

Siblings

- It's important to keep the whole family in the know.
- I may feel jealous of my siblings' experiences during puberty and their ability to have children.
- Help me to feel loved and special because of my differences, not despite them.
- I may be regretful or sad that I can't share my experience/wisdom with my younger siblings as they go through puberty.

Therapy

- Make sure I know that seeking help is an option.
- Know that it is okay for me to go see a therapist and I'm not "crazy." Being intersex can be hard to handle.
- You are not failing if I ask to see a therapist.
- Research support groups and ask if I'd like to go to one. It's empowering to meet other intersex people.

Understanding

- Try to meet other parents of intersex kids. Create your own network so you don't feel alone.
- Don't make assumptions about how I feel: **ask**.
- Listen.
- Be sensitive with your actions and words. I am the affected one, not you.
- Yes, things will affect you, but your priority is to be there for me through these life-changing moments.

"Your feelings about your child are valid, but at the same time your intersex child is going to grow up to be an autonomous person. You have to realize that your vision may not always be congruent with that reality."

As guardians, your decisions affect our destinies. Remember, each child is unique and will have different ways of coping. Be prepared to give us multiple forms of support during our journeys.

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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InterACT
Advocates for Intersex Youth



What We Wish Our Parents Knew

interACT Youth is a group of intersex advocates in their teens and twenties, working to raise intersex awareness. We all had unique experiences with our parents and created this brochure as a way to prepare other families with intersex kids for the journey ahead of them.

This is not something that you or I can go through alone; we need each other!



Working Together

- This will be a harder journey than you might realize.
- Take time to cope with your feelings on your own.
- This is not your fault.
- Recognize how significant this is for my identity.
- Even though I have come to terms with my reality, that doesn't mean I've gotten over it.
- Please don't tell me how I should feel.
- Don't compare me to people who are "worse-off."
- I need you to create opportunities to discuss my body. I may have a hard time doing that on my own.
- Don't keep secrets about my body from me. I don't want to wait until I'm older to find out that you knew about this.
- Give me information in chunks. Hearing everything at once can be overwhelming.
- Communicate as parents before talking to me; you should be prepared to handle my reaction together.
- Be ready to answer my questions. I don't want to resort to the internet for answers.
- Don't treat my diagnosis as a burden, and don't pity me. It makes me feel like there's something wrong with me.

Disclosing To Others

- I wish I wasn't left out of the conversation when you disclosed to others in the family.
- If you've already told other people, please tell me. I would rather not find out later on my own.
- Let me know if there's somebody you want to tell. I know you need to talk about it too, but it's my story and I should have a say in who gets to hear it.
- Empower me to decide who to tell, and to think about the pros and cons of disclosing. I don't want to tell someone and regret it later.
- Be my advocate, especially if I'm too young to advocate for myself.
- My teachers and textbooks won't have information on this, which can make school difficult.
- Ask me if it's okay to send pamphlets anonymously to my school. If they know they have an intersex student, they may be more sensitive.
- Be sensitive when discussing "typical experiences." Talking about realities that I won't experience can be very hurtful (e.g. pregnancies).
- Help family members understand the realities of my body -- and that asking about it can be triggering.
- There's a difference between privacy and secrecy. Telling me I can't tell anyone makes it a very shameful thing.

Dealing with Doctors

- Give me the option of who I want to attend my appointments. I may want both of you there!
- Sometimes I need to speak privately with a doctor. Look for those times and ask if you should leave.
- Let me know what my rights are as a patient. If you don't know, then find out before putting me in an unsafe environment.
- Doctors are going to be very curious about my body. Don't let them treat me like a guinea pig.
- I may not understand how multiple doctors examining me might affect me later. Empower me to say 'No' to uncomfortable experiences.
- Do your own research, become an expert about my body. Don't let any doctor talk you into something irreversible without being fully informed.
- Genital exams are bad enough as an adult. Imagine how they must feel to a child! Help me feel as comfortable as you can about these exams.
- Include me in the conversation with my doctor. Don't talk about me as if I am not there.
- Be more informed about my HRT options and offer insight about the effects it can have on my body. Be open to trying different options.
- Don't let doctors pressure me into immediate action. Oftentimes no immediate action is needed.
- Consult a diverse team of professionals and community members who can help us understand and cope with these experiences!

"I might act like I'm okay, even if I'm not."

