

What does it mean to be intersexed and how common is it? ^[1]

(1) Dear Alice,

Can you explain to me what "intersexed" persons are?

(2) Dear Alice,

How common is a hermaphrodite (looking for percentages)?

Answer

Dear Readers,

Like fingerprints, genitalia are unique from person to person, including those who are intersex. Someone with an intersex condition could have external genitalia that are ambiguous or their genitalia might be different from their genetic sex. They could have female genitalia on the outside but be genetically male, they may have both testes and ovaries, or they may have some other combination where the lines between male and female organs are blurred. Also called disorders of sexual development (DSDs), these conditions can be due to genetic or hormonal irregularities. Sometimes DSDs are noticed at birth, while others may not be detected until puberty. Some people might simply ignore irregularities and never seek care, or they may never even realize they have discrepant genitalia. It's hard to say how common it is to have an intersex condition because every case of intersex is different. If you had to put a number on it, though, most estimates are around 1 in 2000 live births to 1 in 5500 live births worldwide.

Although the age-old tale of "When Sperm Met Egg" may make it seem like development would be straightforward, fetal sex differentiation is actually a complicated process involving chromosomes, genes, gonads (ovaries and testes), hormones, and hormone receptors. Disruptions can occur in any of these elements at a couple of different critical moments. The end result for an intersex person can vary widely. Here are just a few examples of some of the more well-known intersex conditions (if you are interested in even more information about the wide variety of DSDs, you may want to check out [Accord Alliance](#) ^[2]):

- **Congenital adrenal hyperplasia (CAH)** ^[3] is the most common manifestation of intersex and can affect females or males, but only causes ambiguous genitalia in females that are affected. In CAH, genetic females develop an external male

appearance (such as more body hair or an enlarged clitoris).

- **Klinefelter syndrome** [4] affects males only. Those with Klinefelter syndrome have an extra X chromosome, which can lead to small testes and infertility. They may also have low muscle mass, enlarged breast tissue, or little body hair.
- **True gonadal intersex** is what was formerly referred to as ?hermaphroditism.? It's a condition in which a person has both ovarian and testicular tissue. People with true gonadal intersex may have predominantly male or female external genitalia, or they may have a mix of both.

The day-to-day experience of an intersex person largely depends on how they choose to manage the condition. Some medical facilities still perform genital ?normalizing? surgeries when intersex individuals are too young to make a decision. However, the recommendation is that if medically appropriate, decisions about what to do (e.g. if a child will have ambiguous genitalia removed) aren?t made until a child is old enough to participate in the conversation. Many intersex people choose to live their lives no differently than anyone without an intersex condition, especially when they have supportive friends, family, and sexual partners. Still, intersex people may have to overcome challenges, such as deciding their gender identity [5] or how to have a pleasurable sex life with an uncommon reproductive arrangement downstairs. Fortunately, if they are interested in receiving treatment or care, there are a number of options available:

- **Surgery**, such as reassignment surgery [6], can be an option if intersex anatomy interferes with a person?s health or sex life.
- **Mental health services** may help people come to terms with, embrace, or weigh difficult decisions about managing their condition.
- **Support groups** may be a resource for those looking for a place to talk about common challenges of intersex ? and share emotional support and practical tips.
- **Regular visits with a health care provider** can be a good idea in order to monitor for any physical complications, such as tumor growth that can occur in some intersex cases.

Asking questions about intersex conditions is a great way to keep the conversation going and increase understanding and acceptance of folks with intersex conditions. The *Go Ask Alice! Sexual and Reproductive Health* [7] archives can be great places for more reading on related topics. There are also lots of support groups and websites available to those with intersex conditions and their friends and family, like the AIS-DSD Support Group [8], CARES Foundation [9], and DSD Families [10]. Stay curious!

Alice!

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