

Introduction

The birth of any child is an exciting time for parents and family. There are always many questions and concerns, but in this day and age most prospective parents are sufficiently aware of any potential issues arising from the birth of their child that they are ready to cope with most eventualities. The medical profession and support groups are working together to ensure parents are better equipped to deal with a growing number of situations that may follow the birth of a child.

One such situation where communication between parents, the medical profession and support groups is very important, is the birth of a child with genitals that are a variation of what most people consider 'normal' male or female. There are immediate and long-term matters that need to be considered, but most importantly to start with is the fact that atypical genitalia (sometimes referred to as 'ambiguous' genitalia) are not a threat to the life of your child. The medical profession has an excellent understanding of any underlying health problems that may be present with such a birth and are well placed to manage any of these. So that you may better understand the situation that you and your child face, this guide has been prepared to explain some potential issues to you.

Contact us for support.
We've been through this too.

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Recommended treatment paradigm

- 1 *Obtain an accurate diagnosis. Obtain complete information about your child's condition.*
- 2 *Raise your child as a girl or a boy – expert medical advice will help you decide.*
- 3 *Contact peer support groups that deal with your child's specific diagnosis. Other general intersex support groups can also help connect you with parents who are in a similar position.*
- 4 *Seek appropriate counselling to help you (and your family) deal with your child's condition.*
- 5 *If surgery is recommended discuss all treatment options and seek a second opinion. Do not rush into making a decision. Always consider the option of no treatment.*
- 6 *Inform your child about their body in stages as they become old enough to understand certain concepts (such as people are all different, not everyone is able to have children, etc).*
- 7 *Ensure your child is fully informed of their condition by the time they are around 16 years old, and allow them to make decisions about their treatment (such as hormone therapy and any surgeries).*

A guide for parents of children with atypical genitalia



Peer-support, information and advocacy for people with Androgen Insensitivity Syndrome (AIS), other intersex variations and their families

How did this happen?

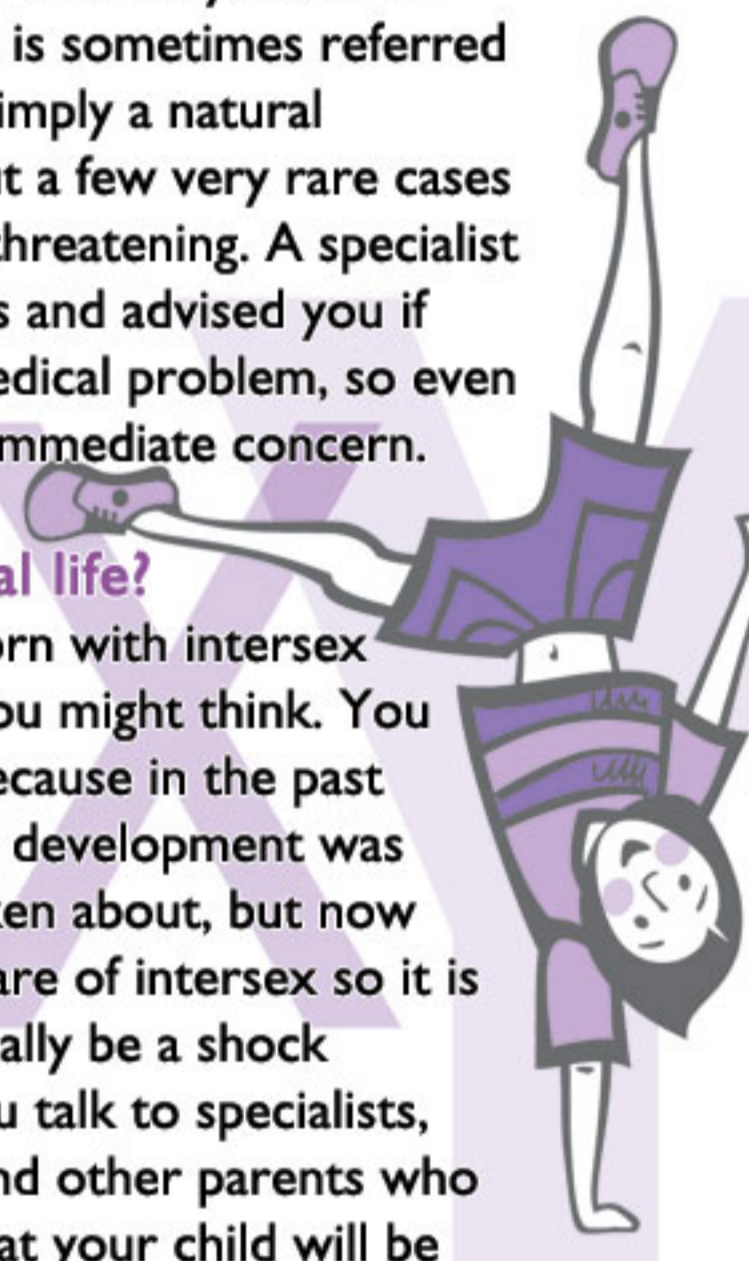
All children's sexual reproductive organs (including genitals) start out exactly the same way and have the potential to develop before birth anywhere along a spectrum with male at one end and female at the other. Children that are born somewhere along this spectrum have what are called 'intersex' variations. Some children with intersex variations are born looking as any other boy or girl but many are born somewhere "in between". This is sometimes referred to as atypical genitalia. This is simply a natural biological variation and in all but a few very rare cases does not indicate anything life threatening. A specialist will have taken immediate steps and advised you if your child has an underlying medical problem, so even in these cases health is not an immediate concern.

Will my child have a normal life?

Many children each year are born with intersex variations; it is not as rare as you might think. You may not have heard of these because in the past anything that concerned sexual development was considered taboo and not spoken about, but now more and more people are aware of intersex so it is easier to talk about. It may initially be a shock however you will find when you talk to specialists, members of a support group and other parents who have dealt with these issues, that your child will be just fine. People with intersex variations live happy and productive lives, have successful careers in their chosen profession, are married, have families and do all the things you hope any child will one day achieve.

What should I do?

Like any medical condition there are some situations early on that you will have to deal with. Family and friends will want to know if your child is a boy or a girl. With family, it may be easier to tell them that doctors are not completely sure, so they just want to do some tests to make absolutely certain. With friends, it is probably better initially to tell them that you have had a boy or girl, specialists will be able to give you some initial guidance with this. Don't worry if it turns out that this initial judgment is not later the case, there are ways of explaining this as having been a mistake that will not draw too much attention.



You can also provide close family and friends with a brochure about the condition if you feel that's appropriate.

Is my child a boy or a girl?

Undoubtedly the hardest decision you will have to make at this early stage is whether you should raise your child as a boy or a girl. It is important to make a decision to raise your child as either a boy or girl, but remember, only your child will really know if they identify as male or female (this is called their "self identified gender"). It used to be widely believed, that a child's self identified gender could be created by simply raising a child as either a boy or girl. There is ever increasing evidence that shows children already have a self identified gender when they are born and although this can be influenced by upbringing, it cannot be completely erased. Specialists can perform tests that will assist determining if your child is likely to identify as male or female. This is accurate in most, but not all cases. Even in cases where your child rejects the sex he or she is being raised as, there are specialists and support group members that can help you should this situation arise.

Once a decision is made to raise your child as a boy or girl, the most important thing is to take your time and carefully consider the next steps you take. There is a temptation with any childhood medical condition to want to deal with it straight away or make it "disappear" so that you can get on with other things. As mentioned earlier, an intersex variation is not a threat to your child's health, so there is time to consider what you think is best for your child and for you as a parent.

Surgery – thinking through the alternatives

After a decision is reached to raise your child as a boy or girl, you will have to decide what treatment your child should undergo early in life and what treatment to leave until your child can decide for themselves. There are advantages to both early and late treatment and it is very important to weigh these up very carefully before making a decision on behalf of your child as some treatments are irreversible.

Some people born with atypical genitalia are given surgery to 'cosmetically' alter the appearance of their genitalia when children, some choose to have this as teenagers or adults, and some choose not to have any surgery at all. The legal position about whether parents can or cannot consent to irreversible, non-therapeutic surgeries on children and adolescents is currently uncertain, but **consideration should always be given to all possible treatment options**, including the benefits gained from not performing surgeries at all.

Early surgery may avoid certain social situations that you and your child would rather not have to face. There is also evidence that children heal quicker and more successfully. However, should the child decide later this is not what they wanted, it is impossible to undo some surgeries and this can make it very difficult for both the child and parents to deal with. Support groups and specialists will of course help should this situation arise, but there is a limit to what can be done medically in such circumstances. Surgery also has the potential to adversely effect sensitivity of the genital area and whilst technological improvements have reduced the effect of this, there will always be some nerve damage with each surgery.

The other choice is to leave any decision about surgery to your child once they are old enough to understand and make a decision for themselves. If they decide to have surgery they are making the decision they feel is best for them. This is especially important if their self identified gender turns out to be different to what was decided for them as a child, as then they wouldn't face the complexities of undoing something they feel was inappropriate. However, there may be some difficult social situations that your child and your family may be faced with such as what to tell baby-sitters, how to avoid a child being teased in change rooms at school or what to tell the child about their own body.

Specialists and support groups all recommend telling the truth to a child about their condition, in stages that the child can understand.

