



# I Think I May Be Intersex

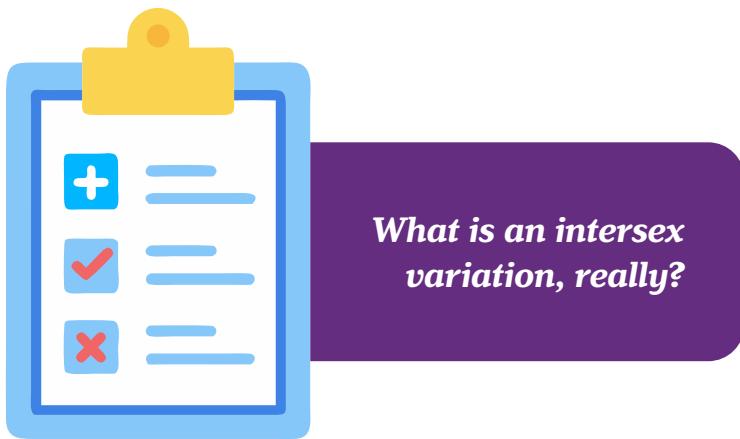
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**So you think you may be intersex!** Whether it's from weird doctor visits as a kid, a partner making a comment, or reading your own medical records, you're suspecting something might be up. This guide exists to take your suspicions and help turn them into actionable steps. This may be a fresh diagnosis for you, something your family knows and hasn't told you, or even a new understanding of a condition you've had your whole life. Maybe you're experiencing (or not experiencing) puberty right now. While this is a confusing time, you are in no way alone. Intersex people make up about 1.7% of the population, which is as common as redheads or people over 85. You've definitely met an intersex person before, even if you didn't know it!



Intersex is an umbrella term for a wide spectrum of physical variations that cause a person to develop primary or secondary sex characteristics that don't fit with the traditional medical understanding of "female" or "male" bodies. Many medical spaces use rigid, outdated definitions of intersex that exclude certain variations. You might be told that you aren't really intersex unless you have a chromosomal variation, or a genital appearance that

falls within a specific range, or other items on a checklist that was almost certainly invented by a non-intersex person. Queer Coaliton rejects this limited framework and welcomes all intersex people, including those with chromosomal, physical and hormonal variations.

If you have a sex variation, you are not required to self-identify as intersex, but we strongly encourage you to seek out intersex people who share similar experiences with you either way. Being intersex is not an entirely separate third category that excludes you from identifying as a member of the male or female sex—although you can absolutely just say you're intersex—and your gender can be influenced by a diagnosis as much or as little as you want. Doctors cannot dictate your identity. You get to decide what feels safest and best for you.

#### **Disclaimer:**

- *We are not doctors and this booklet cannot give you a concrete diagnosis.*
- *Intersex variations can manifest or be discovered anytime—at birth, at puberty, in old age.*
- *More variations are being found all the time.*
- *Plenty of knowledge about what it's like to be intersex can only be found in community, not with doctors.*
- *The medical framework of intersex is not the only way to understand sex variation, nor even the best way.*
- *The infinite diversity of the human body is impossible to capture in a series of boxes, no matter how many boxes there are.*
- *Many cultures throughout human history have had unique roles for intersex people.*

# Common Potential Signs of an Intersex Variation

Like most binaries, **AFAB** (assigned female at birth) and here are based on what is most common. If you're looking encourage you to dig deeper by cross-referencing your

**AMAB** (assigned male at birth) are arbitrary. The categories at these symptoms and seeing a lot of stuff you relate to, we list of signs with interACT's Intersex Variations Glossary.

## AFAB:

- Speech issues
- Webbed neck
- Clitoromegaly (large or permanently swollen clitoris)
- Broad chest with widely spaced nipples
- Pain during sex
- Deepening of voice
- Muscle mass increase at puberty
- Hypergonadism
- Irregular periods
- Lack of a period
- Arms that turn out at the elbows
- Ovarian cysts
- Short fingers and toes
- Partial fusion of the labia
- Genital growth
- Kidney issues
- Insulin resistance
- Abdominal pain
- Large breasts
- Lack of breast growth
- Extra facial and body hair
- Split clitoris
- Heart issues
- Ovotestis

## AMAB:

- Low sperm count
- Delayed tooth growth
- Crossed eyes
- Issues with reading, writing, and math
- Erectile dysfunction
- Gynecomastia (breast growth)
- Undescended or partially descended testes
- Wide-set eyes
- Poor motor control
- A genital chordee (a bend in the penis)
- Low muscle mass
- Congenital anorchia (absence of testes at birth)
- Small testes
- Balance issues
- Lack of muscle mass or inability to create muscle mass
- Bent pinky
- Small penis
- Hypospadias (urethra not on the tip of the penis)

## EVERYBODY:

- Bone density issues
- Early-onset osteoporosis
- Height discrepancies
- Delayed or absent puberty
- Fast and early growth spurts
- Low libido
- No growth spurt
- Early puberty
- Issues with incontinence
- Low set ears
- Acne
- Issues with hypertension
- Scarring on the abdomen or genitalia
- Fatigue
- Balance issues
- Infertility

- Ovotestis
- Hair loss
- Numbness or sensation issues in genitals
- Patchwork skin coloration/ discoloration
- Autoimmune disorders
- Different colored eyes
- Less body hair than average
- Dyspraxia
- Ambiguous genitalia
- Hearing issues
- Glucose intolerance
- Fatty livers
- Hot flashes
- Weight gain
- High blood sugar
- Development delays
- Issues with fine motor skills
- Aromatase deficiency

# Conversations With Family and Loved Ones

Conversations with people about your body can be alienating and awkward. It can be especially hard to ask a guardian about concerning things you found in medical documents or scars you want answers for. The first step we recommend when approaching these situations is remembering to ground yourself. Take deep breaths, situate yourself in your body, observe and acknowledge how you feel, and stay resolute. You deserve answers, you deserve to share your truth, and you deserve to be treated with respect. Unless your family is very casual and open, we suggest going in with a list of specific questions you want to address so you have something to refer back to if you start to feel shaky, defensive, forgetful, or overwhelmed by any of the myriad emotions these talks can bring up.



## Getting Answers

When you introduce the topic of intersex, you will often be met with invasive questions about your reproduction, body parts, and feelings—think about what you feel safe and comfortable sharing beforehand. Stick to your boundaries and your list of questions. You deserve answers, so be ready to drag the conversation back on topic if they keep changing the subject. If an immediate guardian refuses to give you the answers you’re looking for, consider an aunt, uncle, grandparent, or family friend that was around when you were a kid who might be able to help. And remember one of our favorite memes: you can just leave! If it sucks, hit da bricks!

## Coming Out as Intersex

For many people, saying you’re intersex is apparently an open invitation to discuss your anatomy, sensation, memories, trauma, experience with doctors, experience with self exploration, experience with partners, how you go to the restroom, how you found out, why you expect this, and more. It’s also safe to expect reactions that range from defensiveness, disgust, fear, guilt, and anger all the way to curiosity and acceptance! If a guardian did do any sort of medical or social intervention, they may feel like you’re going against their wishes or turn aggressive to hide their guilt. They may make it all about themselves and their feelings, instead of how you feel about your body and the situation. Reminding them this is about you and not them may make them angry, so only do so if it is safe, but always remember that you are the person most affected and it is not your job to handle their guilt or emotions for them. Your bodily autonomy comes before their feelings.

If a family member or loved one reacts with disgust, remind them that your variation is natural, nothing to be afraid of, and not contagious. They're not going to "catch being intersex" from you (oftentimes, you caught it from them!). Maybe bring a statistic about how common your variation or suspected variation is. After the conversation, take time to regulate, self-soothe, or reach out to other intersex peers, friends, or family. These conversations can be extremely hard or plain old anxiety inducing, and you deserve to take care of yourself and get the acceptance and support you need. Gearing up for a hard conversation and having it go smoothly can also throw you for a loop—your feelings are valid no matter how confusing to others they may be!

## ***Diagnosis and Testing***

At some point in your investigation, you'll likely have to dive into the wonderful world of healthcare. The first step is doing research into your medical history. You can request your records from your past medical providers. We also recommend getting your parents' records if you can, especially if you have biological family with similar experiences.

*An in-depth explanation on how to access medical records can be found at:*

[hhs.gov/hipaa/for-individuals/right-to-access/index.html](https://www.hhs.gov/hipaa/for-individuals/right-to-access/index.html)

*More information can be found at:*

[hhs.gov/hipaa/for-individuals/medical-records/index.html](https://www.hhs.gov/hipaa/for-individuals/medical-records/index.html)

When investigating medical documents, here are some things to look out for:

- Diagnoses of sex variations, "hermaphroditism" or "pseudohermaphroditism," polycystic ovary syndrome (PCOS), "hormone imbalance"
- Childhood surgeries, especially during infancy, often described as hernia surgeries
- Hormone replacement therapy, birth control, and/or puberty blockers
- Early-onset or delayed puberty
- Fertility issues
- Weird descriptions of genitalia, especially "ambiguous"
- Abdominal masses, especially on the ovaries
- Abdominal and/or pelvic imaging, usually ultrasounds
- Crossed-out/rewritten sex assignment on birth records

Once you have enough info to take to a doctor, it's time to get tested! There are lots of different kinds of tests for different variations. They can take some time, and some are more invasive than others.

*Here's a rundown of a few:*

*Karyotype Test*

- Investigates and counts chromosomes

*Genetic Test*

- Extra helpful if there is a known history of intersex variations in the family

*Biochemical Tests*

- Check levels of relevant hormones, including luteinizing/follicle-stimulating/anti-Müllerian hormones as well as estrogens and testosterone

### *HCG Stimulation Test*

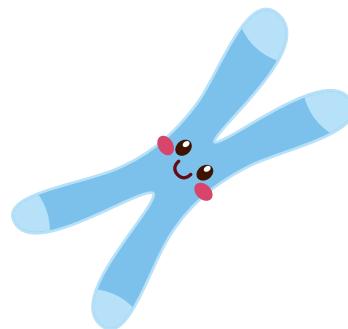
- Series of intramuscular injections, many different protocols for different variations

### *ACTH Stimulation Test*

- One hour, one injection
- Measures the ratio of different hormones in the production pathways of the adrenal gland
- Tests the hormone “assembly line”—what specific steps are not working as intended?

### *Imaging Test*

- Ultrasound, MRI
- X-rays with contrast dye in bladder used to be common



### *Direct Examination*

- Manual pelvic exam
- Abdominal laparoscopy
- Biopsy

### *DEXA Scan (Dual-Energy X-Ray Absorptiometry Scan)*

- Scans for bone density with low dose X-rays
- Extremely important, as many intersex folks have poor bone health
- Try starting these fairly young if you have an intersex variation or suspect you are intersex

You are more than welcome to have someone come with you or have the doctor explain everything to you before and/or during the test. You can refuse a test or treatment at any time. Queer Coalition strongly recommends always getting a second opinion on your test results when possible.

Most of these tests aren’t done at your average clinic and will require a referral. You’ll likely have to begin by talking with your primary care provider, telling them about some specific variations you think you may have and listing the reasons why. If it goes well, you’ll get referred to a specialist! Endocrinology is generally the place to be, but you might end up needing to see a geneticist, OB/GYN, and/or a urologist. Unfortunately, because many doctors have not been trained to diagnose or treat intersex variations, it’s important for you to build expertise in advance and be prepared to educate the provider.

A prior authorization may have to be done to get insurance to cover a test, and in some cases, they may not cover it at all if there is no recorded family history of a variation.



# Advocacy in Medical Settings



Unfortunately, getting diagnosed and treated effectively can be an uphill battle. Most doctors do not have expertise in intersex care and many will be indifferent or outright hostile. Even if you come to an appointment with very strong evidence of a potential intersex variation, you are just as likely to be brushed aside as you are to get a wonderful doctor who works with you. To be prepared, here are our suggestions for self-advocacy in the medical space:

## 1. Write things down before the appointment!

Whether it's due to nervousness or just the natural flow of the conversation, you may forget to bring things up. Tracking your concerns and the doctor's responses can show you what's being addressed and what isn't. A written list can help make your provider slow down and prevent them from "forgetting" or moving on. You are the world's foremost expert on your own body and your concerns deserve to be addressed comprehensively.

## 2. Decide what questions, tests, medications, and procedures you're comfortable with and stick to it!

You can expect doctors to dig in to your anatomy, sensation, memories, trauma, experience with doctors, experience with self-exploration and pleasure, experience with partners, how and how often you go to the restroom, your weight and weight history, etc. Try and figure out beforehand what feels actually necessary for them to know and what ways you feel most comfortable shutting down questions that are not relevant. If a doctor has a good reason to ask for a certain exam or medication but you're still not sure about it, you can come back at a later time. If they want to prescribe something irrelevant or do a useless test, you can clearly state that it's not relevant and tell them to input your refusal into your chart. As we've explored, intersex conditions can be diagnosed in a variety of ways. You can write those responses in advance and have them on hand. If talking to authority figures is hard for you, you can always practice with a friend, like a practice interview!

## 3. Always have a paper trail via email or direct messaging!

While needing a referral for some tests is normal, sometimes doctors will refuse or "forget" to do this and your investigation will stall out. You can also call your clinic and insist that an issue is handled promptly, but if multiple attempts go nowhere you will likely need to try another provider. While you should not have to do this, many intersex people have to try out several doctors before finding one who is competent and effective.

#### **4. Consider bringing someone else with you!**

There should be no issue with having another person in the room, but you could also have them on the phone if they can't be there physically. In Illinois if your doctor consents, you can also record your appointment. Calling someone before or after can help too, as can bringing a fidget toy or comfort object.

#### **5. Remember that you are a patient, not a science experiment or a learning opportunity!**

You do not have to educate your doctor on the condition you think you might have. If you feel like you are being treated with anything less than full human dignity, you can say so. If your provider invites other people into the room and you're uncomfortable with that, you can insist that they leave.

Healthcare happens on your terms.

#### **6. If a doctor hears you describe your body and immediately suggests physical or hormonal intervention, press pause!**

Take your time to seriously look into what that would look like for you and if it aligns with what you want for your body and life. The sense of urgency is usually fabricated and there is almost never an actual need to start taking medication that day. Even puberty can be put off for a few months to make a decision about if you want hormone replacement therapy.

#### **7. Don't hesitate to switch providers!**

If a doctor isn't the right fit or if you get weird vibes, start working with somebody else. Don't worry about their feelings, don't let the sunk cost fallacy get you.

Entering a medical facility can put you in a rough position.

Beyond the extremely common trauma response many intersex people feel, the current model of healthcare generally demands intervention and "correction" of intersex variations. Doctors have lied to intersex patients about their bodies to justify unnecessary surgery, especially by saying a natural body part is a tumor or a hernia and needs to be removed. We encourage you to remember that you have power in those situations, especially the power to refuse treatment and the power to leave. **Always make decisions based on what you truly want.** For more info on your legal rights, see Illinois' Medical Patient Rights Act ([tinyurl.com/patient-rights-il](http://tinyurl.com/patient-rights-il)) or your local equivalent.

## **Resources**

interACT, a national intersex advocacy organization and knowledge hub: [interactadvocates.org](http://interactadvocates.org)

interACT's primer on intersex traits and variations: [bit.ly/interACT-glossary](http://bit.ly/interACT-glossary)

InterConnect, a national intersex support group: [interconnect.support](http://interconnect.support)

Intersex Justice Project, a Black- and Brown-centered activist organization: [intersexjusticeproject.org](http://intersexjusticeproject.org)

SLIM (Strategy Lab for Intersex Movements), a center for intersex activism strategies and education: [slimstrategy.org](http://slimstrategy.org)

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