

## Take Home Tips

- Don't rush, take the time to consider all possible options before making decisions
- Ask questions of your health professionals
- Remember you are not alone, speak to those who have lived experience
- Self-reflect, know what is driving your decision making
- Consider your child's/tamaiti's right to bodily autonomy and self determination
- Seek psychological and peer support when you are ready
- Be norm critical, challenge outdated societal stereotypes and norms around gender
- **Loving and accepting your child/tamaiti is the best medicine for a healthy happy child /tamaiti**

## Supports and Resources

**Intersex support for parents:** [www.facebook.com/groups/IntersexPS](http://www.facebook.com/groups/IntersexPS)  
Moderated private group for parents of children with a VSC

**Intersex Aotearoa:** [www.facebook.com/intersexaotearoa](http://www.facebook.com/intersexaotearoa)  
Advocacy and education

**VSC - A practical guide for parents in Aotearoa:** [vsc.org.nz](http://vsc.org.nz)  
Website with information for parents -more detailed version of this pamphlet

**DSD Families: top tips for talking:** [www.dsdfamilies.org/parents/talking](http://www.dsdfamilies.org/parents/talking)  
Guide for talking to children about their VSC

**Youth&I: Stories from young people with a VSC:** [youthandi.org](http://youthandi.org)

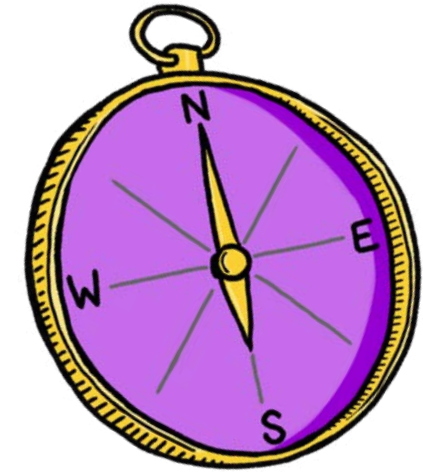
**Intersexion:** Award winning NZ documentary available at your local library

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## Variations in Sex Characteristics/ Ira Tangata



## Navigating Healthcare Decision Making



The information is based on research here in Aotearoa in collaboration with those with lived experience, health professionals, and researchers from the University of Otago.

**A brief guide for parents  
and caregivers in Aotearoa**



## Kia ora, nau mai, Haere mai

Welcome to this brief guide for parents or caregivers of a child/tamaiti with a variation in sex Characteristics\*/Ira Tangata (VSC) here in Aotearoa. The aim is to give you the information to strengthen your skills to best support your child/tamaiti now and for their future.

### Every Person's Body is Unique

Innate variations in sex characteristics (VSC) manifest in a spectrum of ways, many occurring naturally and in most cases are not life threatening. The cause is not always known but science tells us VSC often results from variations in chromosomal, hormonal processes and or gonadal development. These variations can be diagnosed at birth or present at puberty.

There are over 40 variations, and many people may not be aware such variations even exist. Most people only know the name of the specific variation relevant to their child /tamaiti (for example, Congenital Adrenal Hypoplasia or CAH) and are not aware of other variations.

### Getting the News

It can be a bit of a surprise to learn your child /tamaiti has a VSC. It is important to take a deep breath and some time to process what you know and what you need to find out. Ask to talk to other parents who have a child/tamaiti with a VSC.

### What we do

The most important thing to do is to talk to people you trust and take the time to be fully informed. Take time to consider not only what this means for you child/tamaiti now but for their future.

It is important to take the time to reflect on your own point of view and how this may impact on your decision making. Our own views and beliefs can blind us to different ways of thinking about what is considered "normal." It is helpful to try and expand our understandings of the norms we might take for granted as truth when in fact it they can be driven by certain societal structures we have adopted at any given point in time.

We use the umbrella term VSC as it is seen as a more inclusive term -we recognise this may not suit everyone. Others may use/prefer Intersex, Differences in sex Development (DSD), Takatāpui or Ira tangata.

## Privacy v Secrecy and Telling Others

It can be difficult deciding who to tell about your child's/tamaiti's variation. You may want to keep things private until you feel clearer in your own mind and have processed your own feelings and thoughts.

Privacy is about taking time to be with your own thoughts and feelings. Everyone is entitled to privacy, including your child/tamaiti. Maintaining privacy can involve choosing a small circle of trusted people who you can talk to. It can also mean that you and your child/tamaiti can choose over time what you share with others.

Secrecy, on the other hand is intentionally hiding information; this can be unhelpful and even hurtful. Secrecy often creates an atmosphere of shame for those who are at the centre of the secrecy. Keeping things secret can mean you don't access the support you need.

Having a VSC is one part of what makes your child/tamaiti unique. Encouraging acceptance early on will enable your child/tamaiti to feel confident in their own body.

### Taking a Balanced Approach

Parents and health professionals are tasked with balancing the health needs of their child/tamaiti and with thinking about their child's/tamaiti's right to have agency over their own bodies. This means gaining understanding about what is essential for your child/tamaiti now and what may be delayed until your child/tamaiti becomes a young adult/rangatahi. This would give them the opportunity to choose to consent to what happens to their body.

Options for healthcare may be straightforward depending on your child's/tamaiti's variation. It is best to find out what the options are for your child's/tamaiti's specific variation as they will all have different things to consider. In some instances, there is limited robust research as to outcomes for interventions. This includes timing of interventions, that is, whether to do them early or later.

This is where things can become complex and confusing especially if opinions vary between those you speak to or read about from online VSC peer based support. Take your time, don't rush, gather as much detail as you can from a variety of sources, health professionals and VSC support groups. Remember it is alright to ask for a second opinion, whether that be from a doctor or a parent with lived experience. Seek out information that balances different opinions so you can weigh the pros and cons. Make sure the information is specific to your child's/tamaiti's VSC.

## Decision Making Process Summary

Important questions to consider before you make healthcare decisions.

### Communication

- Have I been provided full information?
- Have I been given options?
- Has supportive and sensitive language been used?

### Support

- Have I been offered and got the support needed?
- Have I got access to peer support?

### Expectations

- Whose expectations am I meeting - mine, society's, my family's and friends', or what I think will be the expectations of my child/tamaiti?

### Recognition of those with lived experience

- Have I considered what those with lived experience have said?

### Future Thinking

- In the future will my child/tamaiti be happy with me and the decisions I am making for them now?

### Identity

- Have I considered identity develops over time and is deeply personal?
- Imagine how it will be in 15/20 years from now when your child /tamaiti is a young adult/rangatahi

### Bodily Autonomy

- Does my child/tamaiti have the right to decide what happens to their body?
- Can some decisions be delayed so my child can exercise self-determination and decide for themselves?

### Norms/ Stereotypes

- Have I considered what norms and stereotypes I am accepting or rejecting?
- Is diversity and acceptance of difference a part of my thinking?

