

Five Tips for Talking about Bladder Exstrophy

When you're ready to sit down and discuss your condition with friends and family, consider these tips.

1. **It's a process, not an event.** Talking about bladder exstrophy is a process that takes time. It's not necessary to share everything with everyone all at once. Start with what and with whom you're comfortable sharing.
2. **Bladder exstrophy is a medical issue and there is no reason to be ashamed.** When talking about bladder exstrophy, you can start with the medical aspects of your urinary incontinence. For example, **"I have bladder exstrophy, it's a medical condition and I need special supplies and extra time when using the bathroom."**
3. **Get help from your medical providers.** Your medical providers can be a great help in educating people at daycare and school. Ask your medical team to call and talk to the school nurse or your child's teacher. At a minimum they should write a letter explaining that your child has a medical condition and highlight what your child will need at school in regards to supplies, special consideration in regards to restroom facilities and reminders for timed voiding.
4. **Set the tone for how you want the conversation to go.** As you seek support from friends and family, don't brush off what you are experiencing, make light of it, or make fun of yourself. **Open up the topic with a discussion about urinary incontinence symptoms, or kidney issues.** One suggestion is to start the dialogue by saying something casual such as, "Do you think you go to the bathroom a lot? I sometimes find that I'm in the bathroom frequently. This is because I was born with a medical condition."
5. **Connect with others!** Talking with other children and families who have bladder exstrophy makes it easier to talk with others. Parents, give your children time to talk with other kids alone, without your support. Camps such as **Youth Rally** <http://www.rally4youth.org/campers.php/> in the United States and **Ostomy Canada Youth Camp** <http://www.ostomycanada.ca/events/ostomy-youth-camp/> in Canada are great places for your child to spend time with other kids with bladder exstrophy, ages 9-18. They not only get comfortable about their condition, they have fun white water rafting, mountain biking and doing crafts. Other family camps local support groups are listed on the A-BE-C website.

