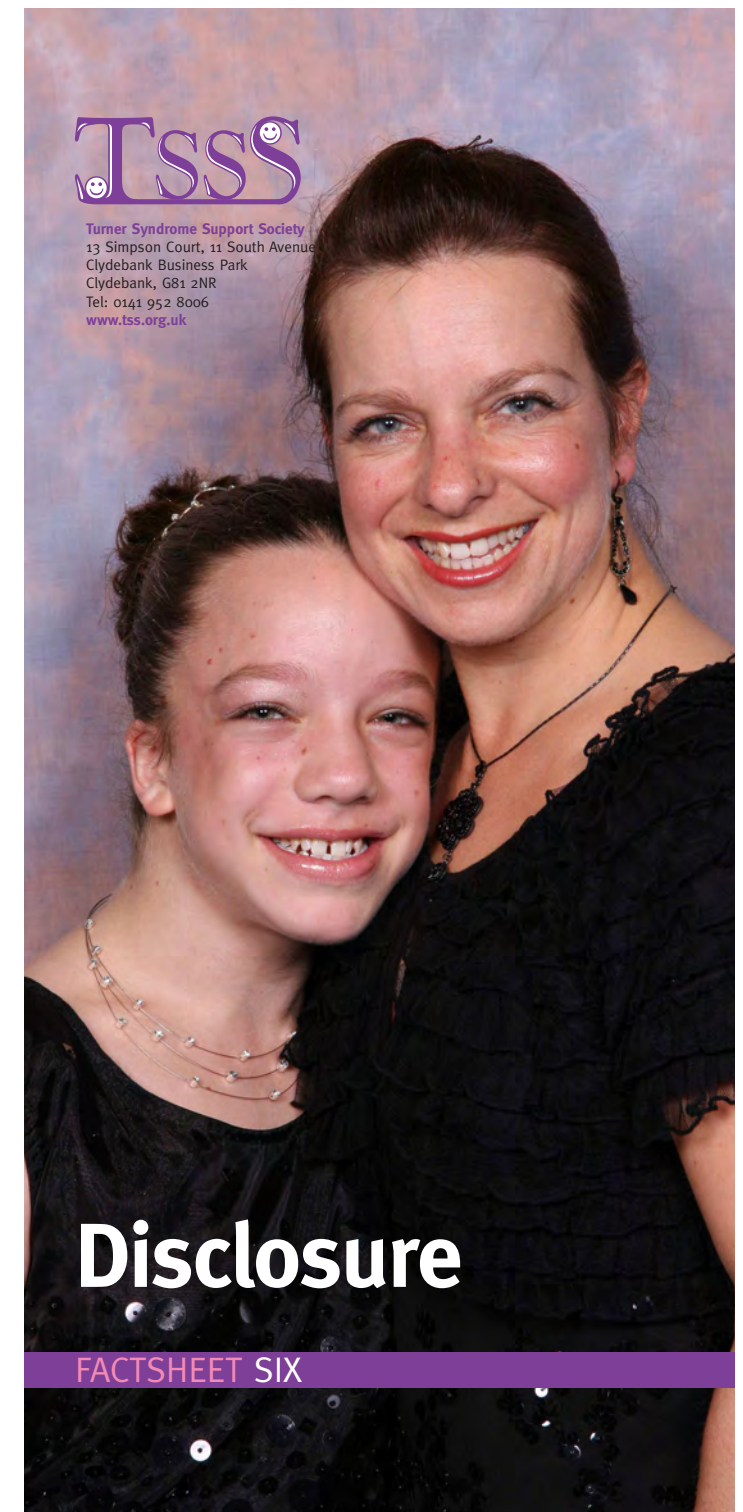
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Further information about Turner Syndrome can be obtained from:

Arlene Smyth,
Executive Officer, Turner Syndrome Support Society [UK]

13 Simpson Court,
11 South Ave,
Clydebank Business Park,
Clydebank G81 2NR.

Photos courtesy of www.charliesmissus.co.uk



Disclosure

Discussing Turner syndrome with your child may be extremely difficult and challenging. There are so many aspects to the condition. It is not uncommon for parents to withhold information from their child or just to disclose selected aspects. There is no right and wrong way to deal with this; it is very personal to your own family situation. There are no hard and fast rules; everyone is an individual and you know your own child. How you decide to deal with disclosure is entirely your decision. However, this leaflet discusses some of the issues and attempts to provide some direction and support.

What could happen if I don't tell my daughter that she has Turner syndrome?

We all want to protect our children from things that we think will harm or hurt them. Some parents just want to protect their daughter from the ill-perceived 'stigma' of Turner syndrome and the so-called 'heartbreak' of infertility. These are very natural reactions. However, failure to disclose this information to your daughter may result in problems when she reaches the age at which she understands her condition, and becomes responsible for her own health and social welfare. Attempts to 'protect' your child and keep secrets from her can backfire as many children experience anger and feel upset if they discover some aspect of their lives that has not been told to them. They may also feel that their family has betrayed them or they lose trust in them.

It would also be very upsetting for your daughter if she hears about her condition unexpectedly e.g. by overhearing conversations or from a health professional who assumed that she already knew she had Turner syndrome.

People with disorders involving sexual development often say that the shroud of secrecy surrounding their condition was harder to adjust to than the medical features of the condition and its treatment. The sense of 'betrayal' by health professionals and family members can also reduce their value as important sources of information and support.

Why is it important that she knows about her condition?

It is important that everyone involved with your daughter is as informed as possible in order to ensure that she receives the best possible care and support throughout her life.

Knowledge is an extremely useful tool. The more information she has, the more aware she will be of any medical problems that may arise and the better equipped she will be to handle any issues that may come her way. She will also be able to understand aspects of her life that may be different to other girls and ensure that she keeps herself fit and healthy.

Your daughter will need a wide range of external support and understanding not only from her health professional team, but also from her friends, school and workplace. The more support and understanding that she receives the easier and more positive her life will be.

