What we WISH our parents KNEW

Inter/Act is a national project led by young people with DSD/intersex traits, ages 14-25.

Telling our own stories and speaking our truths is vital; we decided that it was time to share our thoughts on what we wish our parents knew. Please help share this knowledge with anyone who may need it.

“Your feelings about your child are VALID, but at the same time your intersex child will GROW UP to be an AUTONOMOUS person. You have to realize that your vision may not always be congruent with that reality.”

Understanding

* Take initiative to meet other parents. Create a network for yourselves so you don’t feel alone.
* Don’t make assumptions about how I’m feeling about things; ask.
* Listen.
* Be sensitive with your actions and words because I am the affected one, not you.
* Yes, there are things that will affect you, but your priority is to be there for me as I go through a life-changing event.

Working Together

* This is going to be a harder journey than you might realize.
* Take time to cope with your feelings without me there.
* This is not your fault.
* Recognize how significant this is for me in terms of my identity.
* Even though I have come to terms with my condition, 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.”
* This isn’t something that you or I can go through alone; we need each other.
* I need you to create opportunities to discuss my condition. I’m just a kid and might have a hard time doing that on my own.
* Don’t keep secrets from me. I don’t want to wait until I’m older to find out you knew about this.
* Give me information in chunks. Hearing everything at once can be overwhelming.
* Communicate as parents before talking to me; you need to be prepared to handle my reaction together.
* Be ready to answer my questions. The internet can be an intense place, and I don’t want to search for answers there.
* Biology textbooks don’t have information on this.
* Don’t treat my diagnosis as a burden, and don’t pity me. It makes me feel like there’s something wrong with me.
* Don’t make assumptions about how I’m feeling about things: ask.
* Listen.
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Dealing With Doctors

- I want both of my parents to come with me to appointments. It shows you care, even if you don’t end up staying in the room.
- Sometimes I need to speak privately with a doctor. Look for those moments and ask me 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 having a roomful of doctors examine me might affect me later. Help empower me to say ‘No’ more often to teaching opportunities and multiple doctor exams.
- Do your own research, become an expert in my condition. Don’t let any doctor talk you into something irreversible without being fully informed.
- Gyno exams are bad enough as an adult. Can you imagine how they must feel as a child? Help me feel as comfortable as possible about these situations.
- 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 choices 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. Often times it’s not necessary.
- Consult a diverse team of professionals and community members who can help us deal with these issues.

Disclosing to Others

- I wish I wasn’t left out of the conversation when you disclosed to others in the family.
- Let me know if you want to tell someone. I know you need to talk about it too, but it’s my story and I need to know who knows.
- If you’ve already told other people, please tell me. I might be hurt, but at least I won’t find out later on my own.
- Help me think early on about the pros and cons of disclosing. Otherwise I may tell someone and regret it later.
- Empower me to decide who should be told and who shouldn’t.
- Be my advocate, especially if I’m too young to advocate for myself.
- 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.
- There’s a difference between privacy and secrecy. Telling me I can’t tell anyone makes it a very shameful thing.
- Be informed about my HRT choices 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. Often times it’s not necessary.
- Consult a diverse team of professionals and community members who can help us deal with these issues.

I might act like I’m okay, even if I’m not.

As guardians, your decisions AFFECT OUR DESTINIES. REMEMBER, each child is unique and we may have different ways of coping. Be prepared to give us multiple forms of support during our journeys.