



Fertility, relationships and intimacy

A guide to offering support to an adult with a variation in sex characteristics

This guide has been written for the families, partners and friends of adults with variations in sex characteristics (VSCs), diverse sex development (DSD), a sex chromosome condition, or intersex traits. This may include but is not limited to: complete and partial androgen insensitivity syndrome (AIS), Swyer syndrome, classical and non-classical congenital adrenal hyperplasia (CAH), hypospadias, Klinefelter syndrome/XXY, Mayer-Rokitansky-Küster-Hauser syndrome (MRKH), 17Bhsd3, and Turner syndrome.

We have chosen to use variations in sex characteristics as an umbrella term to include people with a range of experiences as this term is becoming widely used, and has been adopted by UK governments.

We understand how complex language can be, and respect everyone's right to use the terminology they are happy with, for example some may prefer the name of their diagnosis or variation. We also recognise the importance of self-determination and believe everyone needs to find their own narrative and a community that feels right for them.

<https://sites.exeter.ac.uk/reprofutures/>

We have a collective responsibility to support and care for each other and to change our society to make it a better place for everyone.



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Many people aren't sure of the best way to support someone with a variation in sex characteristics (VSC) who is dealing with fertility challenges. Some approaches can be quite straightforward, and others may need more time and commitment. Although there isn't a 'right' way, here are some ideas for how to support a friend, family member or partner with a VSC.

Understanding the challenges

Learn and reflect

You will be able to offer better support if you're well-informed, and reading information and learning about the VSC diagnosis is a good start. Ask the person with a VSC how they would like you to do this. They may prefer you to only read information they have collected, allowing them to check and stay in control of the resources and guidance you use. If they're happy for you to find information yourself, you could watch films, read books, or look for personal accounts online. Researching on your own will allow you to work through your own emotions as you learn more about the VSC and any fertility challenges.



Challenge attitudes and beliefs

You play an important role in supporting someone with a VSC. Whilst healthcare professionals may provide assistance with specific needs or medication, treating VSCs as simply a ‘medical problem’ isn’t helpful. Our social attitudes transform the way we feel about each other and ourselves.

Everyone has a part to play in thinking about the expectations and pressures we put on each other: about how our bodies should look, what types of intimacy and pleasure count, how to approach decisions around starting a family, and what kind of lives and goals are seen as meaningful and valid.

It’s important to reflect on some of your own values in order to provide open-minded support.

“It’s not me who’s wrong or who’s got something wrong with them, but I’ve got to live in a world that has expectations and pressures and ideas.”

Shame, stigma, and secrecy can make it difficult to talk about VSCs and fertility, and they can prevent people with VSCs from reaching out or accepting support from others. Be ready to listen and support the person with a VSC to share their feelings and desires. Part of your role may be helping to build trust and confidence and creating an atmosphere where open conversation feels possible.

Celebrate the person with a VSC and their decisions, and work with them on exploring the different options available.

There are many ways of having children, or indeed of having a happy and fulfilling life without becoming a parent, all of which are as valid as each other. Empower others to live their best life.

“I think there’s something really lovely about saying “I’m like this,” and someone thinking that’s just a great way to be.”

Being supportive

Listen

Be ready to listen patiently without judgement - this could help the person with a VSC to feel confident sharing their feelings and desires. You may not always know what to say, and that's okay. Focus your attention on the person with a VSC as an individual and what makes them feel happy and content. Avoid making comparisons to others or suggesting they need to strive for a specific kind of life. Everyone is different and assumptions can be unhelpful, even small critical comments can have a lasting impact.

Support the independence of the person with a VSC

Encourage them to make their own decisions as much as possible, particularly on issues relating to their body and any care or treatments. Ensure the focus is on their feelings and desires, and support their decision-making through discussion and reading information together.



Make room for topics unrelated to fertility and VSCs

Take a measured and respectful approach to discussing fertility to ensure it doesn't become all-consuming. It's understandable for you to care about this topic and to ask questions. However, take care to prevent fertility or parenting becoming your only focus when talking to each other. Make room for everyday chat too.

Advocate

With their agreement and following their lead, consider how you can advocate for the person

with a VSC. Whether in conversation with friends, relatives, healthcare professionals, or to others, speak out against any pressures or constraints that could be internalised by the person with a VSC and result in their stigma or discomfort. You have an important role to play in showing them that they're not alone.

Explore talking and physical therapies

You're not the only person who can provide support: sometimes it can be helpful for a person with a VSC to speak privately to a professional who won't have the same emotional connections, for example a counsellor or clinical specialist, or to consider physical therapies which can improve mental health. People also deal with their circumstances in different ways. This can sometimes include destructive behaviours, which you may not be best equipped to support. Search for professionals with specific specialisms and expertise; relevant cultural awareness and sensitivity can also help.

Avoid looking for simple solutions

Try not to offer platitudes or impose parenting 'solutions' and advice on a person with a VSC who's experiencing fertility challenges (e.g. adopting, fostering) unless they ask for your help. Available options will be partly determined by their personal and cultural values. Accept them, their circumstances, and decisions. Sometimes things may feel uncertain for them, but you can't fix this.

Be careful if there's been any conflict between you in the past, particularly regarding their VSC, medical treatments, or fertility. This may mean trust needs to be re-built, and that you will need to be especially sensitive in your approach. Give them the time they need before feeling comfortable to discuss these topics with you.

Planning for the future



Stay open-minded

Avoid projecting your future hopes and aspirations onto the person with a VSC. These feelings and desires are valid, but they may be under a lot of pressure, and it's important for you to avoid adding to this with your own worries and to speak to them as calmly as possible. Ensure you explore their own perspectives. Their happiness and comfort are important. Even though their goals may be different to your own, try to support them in exploring what's right for them.

Avoid negativity

Give yourself time and space to process and consider how you present your emotions to the person with a VSC. Responding to them with a strong negative reaction, such as shock, sorrow or denial, will reflect your views more than it reflects theirs. Hear how they feel and what they want first, assumptions can feel restrictive.

Be open to change

For some people, feelings and priorities change over time, whereas for others they stay the same. Be flexible and ready to listen and accept if a person with a VSC changes their mind on parenting. Consider supporting them in looking for different kinds of reproductive, medical or psychological support if they decide it would be helpful at any stage, even if it wasn't wanted in the past.

Take it slowly

It's important for a person with a VSC to receive time to process the ramifications of their diagnosis, even if they've known about it from a young age. Don't put pressure on them to make any urgent life-altering decisions about parenting or fertility options. Depending on their age and situation, some people may not feel well prepared to talk or think about parenthood when they're first diagnosed with a VSC, or when they start to think about the impact. This may change later. Listen to their preferences and respect different personal and cultural attitudes towards privacy and openness.

"You're never going to be moving on at the same speed, but you're going in the same direction and that's the trick."

Social life

Celebrate their family roles

Embrace the other roles played by the person with a VSC that involve caregiving or guardianship, whether as a brother, cousin, aunt, or other. This may not feel equivalent to parenting for the person with a VSC, but you can celebrate and recognise their value in this relationship.

Prioritise inclusion

Don't be over cautious and exclude someone with a VSC from potentially upsetting social events which are family-focused (e.g. sharing a new pregnancy, attending a baby shower). Always ensure they're invited and give them the control to make decisions for themselves. If they do attend, they need to be allowed to manage their participation in whatever way works for them on the day. Try to be understanding and sensitive without avoiding issues that may come up.

Assist with communication

People with VSCs have differing attitudes to privacy and sharing details of their VSC and any fertility challenges. For some, telling close friends, family or partners may feel important, and this can lead to further support. However, it's crucial for them to be in control of who is told, how, and when. You could offer help with this: some people might appreciate assistance as they prepare to share information by thinking through the timing and dealing with any potential consequences. This needs to be at their own pace and without any pressure.

"It feels almost like a double bind: you want the support but then you don't know how people will react."

Negative or judgemental comments from distant family and friends outside of their immediate circle can be hurtful. They may not know about the VSC and this can be especially difficult to manage. Consider asking the person with a VSC if you can provide any support with handling challenging remarks.

Explaining the details of a VSC and any fertility challenges can be emotionally taxing and stressful, even if the person with a VSC would like to share this information. They may appreciate help with managing these situations and dealing with responses in some circumstances, and an offer of support could be very welcome.

“I find it really energy draining to talk to people about my diagnosis and our fertility journey, et cetera, because I have to constantly manage what they think, what they know, educate them.”



Caring for yourself

Take time

Take care of yourself and make time to work through your emotions. Think deeply about your own attitudes and expectations. You may need to start doing this before you're ready to speak to the person with a VSC about their own feelings.



Seek assistance

You may find it helpful to receive personal support to process the situation and manage your response. Receiving confidential help from a counsellor or other third party, such as peers in a similar situation, may also help you to provide better support to the person with a VSC. The person you're supporting may not always be best placed to support you in turn, as they may still be processing their own feelings.

Access a community or support group

Consider joining a VSC support or community group to find solidarity amongst other people close to someone with a VSC, who will have some understanding and awareness of your position. You could do this with or without the person you're supporting, depending on their preference. Either way, they may still benefit from you attending. Discussing and learning from others with similar experiences in an open environment can be just as important as speaking to healthcare professionals, or even more so.

Guidance for partners

Communicate

Have open and respectful conversations and voice your perspectives, needs, and desires with honesty when appropriate. Allow these conversations to be an ongoing process, not a one-off. Talking about this can get easier over time, and will help to avoid misunderstandings or potential conflict. Finding the right direction for both of you will require collaboration and improvisation.

Respect their needs

For some people with a VSC, their medical history may have had an impact on their relationships, confidence, and feelings about sexual intimacy and their body. Consider ways of showing your partner acceptance and be sensitive to their pace.

Listen to your partner

Respect their boundaries and decisions, support their choices, and follow their lead.

Be attentive and compassionate to their needs and avoid placing any undue pressure upon them. This includes accompanying your partner to appointments if they ask, but don't assume you must be present - some of this may feel personal or private for them.

It's important for you to respect your partner's decisions about who they choose to share information with, but you may want to let them know if this causes any problems for you. For example, if you feel unable to ask for support from friends or family. You might be able to find a way around this together.

Work together

Keep an open mind about new experiences and alternative ways of having a family if this is what you both want, or pursuing your aspirations in different ways (e.g. teaching or mentoring). Work with your partner

to imagine a shared and meaningful future which would make both of you happy. Building this together can be exciting.

Understand your differences

Recognise that fertility challenges may impact your partner in a very different way to you and be sensitive to the fact your partner may not have had the opportunity to explore or understand these topics before, regardless of how long they've known about their VSC or issues with fertility.

If your views are different, still be receptive to your partner's reaction and any disappointment, confusion or other difficult emotions they may feel. Give them time and support them in grieving if applicable. Look after yourself as well, and take time and space to focus on your own feelings and desires.



Value their enjoyment

It can be difficult for some people with VSCs to feel comfortable with sexual pleasure and it may take time for them to recognise the value of their own enjoyment and bodies. Where appropriate and according to your own comfort, try to celebrate and encourage their pleasure, and support open communication about sex and intimacy.

In some cases, your partner's sex drive may change in response to hormone therapy or fertility treatments, if applicable. This may

adjust over time, but open communication and honesty about sexual compatibility is important. You should both take care to understand each other's perspective, and only do what feels comfortable.

Some differences may be difficult to resolve without additional support. If intimacy causes any conflict or difficulties for either of you, consider attending relationship or psychosexual counselling, either together or separately. This may help you to explore any hurdles together and learn how to communicate your experiences, whilst avoiding any harm.

"I think things can get to a point where you think, 'you know, this really isn't working, there's too much stress,' and you feel the need to see somebody. But you need a partner who also goes, 'Yes, right, we need to do it as a couple', because that's the situation you're in."

Address external pressures

If you receive pressures about fertility from your family which feel uncomfortable for you or your partner, try to actively address these expectations. You both have a right to space, time and privacy, and this is your life to plan.

Be willing to challenge prescriptive approaches to relationships and family. This may involve some deeper thinking about your personal, family, or cultural values. We can all feel pushed into particular directions, and we may feel shame about taking different routes, but challenging these rules is valuable. Your partner is not at fault, fertility is a spectrum and never a given, and there isn't only one 'right' way of living a happy life.

This guidance was co-produced by the Reprofutures project, which included people with VSCs, support and community groups, and researchers. Our research involved a total of 28 people from across the UK, with diagnoses including Mayer-Rokitansky-Küster-Hauser syndrome (MRKH), classical congenital adrenal hyperplasia (CAH), XXY/ Klinefelter syndrome, androgen insensitivity syndrome (AIS), 17Bhds3, and hypospadias. This work was funded by the Exeter Engaged Research Exploratory Awards and the Wellcome Centre for Cultures and Environments of Health, University of Exeter. All quotes in this pamphlet are taken from research participants with VSCs with their permission.

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VSC organisations and groups in the UK

Interconnected

UK (all VSCs)

www.interconnecteduk.org

Klinefelter's Syndrome

Association UK

www.ksa-uk.net/

Living With CAH

www.livingwithcah.com

Living MRKH

www.livingMRKH.org.uk

MRKH Connect

www.mrkhconnect.co.uk

Ragdolls UK (Turner Syndrome) –

www.ragdollscharity.co.uk

Turner Syndrome Support Society

www.tss.org.uk

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