

Surgery

- I had surgery when I was just three. I still wish my parents were given more options. I regret that I have a huge scar and no say about what happened to my own body!
- Unconsented surgery on my genitals wrecked my sense of self and my confidence as a partner and lover.
- My parents weren't told they had a choice. Always offer a nonsurgical option. Surgery is a last resort for everyone else. Why should it be different for us?
- If doctors had been more honest about potential surgical success, my parents would have made different decisions on my behalf.
- Do not tell us that only a medical eye could tell the difference between a "normal" body and a surgically altered intersex body. It's devastating to hear and it's completely untrue.
- Do not tell a child that surgery is the only way for them to have "normal sex."

Emotional Support

- I need you to inform me about peer support options.
- Support groups offer a unique support that we can't get from our doctor, friends, or family.
- Being intersex impacts me more mentally than it does physically. Provide me with options for therapy.
- Joining the intersex community gave me a sense of belonging and helped me to heal and grow.
- My peers were experimenting sexually while I was scared of my own body. I didn't have anyone to talk to about it.
- My parents never told anyone else, and their silence affected my entire family. I wish they didn't feel so alone. Peer support groups and therapists are important for them too!
- Make us feel truly comfortable sharing our feelings. Encourage us to express ourselves.



InterACT
Advocates for Intersex Youth

interACT Youth

is a space for intersex youth to raise their voices, share their stories, and change the world. interACT Youth is a project of interACT: Advocates for Intersex Youth.

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"Doctors need to be honest about the frequency of failures and complications. The rosy picture that was painted for me couldn't have been farther from the truth."
- Sarah, age 20



What We Wish Our Doctors Knew

interACT Youth
is a group of intersex
advocates in their teens
and twenties working to
raise intersex awareness.

We decided it's **time we told
our own stories** and spoke
our truths. In 2012, we started
a conversation about **what
we wish our
doctors knew.**

We're sharing that with
you now, and we hope
you'll pass it on.

Disclosure

- Be honest. I have a right to know about my own body. Secrets make me feel like I should be ashamed.
- I'll end up doing my own research online, and would so much rather hear it from you.
- I wish that I had known about everything at age thirteen, when my parents knew.
- Please don't lie to my parents, or advise them not to tell me about my own body.
- I'm not as fragile as you may think I am. I can handle the truth!

"For most of my life, my doctors knew more about my body than I did. None of them ever took the time to explain my condition to me in depth. I felt confused and alone."
-Ali, age 23



Medical Exams

- Brief the nurses and medical assistants who are going to work with me.
- Don't patronize us by speaking to our guardians instead of us.
- Ask the patient how they would like the exam to go. It's okay to give us some control.
- Engage with patients as experts on their own experiences.
- It's ridiculous to think genital exams wouldn't bother a child! Even adults hate them!
- Give us the option of who we want in the room with us. This includes both family members and other medical professionals.
- Don't stick your fingers up a child's vagina if it's not absolutely necessary.
- Don't give a genital exam if it is simply for your own curiosity.
- Don't ask young kids if they have questions right after they've been shell-shocked from the genital exam you just gave them. Give them time to process.
- Help a child to understand the difference between a standard genital exam and molestation.
- Have a pediatric speculum nearby.
- Don't take pictures of my genitals!



Communication

- Don't assume I am comfortable with the medical term "DSD" versus intersex. Ask me what I prefer.
- Being intersex doesn't mean I'll have a certain sexual orientation or identity. Don't assume you know how I identify, and don't assume I'm confused about it. Just tell me the facts about my body.
- Don't speak in absolutes, i.e. "This vagina will never be sufficient for marital relations."
- Don't ask me things that wouldn't pertain to my body. For instance, if you know I don't get my period, don't ask me when I had my last period.
- Please know what you're talking about. We shouldn't have to educate our doctors.
- If we DO have to educate you ... **listen.**
- Don't emphasize how rare this may be. That just makes me feel more alone.
- My doctors told me I'd never meet anyone else like me - it turns out I've met many!
- Do not treat me like I'm a once-in-a-lifetime opportunity for you. This isn't about you.
- Please don't forget to remind me of the *positive aspects* of my variation.
- Encourage us to email or call you if we have questions or concerns. And mean it.

"After many years of complications, I was referred to a doctor who was one of the finest people I've ever met. She cared for me. She would sit with me for an hour and just talk ... What was I feeling? What did I want? What worked and what didn't? Because she took the time to get to know me, it made all the difference in the world."
- Monica, age 26

