

Guidance to Answering Notepad Questions

The Notepad resource is the outcome of a project funded by the British Society for Paediatric and Adolescent Gynaecology. It has been developed by the UK Charity dsdfamilies to be used as a clinical tool in the DSD (and related conditions) clinic to support young people in asking the questions they may have.

As a supplement to the Notepad we have tried to give examples that may help providers 'get going' in answering the Notepad questions in clinical settings (page 2). As a small charity we are limited in the amount of work we can do and we would welcome Britspag members together with other DSD networks or sub-groups to continue to update this work, our only ask is that DSDfamilies is credited in any future iterations of the work.

Example answers have been drafted by Nina Callens and edited by Caroline Sanders. We asked for input from two youth ambassadors (Esme and Gabrielle) and an adult with DSD (Jo). All agreed that these answers provided a good place to start. Further, where the ambassadors and adult with lived experience wanted to reinforce a specific point we included their contributions in full.

The supporting information is written in a way that is accessible for a wide audience. The language aims to be simple and inclusive – by providing explanations around key words that we often hear people are unsure about. Remember the answers are to just ideas - crafted in ways that can be shared directly with the young person in the healthcare setting.

Start by thinking about what you already understand about communication with young people as they learn about their DSD. How might you answer the Notepad questions, have you checked out quality blog postings and informed social media recently?

Our ambassadors suggested the following;

- **Read some** of the work from our youth consultants
 - Esme's blog
<https://www.youngminds.org.uk/young-person/blog/dsd-and-mental-health-as-a-young-person-what-is-normal/>
 - Read Gabrielle's 'Through my eyes' Part 4 of the Notepad resource package.
 - Scroll through the posts on the Instagram account @yourpace.dsd you don't need to have an insta account to do this - <https://www.instagram.com/yourpace.dsd/>
- **Look for** new publications in book stores or online for example Lih-Mei Liao 'Variations of Sex Development' published by Cambridge University Press. The book discusses psychological practice in healthcare for people and families impacted by a range of 'intersex' variations from a position of supporting individuals, caregivers, and those working with families.

Finally, **keep in mind** these following key points:

'Every part of the body can vary in shape, size and function and the reproductive system is no different' (Jo)

- Remember that we are talking about differences in bodies. People may identify with many sexual or gender identities, being lesbian, gay, bisexual, trans, queer, intersex, asexual, or other non-normative identity or orientation (LGBTQI+) does not mean 'no' choice or 'no' access to healthcare. Do not pressure young people because of your sex and gender expectations. Have young people explore what it means for them.
I love this! Should definitely be reinforced a couple of times! (Esme)
- The issues that young people actually face, including infertility, and specific health needs associated with their variation can become lost in discussions about gender identity.

*Definitely important - people have different views about gender and there is no right or wrong way to be a boy or a girl.
It is good to challenge gender stereotypes. (Jo)*

Guidance on the specific notepad questions by section

My Body and Me

Does my condition have a name, how did it happen ? How often does it happen?

Example answer: Some people want to know what specific condition they have, perhaps because they want to look up more information about it, or find others with the same condition. Oftentimes the specific condition has a rather medical name, referring to the specific genetic or hormonal background. Sometimes, the condition is named after the people who first 'discovered' it or described it in the literature. Sometimes, DSD is used to describe how your body has developed. The first D can stand for Diverse, or Difference, or Disorders. When we use the letters 'DSD' we refer to differences of sex development.

At the minute, the preferred umbrella term is Variations of Sex Development (Jo)

In general, DSD happens while an embryo develops into a baby in the womb. The body parts to do with being a boy or a girl are affected by chromosomes that give the body messages about how to develop and by hormones (chemicals) that come from certain tissues in the body. How often this happens is really hard to say. Sometimes all we can say is 'rare'.

Some people may wonder why they have never heard of the term 'DSD'. In part this may be because you are unlikely to hear about it unless it affects someone close to you.

Some advocacy or activist groups refer to this mixed group of conditions as 'intersex' or 'intersex traits' or 'intersex variations'. These terms are used differently by individuals – some like one term better than another. Think about what you want to use for your condition/diagnosis, and what that language means to you.

Check out: <https://www.dsdteens.org/puberty-and-you/your-puberty-by-condition/>

How is my body different to that of my friends?

I think it's important to start with the fact that everyone's body is different, so you'll find that none of your friends' bodies are the same and most people would not willingly tell you if there is something different about their bodies. (Gabrielle)

Example answer: It seems like everyone compares themselves to other people—looking around hoping that whatever is happening to them is “normal.” You probably hear your friends compare their body parts, sizes, faces, and periods. People focus on parts of their body they feel uncomfortable about, like: “I have too many freckles; I don’t like my hair colour; my eyebrows are bushy; my legs are too big; my breasts are too small; my feet are too big; my neck is too long; I’m not pretty; I have too many pimples....”

Feeling good in one’s skin or body confidence is something we all strive for and it is difficult for many people. Our confidence can be knocked by our very own thoughts and fears or by other people. If you catch yourself caught in a body ‘shame spiral,’ think instead about the things you like about your body and all the great things it can do.

Each person develops and goes through puberty in a unique way. No puberty is exactly alike. We want to help you understand the changes in store for you.

Check out: <https://www.dsdteens.org/puberty-and-you/your-puberty-by-condition/>

Is there someone else in this clinic who I can talk to about how this makes me feel?

When I was told about my dsd at 16 I was also told: ‘there are support groups and further help’. But I received no help until I was 21, and that was only because I searched for it. Maybe it would be even better to give the healthcare professionals a leaflet to hand out to the young person with instagram handles like @yourpace.dsd and @mrkhconnect, support groups and charities to connect with others. (Gabrielle)

As a young person with a DSD, it is so important to be connected with those who may also have a DSD, even if it is not necessarily a similar condition. It is also important to connect with a variety of age groups with DSD’s, those who are older as you can see that your life will turn out okay and normal; and people your own age who you can properly connect or vent to. (Esme)

Example answer: We want to care about you as a whole person, so we are interested in hearing how you’re doing, your hopes and dreams, and any worries that you may have. It’s not easy to share what’s on your mind, and sometimes you might not be sure exactly what you think or feel.

Psychological health professionals are experts in understanding young people’s emotional development and behaviour. The psychologist can explain things to you in a less complicated way and can be very helpful in re-thinking the information you have been told. They will also help you work out how you want to deal with tricky or stressful situations in relation to your health, body and wellbeing.

Having support outside of the hospital can also be very important for your wellbeing. Peer support is when you connect with other people who have experienced or are experiencing similar circumstances. This support can be very helpful in getting another view on what a diagnosis means, and in learning about and exchanging information about your condition.

What does this mean for my health and everyday life, and can I do all the same things as my friends and peers?

Example answer: Your body is a big part of how you live your life, it helps with lots of daily functions and activities. Some of our choices about sports or careers are linked to our physical bodies, also our bodies are part of how we build relationships with self and others as well as how we learn to love, give, or receive care with others.

Parenthood and bodies are often linked together yet everyone's decisions, choices, or style are different. Some of your friends may decide they do not want to have a baby, it's a choice. Some friends will not want to get married or have a relationship, again it's a choice. Wanting to become a parent means understanding what body limitations you have – and it is important to discuss this when you are ready. It is a very sensitive topic and while people may talk about a range of options all come with their own challenges, such as adoption or surrogacy. Finding a space and place to talk about your body, emotions, and expectations is something that takes time.

A grief reaction is fairly common when we learn that our bodies may not be able to do what we hoped for (such as infertility), but that doesn't mean you won't adjust and go on to have a fulfilled life. (Jo)

If you find it hard to focus on the positives, maybe talk to someone you trust (like a close friend, a psychologist, or a counsellor) to let them know how you are feeling. It helps to have someone to share your thoughts and difficulties with.

Do I need to tell my school/college about my condition?

Example answer: Many young people choose not to say anything to school or college, unless they need regular medication for their adrenal glands (as is the case in CAH) and require an emergency kit in school/college. Some people simply let the school know they are well but have medical check-ups and will need time out for appointments.

When an underlying condition can contribute to how people learn in school, it might help teachers to know more about their condition. You can visit the Turner Syndrome Support Society and Klinefelter's Syndrome Association for more information.

Dsdfamilies has produced a leaflet for schools which may be useful:
https://www.dsdfamilies.org/download_file/view/202/183

Is it normal to feel sad or down because of my condition or feel anxious and lonely because of my condition?

Example answer: Absolutely, some degree of sadness or worry is completely normal. You may feel “different” from your peers, and your schedules for school and social life may be disrupted because of appointments at the clinic or doctor’s office. You may not be sure how to share your story or talk about it with anyone.

You may also be dealing with physical challenges, either from your condition or from its treatment. For instance, you may be prescribed hormones that may affect your emotions or mood and in some cases cause new bodily changes. Sometimes, other treatments or procedures associated with managing your condition can be very demanding. You may need time to process what it all means for you. Your feelings may also change over time.

When first hearing that you may not be able to have children the way you hoped for or that infertility is a part of your condition – it’s a difficult process. Some people find it hard to come to terms with this. If your mood or worry is interfering with school, friendships, or family life, talk with your psychologist or counsellor or other trusted person in your clinic team and/or reach out to peers with similar conditions or experiences.

As a young person I think it’s definitely important to get support outside of your everyday family and friend; while they can definitely help you get through difficult times it can be very valuable to speak through your experiences with others who can empathise with you. (Esme)

Will I be able to have a ‘normal’ life?

Example answer: Yes – lets talk about what this means to you and what you mean by normal. Is there something specific you are thinking about such as puberty, hopes, expectations? There will be times when emotions and feelings can be bigger or smaller – when we see others around us change or experience things in life we wanted or hoped for, it can be stressful. Finding the right person(s) to talk to – to listen to you can be helpful.

As a young person I believe that while of course you can have a normal life regardless of your DSD, it can be another reason that peer support is so important. To see someone who is older than you who has had a completely ‘normal’ and happy life while growing up with a DSD is very reassuring, and I would like to be an almost ‘role model’ for other young people with DSD’s when I am older. (Esme)

Questions about medication (may not apply to all)

Do I need to take medication because of my condition and to stay healthy? Or is this medication optional/aesthetic (e.g. to grow a bigger chest if I lack hormones to do so)?

As a young person with a DSD it can definitely feel strange or ‘different’ to take medication, but also remembering that lots of people take tablets or medicine for other things is important. Your friends without DSD’s may even be on the same hormones as you for period issues etc., people take medication each days for diabetes. You are not alone and you are not different for taking medication. (Esme)

Example answer: When you don't have gonads (or have gonads that don't make lots of hormones) taking hormones will be important to help your body go through puberty and stay healthy throughout your life.

Do you want more info on the right kind for you? Check out <https://www.dsdteens.org/taking-the-wheel/in-your-care/hormones-and-your-body/>

Remember: each body is different and may prefer one type of hormone or way of receiving hormones over another.

Sometimes you might not like the hormone action, and any changes in your body—growing breasts? More hair?). If you are having thoughts about your gender or concerns about who you are and who you want to be, talk to someone you trust—like an adult friend, a teacher, a doctor, a parent, a psychologist, or a counsellor.

Do these medications have any side effects? Will I be on them forever?

Example answer: Potential effects of these medications can include:

- weight loss/gain
- mood and wellbeing
- loss or increase of sex drive (also known as libido)
- hot flashes (a.k.a. flushes)
- bone health
- breast/hip development (with E)
- underarm/facial/ pubic hair growth (if responding to T)
- voice changing (if responding to T)
- clitoris or penis growth (if responding to T)

Chances are, you will need to take hormones at least until the typical age of menopause or potentially the rest of your life, because studies on hormones into old age when you have a DSD have not happened yet. Hormones are needed for many things, like your bone strength, heart health, your cognitive function etc.. It's a really good idea to talk to whoever is prescribing the medication if you plan to stop, want to stop, or have stopped taking them. To make what we call an 'informed choice' , having the facts is really important in your decision-making.

Questions around vaginal dilation (may not apply to all)

Why dilate and how do I know when I'm ready?

As a young person I think it is so important to recognise that your body is your own, you should never feel pressured into dilating if you do not feel ready, and you should never do it for a partner who does not have your autonomy and emotion at the forefront of their concern. Your body can often feel as though it does not belong to you, or that medical professionals get to choose what you do with it; but its important to remember that you are always in control. (Esme)

Example answer: Vaginal dilation is a self-led technique to expand vaginal tissue. Dilation kits come in different colours, different materials (plastic and silicone) and different sizes (some longer/wider, some smaller/shorter). The goal of dilation is to have the option of comfortable and enjoyable vaginal penetrative sex. This could be with a partner or alone. Dilation can also be a good way for you to explore your body and become more comfortable with it.

Check our 10 tips here:

<https://dsdfamilies.org/application/files/4515/3632/8183/Dilation-booklet-Feb-16-ecopy.pdf>

When should you dilate? There isn't a fixed formula for all girls and women. However, the leading experts in dilation say that the best time to begin is when you are thinking about sex and romance, or when you have had some experience of exploring your body in sexual ways (either with a partner or by yourself). If you want to try it anyway, that's okay. Don't get discouraged if it doesn't work out at first, try again when you feel more ready for a relationship or sexual intimacy.

What do I do if I can't find a private place to dilate?

There is no rush, that it should be done for yourself and that if you miss a day it is okay. It's not easy to find somewhere private. (Gabs)

Example answer: Dilation isn't loud, it is a discreet activity, what barriers are getting in the way of you finding a quiet and private space?

How quickly can dilation work? Do I have to do it forever?

Example answer: It is a gradual process. It depends on how often you dilate, if any difficulties come up and what feels right for you. Many women see improvement and complete the process between 6 and 9 months. Some need more time and some need less. The more often you dilate, the quicker you will see results. Most experts recommend dilating each day for 20-30 minutes. Most women begin to see improvement in 3 to 4 months, although the dilation process from start to finish will probably take longer.

Many women find that when they have vaginal sex regularly, they don't need to dilate anymore. If you don't really have vaginal sex or if you are worried that it might become tight again, you can always go back to dilation if it seems like the right thing for you.

Can I change my mind and decide to have surgery if I started dilation myself?

Example answer: Some physicians recommend "vaginoplasty" right away, although this happens less than it used to. This surgery aims to enlarge a vagina by taking skin or another part of your tissue (sometimes skin from your legs or buttocks or another part like bowel tissue), making a space, and transplanting the tissue into it. When transplanting tissue, certain vaginal smell and discharge often occur when using bowel tissue (note: this type of surgery isn't common in Europe much anymore). For some, it can mean needing to wear sanitary pads every day to contain the vaginal discharge (it mucus). Another surgical option is called the Vecchietti—in Europe, this is more common than vaginoplasty. It is a technique where the vagina is surgically dilated over 3-7 days. It can be painful, but may have less side

effects than other surgical options. There are so many variations of these surgeries—often named after their inventors. As we noted earlier bodies are all different which means that we don't have a single “best” surgical choice that will suit everyone. This can mean making choices is even more difficult.

Also, there is a lot of maintenance your body will need after you have surgery. **You will need to dilate the area and maintain the V after surgery to keep it from closing.** You may also have to deal with scar tissue and healing tissue, with a risk of losing pleasurable sensations in and around your V—there is no 100% perfect surgery and no one can guarantee you will have no complications. So, although at first impression surgery might seem ‘quick and easy’ it is altogether a riskier option and can be painful.

Therefore, there will be conversations about ‘try dilation first’.

If you do choose surgery, make sure that your doctor has lots of experience in the exact procedure you are having. If at all possible, talk with other people who chose this option, just so you know all aspects of the surgery in the short, medium and long term before choosing it.

Relationships and family

How can I explain this to my family and friends? [Lih-Mei Liao’s 2023 Book 'Variations of Sex Development' has a Chapter on this topic]

Example answer: We all find out about our body at different times and in different ways. You should take time to learn about it yourself before sharing with others. Some parents or even doctors might encourage us to wait to tell people at first. It is not a “secret” if you choose not to tell people until you are ready. A thoughtful young woman with a DSD shared: “Not everyone deserves to know the story—it’s our story and we get to decide who knows and how much.”

Think of this as something private, rather than a secret. The same way some women don’t tell everyone when they are on their period or if they can’t have children, you can always choose to keep private about this. You can also share with anyone you want, when the time feels right for you.

Before you talk about your condition with someone, think about what it really means to you. There is no right or wrong answer. And, chances are, what it means to you will change with time.

Here are some examples:

“I developed as a woman in a different way”

“My condition used to feel like a burden—now I see it as a unique gift. Instead of seeing things as “black or white,” I see a more realistic picture of the world.”

“My AIS really doesn’t tell me anything I didn’t already know. I’m a woman. I’m different. And every person is different in their own way.”

For more examples and stories, check:

<https://www.dsdteens.org/taking-the-wheel/in-your-relationships/what-does-dsd-meant-to-you/>

And

<https://www.dsdteens.org/moving-up/with-your-friends/personal-stories-about-sharing/>

You can also find more tips on sharing here:

<https://www.dsdteens.org/moving-up/with-your-friends/tips-on-sharing/>

How can I explain it in a way that pays attention to my culture, and ethnicity?

Example answer: Youth from different cultural backgrounds and their families are sometimes faced with specific challenges, such as negative beliefs. Take a look Part 4 of this resource to learn more.

My family never talks about sex and private body parts –

--What if I cannot talk with them about this?

What if they do not understand how this can have happened to me?

Answer example: It's important to tell your parents that having this condition is something that you or they can't go through alone; you need each other!

Having this is not their fault, this is not your fault. So can they help with creating opportunities to discuss your body, as you may have a hard time doing that on your own?

On the website www.dsdfamilies.org, there are multiple resources helping parents understand what has happened.

Tip:

Drawings can be easier to understand and remember than words. If it helps, ask your doctor to put the information in diagram for you to take home and look at it again with your parents.

Understanding how you developed (with or without a specific diagnosis) can be really helpful when you begin talking to each other about your body and health decisions. Tell them by the way that they are not failing if you ask to seek help, want to talk to a therapist or would like to meet other people with similar conditions.

It can also be very helpful for your parents to meet other parents of kids with the same or similar conditions. Certain clinics and peer support groups organize family days, but you can also ask your doctor as well to help you get in touch with other families. Creating their own network can be important so they share their concerns as well, and be there (even) more for you in life.

What if my family does not agree with surgery? Or what if my family is encouraging surgery and ‘it’s not for me’?

Answer example: If you are considering surgical options to manage the genitals or gonads, it is important to ask yourself the question of why you want it and who you are doing it for, and the same goes for your family.

For example, when you are thinking about management of your gonads, following questions might be important: Are your gonads producing hormones or will they at some point? Will you need to take lifelong hormone therapy? Will you need hormones to start puberty? Could you have scars? Would there be reasons you might regret it later? Is there a lot of research about these risks for people with my condition? Is it possible that my gonads could produce eggs or sperm, either now or in the next 10-15 years with new medical technology?

We recommend talking to someone trained in DSD care and who can help you think through how you are feeling and what path to take—specifically, a psychologist, social worker, nurse, or peer support are people who could help you think through the options, risks, benefits, and the important things to consider, as well as help you deal with family pressure. Ask your doctor to refer you to someone who could give you psychological support as you approach these decisions, and perhaps they can also have family conversations. In those conversations, your parents’ feelings and worries are heard as well, and brought into a safe ‘collusion’ with your reality or vision of wellbeing.

Check out more information on managing the gonads:

<https://www.dsdteens.org/taking-the-wheel/in-your-care/managing-the-gonads/>

If you want more information on genital surgery, check this website page:

<https://www.dsdteens.org/taking-the-wheel/in-your-care/managing-genitals/>

Relationships, Friendships and Peer Support

Is anyone able to tell that I have this condition just by being around me or looking at me?

As a young person with a DSD it’s so important to realise that your concerns about being ‘identified’ as someone with a DSD are completely valid but are ultimately completely unlikely to ever happen. When you look at someone can you tell they have diabetes or a heart problem? More than likely you can’t. (Esme)

Answer example:

Each body—with a different sex development path or not—grows in a unique way. Penises are different sizes and shapes, as are noses, faces, bottoms, legs, as well as vaginas, labias and clitorises! Just from looking on the outside at people walking down the street, it’s near impossible to tell what directions helped that person develop.

Are there places or organisations I can go to where I can meet other people like me?

Answer example: Absolutely. We might be able to put you in touch with other young people, or you might be able to link into peer events put on by the medical team or by peer support groups. Check out

- dsdfamilies (Differences of Sex Development) – www.dsdfamilies.org or www.dsdteens.org
- CAH (Congenital Adrenal Hyperplasia) -<https://www.livingwithcah.com/>
- Klinefelter’s Syndrome Association (KSA) – www.ksa-uk.net
- Turner Syndrome Support Society – www.tss.org.uk
- MRKH Connect <https://mrkhconnect.co.uk/>
- Try and look for Facebook groups too

When I get a boyfriend/girlfriend, will I need to tell them? Can I get support from somewhere with this if I choose to tell them?

It’s important as a young person to remember that you are not being loved simply for your perceived ‘normal body’, fearing feelings may change once you have told someone; you are loved for the complete person you are, all your positives and all of your flaws. (Not that having a DSD is ever a flaw!) (Esme)

Answer example:

Not everyone shares with a boyfriend or girlfriend at the same time. Some people talk about their condition when sex comes up—whether it deals with birth control or genitals. Other people bring it up at an earlier time. And others don’t bring it up at all, or not until a relationship gets serious.

How you share and who you share with is 100% your choice—you don’t expect your boyfriend or girlfriend to share everything about themselves and their body when you just start dating. Some things come up naturally. Other things you might only rarely talk about. It just comes down to how much you want to share and when you are ready.

<https://www.dsdteens.org/taking-the-wheel/in-your-relationships/talking-about-your-body/>

Do you want more info about what to share, when, and how; check out <https://www.dsdteens.org/taking-the-wheel/in-your-relationships/talking-about-your-body/>. There are also some personal stories of how other people talked about this with their close friends and partners. You can also get help from your psychologist or peer support group.

Will sexual experiences be different because of my condition? And will a partner know the difference? If so, how?

Answer example:

This is a question we get a lot. Sometimes we think our partner is an expert on the female or male body, even if they aren’t sexually experienced or don’t know a lot about it. Our guess is that your partner is not as knowledgeable about this as you think.

For instance, there are many reasons vaginas are smaller (or “tighter”) and they can include:

- “vaginismus”—when the area around the vagina closes off instead of relaxing and expanding during entry sex
- imperforate hymen—when someone has tissue covering some of all of the vagina, making it really tight and even painful.
- When women aren’t aroused or “in the mood” for sex, the vagina may not become lubricated and may not expand, making entry sex feel uncomfortable.

If you want to say something, you can always say, “I might be a bit tight, and so let’s take it slow.”

Lots of people think that penises, clitorises, and vaginas are the key to having a great sex life. Sorry to disappoint you, but the most powerful sexual organ is your brain. How you think and feel about your sexual self is much more important than any physical technique someone can teach you.

There are many great websites where you can learn more about this and figure out for yourself what feels right for you.

And remember: Each person’s body is different and responds differently to touch and pressure—creativity and trying new things are key to making sure you both have the best experience possible.

Long-term health care

I would like to understand my past care. Who can I turn to?

Answer example: You may have already had certain types of surgeries or have memories of stays in the hospital.

If you have questions about what happened, ask or write them down for your parents and doctors. They can help you understand what happened, and if they aren’t sure, bring your list of questions to the next visit with your doctor.

Some good questions to ask:

- When was my condition diagnosed?
- How many times did I come to the doctor?
- What treatments have I had? Were they urgently needed for my health or elective (something that you chose that was not medically urgent)?
- Who can see my medical file in the hospital? Is it available to anyone else?
- Are there pictures or photos that were taken of me?(If desired) Can I see them?
- Can I talk to someone one-on-one with my medical records?
- Who made the decisions about my past care—my doctors or my parents or both? Why was it chosen? What was considered when making that decision?
- If I feel upset or angry about anything, what can I do? Is it okay to share that with a doctor, if so how?

- What does this mean about how I take care of my body moving forward?
- What do I do if I don't have Gonads? A large vagina or an opening? Sensation in my genitals?
- What are my current options ?
- Can I give my files to a researcher or be part of research, if I want to?
- Do you know if my gonads were able to produce hormones, eggs, or sperm?

There are plenty more questions you can ask – every question is a good one!

Do I need body examinations and can I say no?

As a young person with a DSD it's so important to try and 'unmedicalise' your body, it belongs to you and you always have the ultimate choice about what happens to you. Never feel pressured. (Esme)

Answer example:

During a visit, a doctor or a nurse will probably check on your body: listen to your heart, weigh you, and measure your height. They may also look at parts of your body like armpits, breasts, back, and genitals to make sure they are growing well.

During puberty, when your body is changing, it's normal to feel uncomfortable about having your body looked at. These 'exams' happen for different reasons, some of which probably have to do with puberty.

Remember: Doctors are only looking to understand your body better and make sure it is healthy and growing well, in order to make good recommendations for your health.

An exam is just something that doctors may recommend, and you can always say Yes or No to it.

Here are some tips:

- 1) Ask the doctor to explain what he or she is doing, for what reasons, and why now.
- 2) Ask in more detail what the examination may involve. Will it be just looking? If there is any touching, can you handle your private parts yourself. If anything material is to be used (like a measure, beads, or a cotton tip/bud), how can you signal to the doctor that it is too uncomfortable. Some doctors show patients their drawings and ask for patients to compare their bodies with the pictures, so you can look yourself and tell your doctor what you see.
- 3) Now that you know the deal, think who you'd like in the room: the doctor (or doctors) only, the doctor and the nurse, your parent?
- 4) If you feel uncomfortable, say so. Even the best doctor can't read your mind. Remember, you can always say "No" and choose not to have the exam.
- 5) Body exams aren't always important. However, if you've noticed changes in your privates and are concerned, then talk to your doctors about it.

Will I need to keep coming back to the hospital for the rest of my life? If not, when do my appointments stop?

Answer example: Doctors haven't really studied these conditions into old age, and because of that, no one can say definitively when to stop appointments or exactly what will happen if you stop taking hormones for example. Some conditions can alter the way the body produces and uses hormones. While we don't know, we encourage you to keep checking in with a doctor or team of doctors who you trust and who will work with you on finding how you feel best – on a body and mind level.

If my feelings change, as I grow older and my personal circumstances change, where can I go to find answers to health questions about my body and/or how I feel?

Answer example: If you are having thoughts or concerns about who you are and who you want to be, talk to someone you trust—like an adult friend, a teacher, a doctor, a parent, or a psychologist— so you can share more about who you are. But we also encourage you in general to find a healthcare team that is specialised in DSD care and has experience in navigating difficult questions and decisions. If you cannot find a specialist in DSD care, here are some good, evidence-driven resources you and your doctors can go to for up-to-date information on DSD, research, and care.

dsdfamilies.org

dsdgenetics.org

AccordAlliance.org

[ESPE E-learning portal](#)

I-DSD.org

Are there any medical procedures I may need to think about in the future?

Answer example: When it comes to future care decisions, there are three things you might need to think about:

- 1) Managing the gonads
- 2) Your hormones
- 3) Managing the genitals

1. **Gonads:** If you have gonads, chances are your doctors talk about them a lot

They may discuss monitoring them. This means looking after them over a long period of time and potentially checking your hormone levels and other things in your blood.

They might discuss removing them. This means discussing with you what the risks and benefits may be and what happens afterwards. These are big decisions:

- Why would I move or remove my gonads? Is there a current problem? Can I wait until later?

This depends on the condition. For some conditions, risks are low in childhood and might increase as people get older (like in androgen insensitivity syndrome.) In other conditions, risks are already high in childhood (like with Swyer's Syndrome.)

The location of the gonads (especially for guys) can matter—guys with gonads in their abdomen area may have higher risks than those with them outside their body or closer to the body's surface. That's why doctors may sometimes request to bring them down with surgery (also known as orchiopexy or gonad movement.) Doctors often can monitor the gonads better if they are near the outside of the body.

- What are the potential drawbacks of keeping them?

With your doctor, be prepared for discussions about tumours . Tumours (often called cancer) are when some parts of the gonads grow too quickly and may become potentially a problem to the rest of your body. Check with your doctors what the specific chances are of tumours with your condition, now and later in life. Many of the chances of a tumour also change with age, too.

Some people might have hernias (when gonads move in the belly) that can cause pain. Doctors can help fix hernias surgically as well, without removing the gonads, as this is something that happens for lots of people.

Be prepared for testosterone (T) effects. Keeping gonads during puberty may provide hormones for your body and help it grow. If you have PAIS, 5ARD, or 17Beta HSD, this could mean many T effects. Know your body, and don't be afraid to ask questions.

-For my condition, what is the most recent estimate of tumour risk? What studies is it based on?

Recent estimates of tumour risk are currently varied because there is not enough research and not enough high quality studies with large groups of patients. This means that the numbers given are often not very reliable and instead a best-informed guess of what the chance of a tumour might be. Typically, though, the estimates are broken down by condition. The best studies make sure individuals actually have the same condition and confirm it with genetic testing. Make sure your doctor knows to look for those articles with genetic confirmation as the type of evidence available.

- Is there any way my gonads have eggs or could make sperm?

This may be a good question about the gonads of people with 5ARD, Ovo-testes, Mixed gonadal dysgenesis, and sometimes PAIS. Some people are able to father children or mother children when the gonads are left in place. For some people, it might be possible to freeze sperm or eggs or even parts of the gonad. But this is rare, and most people with DSD will not be able to biologically contribute eggs or sperm to make a child. Ask your doctors for more information about this.

- If gonads are removed, what would I take for hormones? How often would I take it? How much does it cost?

If gonads are removed, and sometimes if not, people take hormones like testosterone or oestrogen and/or progesterone.

In general, how often you take HRT depends on what kind you take. Pills are usually every day, while shots/injections or patches last longer.

Costs of things like hormones (HRT) change a lot based on where you live and the type you take. There are lots of options like patches, pills, sprays, injections, and gels. Unfortunately, not all options are available in every pharmacy or country, and depending on where you live, they might be expensive.

- Why would I keep my gonads? Are they helping my body? Can I keep them?

The answer depends on your condition. Some people (like those with CAIS) have gonads that produce hormones that can be helpful in helping your body go through puberty and maintaining health. With conditions like Swyer's Syndrome, the gonads don't produce those hormones and carry large risks. And for some people with 5ARD or PAIS, the gonads might cause androgen effects during puberty like body hair, lowering of the voice, growing genitals, etc.

2. Hormones

When you don't have gonads (or have gonads that don't make lots of hormones), your doctor will probably suggest taking hormones to help your body go through puberty and stay healthy throughout your life.

3. Genitals

Managing the genitals is a complicated subject. There are many options to choose from. And, it's important to remember that a reasonable choice is to not do anything. They are not unhealthy.

- Options for expanding the vagina (if desired) for those with a small or 'dimple' vagina
 - Vaginal Dilation: Many women and experts recommend this as THE first and best way to expand the vagina. It is very effective—you just need to make sure you know the helpful tips in our new Dilation section and have the right tools and help from your doctors, psychologist, and even physical therapists.
 - (Mainly in Europe) The Vecchietti (a surgical/laparoscopic form of rapid dilation): In Europe, many people use the technique of treatment called the Vecchietti to help grow the vaginal area in a multi-day process, in the hospital. It's a way that might be preferable to other vaginal surgeries if dilation isn't possible or successful to start.
 - Vaginoplasty: This is a surgery to enlarge the vagina. As with every surgery, this one carries risks and can be painful and leave scars. After surgery, you still need to use dilation to keep the vagina stretchy and working. This is not an "easy way out"—it's a serious medical procedure and should be approached carefully.

-Surgery to change the appearance of the clitoris (a.k.a. clitoroplasty)

Doctors may discuss this as an option.

Some people might have this sort of surgery as a small child, and if this is you, please check out the section on learning about your past care.

For some women, a larger clitoris might make sexual intimacy more pleasurable, and other times, it might lead to uncomfortable erections (e.g. when a clitoris feels stretched and painful, like when it presses a bicycle seat or is pressed by tight jeans) or worries.

Many people (with and without DSD) feel worried about our bodies fitting in. However, the clitoris plays a big part in enjoying your body sexually.

Surgeries in this area have considerable risks and may cause irreversible damage to your ability to enjoy sexual pleasure. Because of this, we recommend that you learn more about sexual pleasure before considering surgical options.

Also, if you are considering surgical options to manage the genitals, it is important to ask yourself the question of why you want it and who you are doing it for, especially because of the risks to sexual pleasure. We recommend talking to someone trained in DSD care and who can help you think through how you are feeling and what path to take—specifically, a psychologist, social worker, nurse, or peer support are people who could help you think through the options, risks, benefits, and the important things to consider. Ask your doctor to refer you to psychological support to help you in this decision.

- Surgery to change the appearance of the penis (k.a. hypospadias surgery and phalloplasty surgery)

When you have hypospadias, the pee hole isn't located at the tip of the penis, but somewhere below, on the shaft or even at the base of the penis. It is actually pretty common – 1 in 250-300 men has hypospadias.

Most boys with hypospadias have no difficulty urinating, even if the urethra is at a different place. Some boys learn to pee standing up even with hypospadias, and some men and boys prefer to pee sitting down in any case.

Some doctors will discuss hypospadias surgery as an option when the hypospadias is severe, if there is a problem with expelling urine out of the urine tube. If the penis is curved upwards or downwards (called chordee), erections can also become painful

Surgery for severe hypospadias and chordee can make the penis look longer, but it cannot actually make it bigger.

That is why doctors at some point can suggest a phalloplasty surgery, to make the penis larger if you have a small penis. This is a very difficult surgery (usually multiple surgeries) and can only be done in late adolescence/young adulthood

Surgeries in this area have major risks, lead to big scars and could cause irreversible damage to your ability to enjoy sexual pleasure, because your penis plays a big part in enjoying your body by yourself and in intimate relationships.

If you are considering surgical options to manage the genitals, it is important to ask yourself the question of why you want it and who you are doing it for, especially because of the risks to sexual pleasure.

Will my condition affect things like menopause, or other changes to my body, as I grow older?

Answer example:

The biggest change to bodies typically happens in puberty. Each person develops and goes through puberty in a unique way. No puberty is exactly alike. We want to help you understand the changes in store for you.

Check out what happens for you condition:

<https://www.dssteens.org/puberty-and-you/your-puberty-by-condition/>

If we look a bit further, no one can say definitively what will happen to your body as doctors haven't really studied these conditions into old age. Some DSD can alter for instance the way the body produces and uses hormones, and affect menopause as well. While we don't know, we encourage you to find a doctor who will work with you on finding the optimal hormone therapy for your body and mind.

Are there any health screening tests that happen for people with typical bodies, e.g. cervical or prostate screening, that I do or do not need?

Answer example: As you get older—especially when you are thinking about sex and relationships—your doctor can be (and should be) a huge resource for problems, issues, or questions you have. Here is a brief list of things you should make sure you think or talk about at a visit.

- How often should I have gynaecology appointments? (For girls with cervixes, think about Pap-smears and cervical cancer screening. Typically, this is once every 3 years.)
- Should I think about taking the Human Papilloma Virus (HPV) vaccine? And how often should I be tested for STIs (sexually transmitted infections)?
- Should my partner be tested for STIs? And how can I ask them?
- (for guys) How often should I have a prostate exam?
- How can I avoid urinary tract infections (UTIs) or bladder issues?
- What is a yeast infection and how is it treated?
- Who can I talk to when I experience sexual problems or issues?

How can I make sure that I'm getting the care I need?

Answer example: We recommend talking to someone trained in DSD care and who can help you think through how you are feeling and what path to take—specifically, a psychologist, social worker, nurse, or peer support are people who could help you think through the options, risks, benefits, and the important things to consider with certain care decisions.

That also takes some confidence in the doctor's office. Confidence is asking the questions you want to ask and taking steps to understand your body.

Confidence is asking questions when you don't fully understand something, like: "I'm not sure I get it, would you mind explaining it again?"

Confidence means sharing what's on your mind.

Confidence means asking for time alone with a doctor if this feels more comfortable.

Confidence means saying no if something doesn't feel right or you don't feel ready.

Building your confidence with doctors takes time. Doctors are busy people. If they don't have enough time to hang around during your visit, feel free to ask: "Is it okay if I call you, email you, or text you with questions?" and "Who can I call if I have questions?"

It takes time for things to sink in; most doctors get that. Even if you don't have questions right now, it's okay. Just as long as you know how you can get answers to questions when you

do have them. And when you think of a question, be sure to jot it down in the 'Notes' section of your phone or on a notepad so you can share it later with your doctor.

How do I get a copy of my health record?

Answer example:

Perhaps your parents already have a copy of your medical records, so you can understand a bit more about past care.

You have the right to have direct access to your medical record information, either by reviewing the record, obtaining copies, or receiving a summary of your care. If you are interested in getting a copy of your medical records, you will need to contact the doctor's office or hospital where you are/were treated. In order for the office or hospital to release your confidential medical record information, you will need to complete and sign some type of authorization for release of information form. Usually there is no charge for records to be sent to another doctor, hospital, or other medical facility for continuity of care. For all other requests, there will likely be a fee to scan or make photocopies of your medical record. For specific information about how to access your health information or to get a copy of your medical records, contact your health care provider or doctor.