

KNOW YOUR RIGHTS WHEN SEEKING MEDICAL CARE AS AN INTERSEX PERSON

YOU HAVE THE RIGHT TO BE RESPECTED



Medical personnel should use the name, pronoun, gender-related terms, and language for your body and intersex traits that match your needs, regardless of what appears on your ID or medical records.

Some facilities have a space on intake forms for this information. If not, it is always a good idea to prepare a short explanation of any identifying information that would be important for staff to know. If your providers disregard this and consistently use the wrong name, pronoun, or other terms, they are not only being disrespectful, they may be violating non-discrimination laws.

If you choose to follow up on a complaint, check to see if the healthcare facility has a patient advocacy or ethics department. Contact information is usually on the hospital's website. You can also reach out to your city's human rights commission, if it has one. If you'd like any assistance, feel free to contact us for help.



YOU HAVE THE RIGHT TO AVOID UNNECESSARY ATTENTION

Being asked invasive questions about our bodies in medical settings is exhausting.

Being subjected to unnecessary exams by providers who are "curious" is not only triggering, it can also violate non-discrimination laws and informed consent protocols. You are not there to be a teaching tool. You are there to receive medical care. Even if you are receiving care at a teaching hospital, you have the right to set boundaries *before* any exam begins.

Know that you don't need to provide information about your body, sexual history, or medical history if it is not relevant to your treatment. It is up to you to gauge your comfort in speaking up when the power dynamics in medical interactions can feel so uneven.

Know that as a patient, you have a right to guide your medical treatment. If you are uncomfortable with a question, you can stop and ask the medical provider to tell you why they need to know. If the question is necessary, they should be able to give you a reason that explains how the information will affect their diagnosis or recommendations (such as: if you are on hormone replacement therapy, we will give you medication B instead of medication A).

The same goes for exams—you can always ask why an exam is recommended. You set boundaries for your body.

You get to choose who is in the room. If you are uncomfortable with medical students watching your exam, you have the right to say so. Your comfort matters. A provider who proceeds with an exam against your expressed wishes can be liable for assault.

Consider planning ahead by writing things down. Have the names and phone numbers of your emergency contacts with you, as well as a list of your current medications and any known medical needs. Think in advance about questions you want to ask your doctor—and what you will say if something makes you uncomfortable. For example, you could practice what to say if your provider asks for potentially unnecessary information or genital exams:

“How will knowing that information change your medical recommendation for me today?”

“I don’t feel comfortable discussing _____ when the reason why I am here is _____.”

“Please explain why that exam is necessary. I won’t consent to exams that are not relevant to the problem I came in with today.”

It may help to practice saying these phrases out loud before an appointment. It can be hard to advocate for yourself in the moment, but having your list with you might help it feel easier.



YOU HAVE THE RIGHT TO GET THE CARE YOU NEED

Discrimination on the basis of sex characteristics is not okay. But we know that people have been denied care or dismissed as “too complicated” just for being intersex. If a medical provider refuses to treat you or gives you worse medical treatment than other patients due to your intersex status, they may be violating the law.

Health disparities in multiply marginalized communities are real. Intersex people who face additional bias—such as for being disabled, transgender, gender non-conforming, an immigrant, Black, indigenous, or a person of color—deserve to be trusted as experts on their own bodies. You have a right to be taken seriously, and to repeat your concerns or ask for a different provider if you do not feel heard. Slowing down the communication can also help make sure you are on the same page. If you feel that your provider is not considering your whole picture, try saying: “I understand that that is your assessment, but it does not match my experience. How would [fact about your symptoms or history] change your conclusion?” or: “I am worried that this recommendation does not take my concerns about [a specific symptom or risk] into account. Can we talk more about that?”

If you have health risks or needs related to your intersex trait—such as adrenal insufficiency, or high blood pressure as an effect of hormone replacement therapy following a gonadectomy—these should *not* be reasons to deny you the treatment or supplies you need.

Your health is not any less important than anyone else's. In an emergency context, trust your own instincts about whether or not to be more assertive. Sometimes the squeakiest wheel gets the grease.

Under normal circumstances, you should be able to request that a support person be allowed into appointments with you. However, many medical facilities are currently enforcing restrictions on visitors for safety reasons related to COVID-19. You should be prepared ahead of time to seek care by yourself. It may help to call a friend, partner, or family member on the phone beforehand to feel safe and supported before you interact with medical staff.

YOU HAVE THE RIGHT TO **INFORMED CONSENT**




All intersex people deserve to determine what happens to their own bodies. There is often pressure to change intersex traits in infancy or childhood, but knowledge is increasing worldwide that delaying non-emergency surgeries on intersex children's genitals or gonads is the best way to give them their own choices.


Sometimes, older youth or adults who are seeking medical care for other reasons still face stigma or pressure to change their intersex traits. You have a right to make these personal choices based on what is right for you.



interACT uses innovative strategies to advocate for children born with natural differences in their genitals, chromosomes, hormones, and reproductive anatomy.

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