

A guide for family members, friends and partners of people with variations in sex characteristics



Easy read booklet

Who we are and what this booklet tells you about



We are a team of people who work at the **University of Exeter**.



We did a **research** project called **Reprofutures**. **Research** is work done to find out new information about something.



We got help to do our project from

- **Exeter Engaged Research Exploratory Awards**
- **Wellcome Centre for Cultures and Environments of Health.**



Reprofutures is a project about people with **variations in sex characteristics** (called **VSCs** for short).



Sex characteristics are some of the body parts you are born with.

This includes sex organs inside and outside of your body, like a penis, testicles, a vagina, ovaries or hormone levels.



Variations in sex characteristics means some of your sex characteristics may be different from what is usually expected.

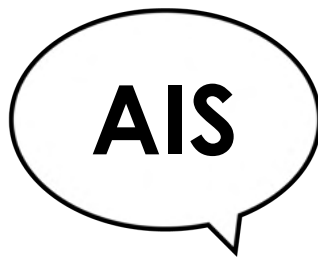


We use VSC to describe lots of different things people might **experience**. **Experience** means things you have done or felt in your life.



People with VSCs might have a different name they use for their experience, like

- diverse sex development
- sex chromosome conditions
- intersex traits.



People with VSCs might have **conditions** called

- complete and partial androgen insensitivity syndrome (called **AIS** for short)
- Swyer syndrome
- classical and non-classical congenital adrenal hyperplasia (called **CAH** for short)
- hypospadias
- Klinefelter syndrome/XXY
- Mayer-Rokitansky-Küster-Hauser syndrome (called **MRKH** for short)
- 17Bhsd3
- Turner syndrome.

These **conditions** are the names for types of sex development which are different from usual.



People with VSCs and people from VSC support groups were part of our project team.



This booklet is a guide for family members, friends and partners of people with VSCs.

Understand the challenges



Learn and think about VSCs

When you support a person with a VSC it is good to learn about their situation and understand the **challenges** they face.



Challenges are difficult problems that happen in life.



You can learn about their VSC **diagnosis** to help you understand better.



Diagnosis means the medical explanation for their condition.



The person with a VSC might tell you what they want you to learn, or they might be happy for you to read, watch films or look online yourself.



If you learn about their situation, it can help you understand your feelings.



Have an open mind

When you support a person with a VSC you should have an **open mind**.



This means you should listen and try to understand new ideas, even if they are different from ideas you are used to.



People with VSCs can feel ashamed and want to keep their condition a secret.



They might find it hard to trust other people and let them help.



This is because **society** says some ways of living are normal and other ways are different and not as good.



Society means the communities we live in and the people we live with.



Fertility

When you support a person with a VSC you should understand about **fertility**.



Fertility means how easy or difficult it is for a person to have children.



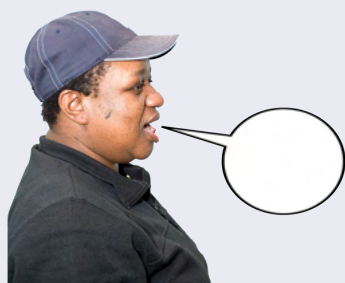
Fertility can be a challenge for people with VSCs.



There are lots of different ways to have children or to have a happy and full life without having children.



Talk to the person with a VSC about what they want and what is possible for them. Support the choices they make.



Here are some things people with VSCs said

I'm not wrong and there's nothing wrong with me, but I live in a society that has a different idea about what the right way to be is.



I like it when I say 'I'm like this' and someone thinks it's OK and a good way to be.

How to support a person with a VSC



Listen to them

Listen to the person with a VSC. This is important. It helps them trust you.



Don't **judge** them. This means don't decide what they say is right or wrong.



Let them tell you how they feel and listen in a kind way. It's OK if you don't know what to say.



Don't talk about other people's situations or tell them how they should live their life.



Support them to make their own decisions about their life and their body.



Talk about other things

Make sure you talk about everyday things. Don't only talk about the challenges they face.



Get professional help

There are **professional** people like counsellors or clinical specialists who can talk to people with VSCs.



Professional means they have special training to do their job.



There are also people who do **physical therapies** who can help. This means they do work on your body to help your mind feel better.



Professional people don't know the person with a VSC outside of helping them.



This might make it easier for the person with a VSC to trust them.



It can be good to get professional help if you are worried about the person with a VSC and don't know how to help them.



Be kind

If you have argued with the person with a VSC about things like fertility or medical treatments in the past, they might find it hard to trust you.



Be kind and wait until they feel happy to talk to you about their situation.

Plan for the future



Be positive

Think about how you behave when you are with the person with a VSC. Be positive about their decisions.



If you show you are shocked or upset, it shows them you are thinking about how you feel and not how they feel.



Be ready for change

The way we feel and what we want can change over time.



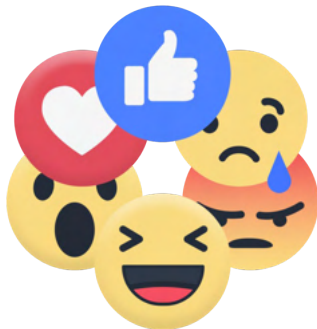
It takes time for people with VSCs to understand what their diagnosis means for their lives.



They might change their mind about things like how they feel about having children.



Don't make them feel like they have to make big decisions about their lives until they are ready.



Try to support them at all times and understand their feelings might change over time.



Here is something a person with a VSC said

We don't always have the same ideas and feelings at the same time, but the important thing is we want the same thing in the end.

Social life



Relationships

Celebrate relationships the person with a VSC has with other people, like being a friend, a brother or an aunt.



These relationships might not be the same as being a parent, but they are important.



Make sure they know their love and friendship matters and makes a difference.



Include people with VSCs

Don't be afraid to ask a person with a VSC to come to social events you are worried might upset them, like a baby shower.



Ask them to the event and let them decide if they want to come or not.



If they do come, let them be part of the event in a way that works for them on the day.

Help them talk about their situation



Some people with VSCs want to talk about their situation and some don't.



Let them decide who they want to tell and how much they want to tell them.



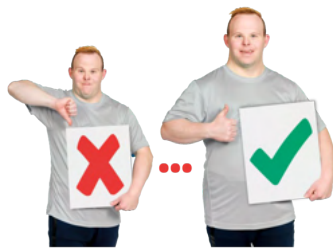
When people say bad things about them it can hurt their feelings. They can find it hard to talk about their situation.



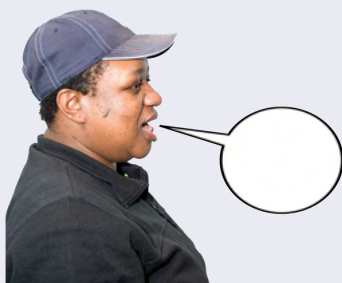
If they are happy for you to help, you can support them by talking to other people about their situation.



You can help other people learn about VSCs. You can help them understand the challenges people with VSCs face.



This helps the person with a VSC to not feel alone and it helps change the way society thinks.



Here are some things people with VSCs said

I wanted to talk to people about my situation so they could support me, but I didn't know if they would react in a good or bad way.



I find it hard to talk to people about my situation. It's stressful to explain my diagnosis and my choices over and over again.

Look after yourself



When you support a person with a VSC it's important to look after yourself and think about your own feelings and hopes.



Remember, the person with a VSC might not be able to support you while they try to understand their own feelings about their situation.



You might want to get professional help from someone like a counsellor.



You might want to join a VSC support group where you can talk to other people in the same situation as you.



You can do this on your own or with the person with a VSC.



Getting professional help or joining a VSC support group can help you understand your feelings better.



It can help you support them better too.

If your partner has a VSC



Talk to each other

If your partner has a VSC it's important to talk to each other in a clear and open way.



Make sure you both say what you think and what you want. Try to understand each other's point of view.



Keep talking to each other. Things can get easier over time as you both get used to the situation.



If your partner doesn't want to talk to other people about their situation but you need support from your family and friends, try to find a way to make this work for both of you.



Find out if they want you to go with them to appointments about their VSC. Support their decision.



Understand differences

The way you feel about things like fertility choices or having children might be different from the way your partner feels.



Listen to your partner and try to understand how they feel.



Support them if they are sad about the situation and make sure you are supported too.



Have an open mind about different ways to have children or think about other things you can do in your life together. Plan your future together.



Affection and sex

Some people with a VSC might not be **confident** about their body.



Confident is when you feel good about yourself.



This can affect their relationships and how they feel about affection and sex.



Tell them you understand if they want to go slowly in your relationship or if there are things they find difficult.



Your partner's **sex drive** might change because of their medical treatments. **Sex drive** means how often a person wants to have sex.



Talk to each other about differences in your sex drives and make sure you are both happy with your sex life.



If there are problems you can't fix together, you might want to get professional help from someone like a relationship counsellor.



You can do this on your own or together.



How other people make you feel

Family or friends might find it hard to understand your situation.



They might make you feel you should live your life a certain way and not agree with the choices you and your partner make.



They might make you feel sad or like you have failed.



Talk to them and help them understand there are lots of different ways to live a happy and full life.



Remember, your partner is not to blame.



Here is something a person with a VSC said

The situation can be very stressful and make problems in your relationship. It's good if your partner supports you and goes through everything with you. It's good to be a team.

Support you can get



Here is a list of websites for VSC support groups

Interconnected UK (ICON UK)

For adults and children with VSCs and the people around them.

[**www.interconnecteduk.org**](http://www.interconnecteduk.org)



Klinefelter's Syndrome Association UK

[**www.ksa-uk.net**](http://www.ksa-uk.net)

Living With CAH

[**www.livingwithcah.com**](http://www.livingwithcah.com)



Living MRKH

[**www.livingMRKH.org.uk**](http://www.livingMRKH.org.uk)

MRKH Connect

[**www.mrkhconnect.co.uk**](http://www.mrkhconnect.co.uk)

Ragdolls UK

For women and girls with Turner syndrome and the people around them.

[**www.ragdollsuk.com**](http://www.ragdollsuk.com)



Turner Syndrome Support Society

[**www.tss.org.uk**](http://www.tss.org.uk)

Thank you to A2i for the words
[**www.a2i.co.uk**](http://www.a2i.co.uk) (reference 34928)