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.

What We Wish Our Doctors Knew

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
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.

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.
- 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!

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!

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

“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