

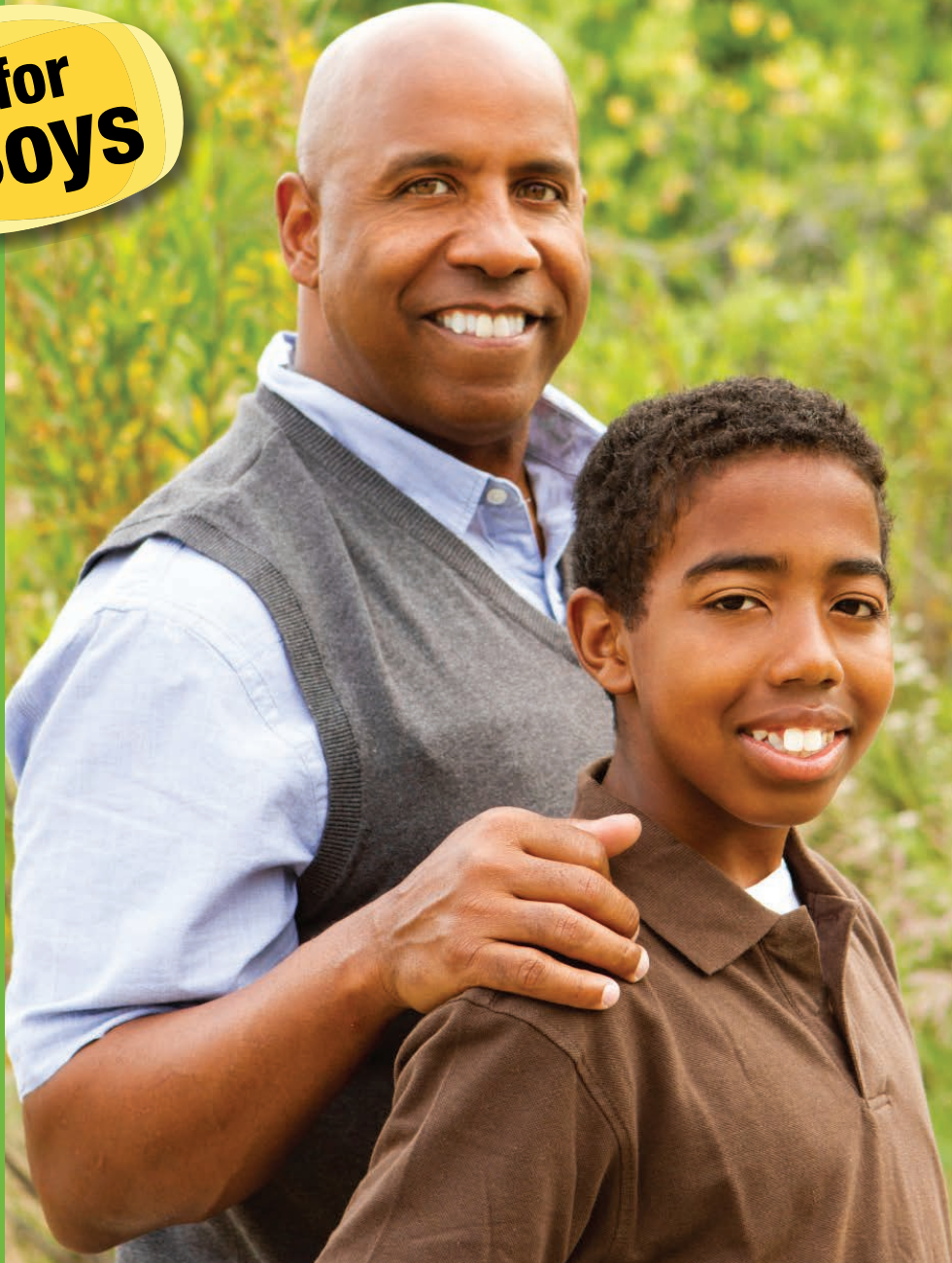


VANDERBILT KENNEDY CENTER

LEND-LEADERSHIP EDUCATION IN NEURODEVELOPMENTAL DISABILITIES

Healthy Bodies

for
Boys



A Parent's Guide on Puberty for Boys with Disabilities

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An appendix with social stories and visual supports may be downloaded at:
kc.vanderbilt.edu/HealthyBodies

**Appendix and visuals
can be found online at:
[kc.vanderbilt.edu/
HealthyBodies](http://kc.vanderbilt.edu/HealthyBodies)**

Puberty can be a stressful and confusing time, especially for you and your son with an Intellectual and/or Developmental Disability (I/DD). In spite of delays in other areas, children with I/DD usually enter puberty around the same time as other children their age. Some boys with I/DD, including those with spina bifida and cerebral palsy, may start puberty early (called precocious puberty). This toolkit gives you resources and tips on how to talk to your son about these sensitive topics.

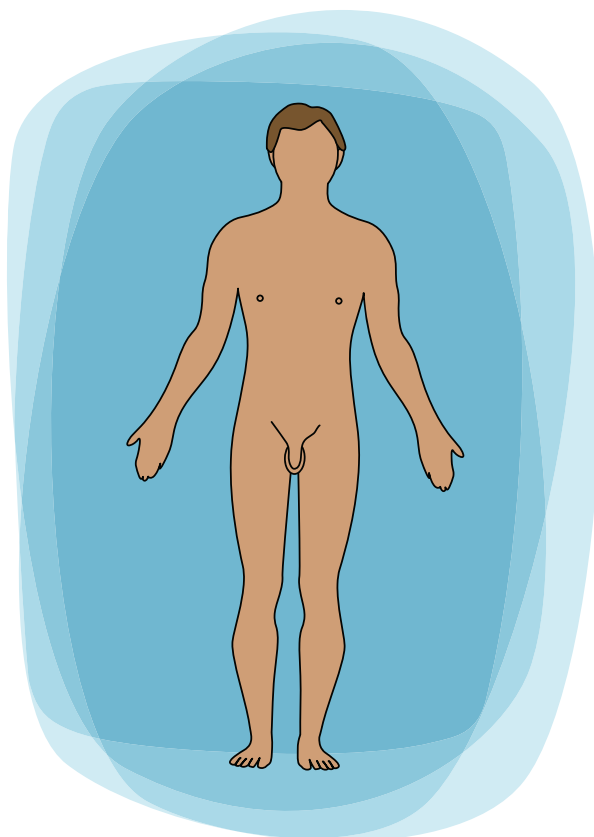
Talking To My Son About These Things

Start early. Talk with your son before obvious signs of puberty begin.

Teach body parts. Use the formal words for body parts (e.g., penis, erection) and bodily functions (e.g., urinate, ejaculation). This prevents confusion and gives your son words to use later when learning about puberty, cleanliness, and reproduction. See *Teaching Body Parts Appendix* for a visual you can use to teach your son the names for body parts and how his body is changing.

Use supports. You know the ways your child learns best. Teach about puberty the same way you teach about other important topics. For example, if your son learns best with repetition, break information down into simple facts and review them often. If he learns best with pictures, try using visual supports or social stories. These supports make hard-to-understand topics clearer. Review the supports we have developed to get ideas about how to teach skills (see *Teaching Body Parts Appendix*). Change them to fit your son's learning style.

Ask a professional. Talk to your son's doctors, teachers, or therapists for other ideas. ■



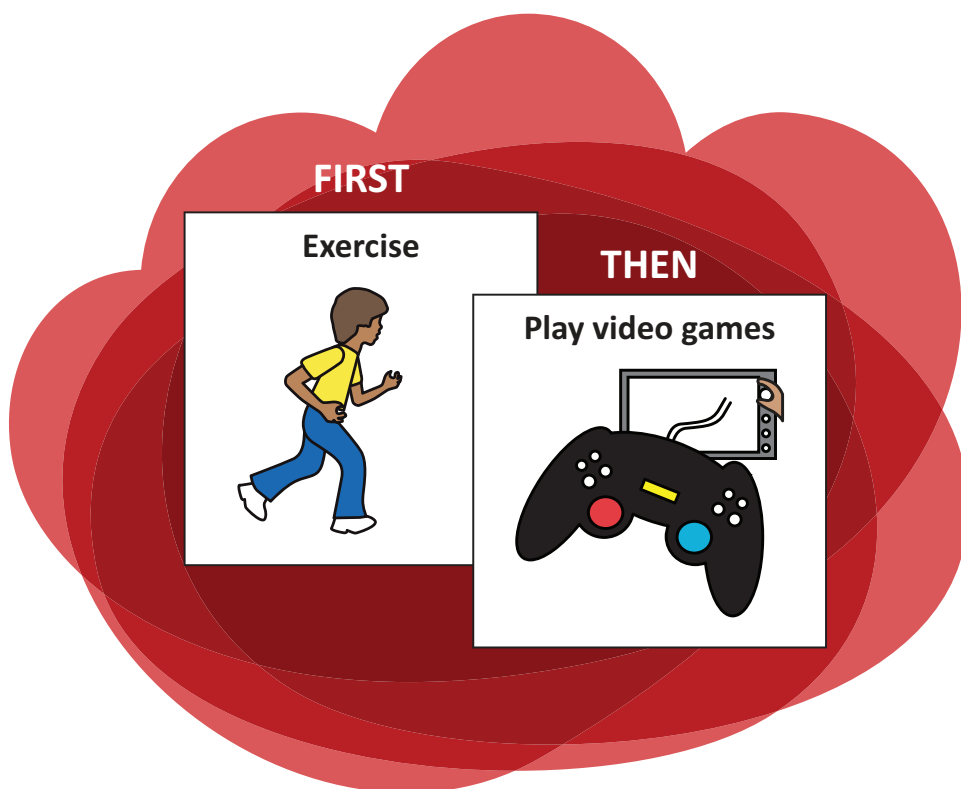
It is important to teach your son how to be healthy from a young age. Hormone changes and some medications can cause weight gain during puberty. Regular exercise and a healthy diet can prevent weight gain and improve mood and self-esteem. Starting these healthy habits early is the best way to help your child be an active adult.

How To Start

Schedule physical activities. Make sure your son has a scheduled time every day for active play, such as hiking, playing games outside, and riding bikes. If he has trouble getting started, provide a menu of options or just join in! Make fun, physical activities a part of your family's daily routine.

Ask a professional. If your son has a motor impairment, ask his doctor, occupational therapist, or physical therapist for safe exercise ideas. Look for adapted or supported sports activities in your area that either are designed for teens with disabilities or that provide accommodations to include your child.

Make exercise rewarding. As your son gets older, switch from “play time” to exercise, sports, or family activity time (such as taking a walk together). If your child does not like exercise, you can encourage it by giving him a reward afterward. At this age, it is helpful to offer rewards that are not food. Try using visual supports such as a First/Then Board. For example, show him “First Exercise” followed by something preferred, like “Then Video Games.” See the First/Then Board Appendix for a blank template that you can try at home. ■



Encouraging Good Hygiene

Good hygiene can improve your son's self-esteem and independence. Good hygiene habits can also reduce the amount of time you spend completing these tasks for him.

Make a picture book. A picture book may be a good starting point for teaching self-care. You and your son can create it together. The amount of information (more or fewer pictures) depends on your child's reading level and memory. Include pictures of supplies needed (e.g., specific body wash, deodorant, razor), and a visual picture schedule of the steps to use them. This picture book can also help your son select items on a shopping trip or gather the items needed for specific tasks, such as showering. Using a picture book may give him a feeling of control and responsibility for completing hygiene tasks.

Create hygiene kits. Think about making hygiene kits for different tasks. You can use old shoe boxes, clear plastic containers, or baskets. Let your son help choose the containers. On the outside of the box, put pictures or a list of the items in the box and a picture of the key task (e.g., shaving). See *Encouraging Good Hygiene Appendix* for pictures you and your son can use to create a kit. Here are a few examples of kits and contents:

- **Shower:** Shampoo, conditioner, face wash, soap
- **Dental:** Toothbrush, toothpaste, dental floss, mouthwash
- **Shaving:** Razor, shaving cream, picture of parts of face to shave
- **Morning Routine:** Body lotion, deodorant, facial cleansing wipes, face lotion, hair brush

Common Trouble Spots: Dirty Hair

As children enter puberty, they may need to wash their hair more frequently. Your son may struggle with keeping his hair clean because the motor aspects of the task may be difficult. He may find the feel of shampoo or water unpleasant. Some children with I/DD may not pay close attention to what their classmates are doing and wearing. Because of this, they may not understand that clean hair is socially important.

- **Make it routine.** Make a schedule to show your son how frequently he should complete hygiene tasks and the steps to complete them. See *Encouraging Good Hygiene Appendix* for an example of a showering schedule.
- **Singing in the shower.** To help your son learn how long to stay in the shower or bathtub, create a music CD of a few songs equal to the length of time he should bathe. Each song change can signal to him when to move to the next step on the schedule.
- **Soften up.** Does your child hate scrubbing his hair with his hands? Let him use a soft sponge to apply shampoo. If the water pressure bothers your child, let him use a cup or pitcher to rinse his hair or use a showerhead with adjustable pressure.
- **A picture is worth a thousand words.** Write a story that explains the importance of showering daily and keeping hair clean. Have fun. Take a picture of your son and other family members when they first wake up in the morning (bed-head and all!) and then when they are clean and dressed. Talk about what other people might think if you went to work or school looking like you did when you first woke up.

Common Trouble Spots: Sweat and Body Odor

Sweat glands become more active during puberty, so it is important to teach boys to control body odor by using deodorant, changing their clothes daily, washing their dirty clothes weekly, and keeping their bodies clean.

- **Don't forget your visuals.** Use checklists and stories to remind your son of what steps to follow to clean his body and why. See *Encouraging Good Hygiene Appendix* for a sample story about managing sweat and body odor.
- **Action schedule.** If your son needs reminders of what area of the body to scrub next, you can use an action schedule that shows which action or step comes next. Include shampooing and rinsing, and body parts to wash with soap. Laminate the schedule so it can hang in the shower. Another option is to use an old Ken® doll, action figure, or laminated paper doll. Separate and number each body part. Attach the doll to the bathroom or shower wall with Velcro. As your son washes each body part, he can place that part of the doll's body in a container labeled "finished."
- **Obstacles.** If applying deodorant is physically challenging for your son, try different types, such as spray deodorant or roll-on. If he has trouble bathing independently due to motor impairments, try adaptive equipment like bath seats, a removable showerhead, scrubbing gloves, or extended/easy-grip scrubbing handles.
- **Smells too strong.** Involve your son in selecting hygiene products, particularly regarding the scent. Some children may prefer unscented products if they are bothered by strong smells. Many products labeled for "sensitive skin" are unscented.
- **Acne.** For some teens, acne can be a problem due to increased oil in their skin, hormone changes, hygiene, and even genetics. Check with your child's doctor about safe over-the-counter acne medications, such as creams, lotions, or washes that contain medications like salicylic acid or benzoyl peroxide. Take a picture of your teen's face or use a line drawing.

Circle the areas where medication should be applied daily. Teach your teen to avoid sensitive spots like eyes, nostrils, and the mouth. Also, consider pre-medicated wipes to make application easier. If your teen has body acne, medicated body washes are also available.



Common Trouble Spots: Body Hair and Shaving

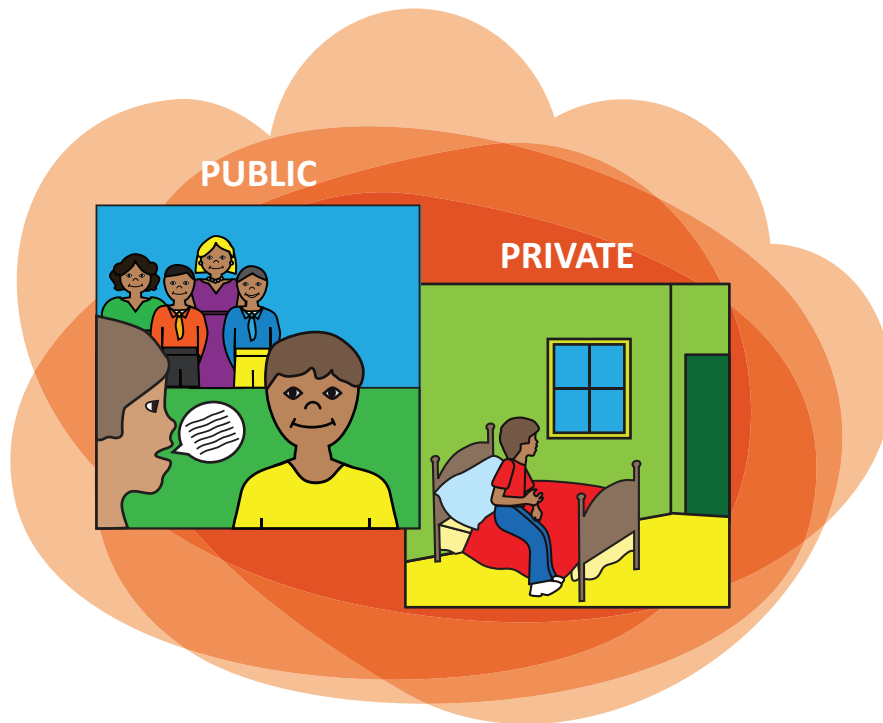
Body hair begins to grow and change during puberty. Use a drawing of the male body (like the one in the *Teaching Body Parts Appendix*) to teach your son where hair grows to prepare him for his changing body. Some adults and teenagers want to shave body hair.

- **Model shaving.** Let your son watch you or an older sibling shave and list the steps. Have him practice with you, step by step. Write down or take pictures of each step for a visual schedule. To help him remember where to shave and where not to shave, use a photo or drawing of a person, and color or number the areas that should be shaved.
- **Schedule shaving dates.** If your son can shave (or does so with assistance), use a calendar with pictures or marks as a reminder of how often to shave and when to change his razor.
- **Limit shaving cream.** If your child needs help with portion control or operating shaving cans, try using travel-sized packets of shaving cream or a shaving brush.
- **Select the right razor.** Boys who struggle with fine motor tasks may benefit from electric razors instead of a traditional razor with a blade. If the traditional razor with a blade is preferred, ask your occupational therapist about weighted razors or a razor universal cuff to help improve grip on the razor.

Common Trouble Spots: Clean Teeth and Breath

- **Create a Visual Schedule.** Use pictures to show the steps of brushing teeth. See *Encouraging Good Hygiene Appendix* for pictures to help your son learn to brush independently.
- **Choose the right toothbrush.** A vibrating or weighted toothbrush may help children who have difficulty holding a toothbrush and brushing their own teeth. Look for a toothbrush with soft bristles.
- **Show when and how long.** Build brushing into your son's daily schedule with picture reminders. Timers may help remind him how long to brush. Dentists recommend two minutes! ■





Appropriate and Inappropriate Public Behaviors

Does your son ever do or say things in public you wish he didn't? Your child needs help learning what is okay to do in public and what is okay to do only in private. Private behaviors include things like going to the bathroom, passing gas, touching private parts for any reason, and changing clothes, just to name a few. Using socially appropriate behaviors will help your son fit in with his peers and reduce the chances of being bullied or abused. Children who know the difference between appropriate and inappropriate public behavior are less likely to get in trouble with the school or police as they get older.

Teaching These Skills to My Son

- **Start early.** Talk about public and private behaviors as a family and set some ground rules, such as: "We are only naked in the bathroom or in our own bedroom with the door closed" or "We put on our clothes or pajamas before we leave the bathroom or bedroom." Remind your child about the rules using simple words or pictures. Use the same rules for everyone in the family!
- **Use visuals.** Make a list of places that are public and places that are private. Then you can come up with examples of behaviors that are okay in each setting. Use visuals to help your son understand and remember these rules. Look at *Public/Private Behaviors Appendix* for ideas and printable pictures to teach the concept of *Public* and *Private*.
- **Use stories.** Stories also can help your child understand these rules and why we have them. Think about the behaviors that are problematic for your child, and write a story that sets clear rules about when and where that behavior is okay. See *Public/Private Behaviors Appendix* for a story about public versus private behavior.

- **Redirect.** Tell your son where to go to perform private behaviors using simple words or pictures. For example, say something like, “You can do that in your (bedroom, bathroom)” or show him a visual labeled “Private.” Direct him to a private area when he does things such as touching private parts or adjusting underwear.
- **When private can’t be private.** Some boys will need help with private tasks, such as getting dressed, bathing, or toileting. Teach your son how and who to ask for help with these private behaviors when he is in public places, such as a school or a restaurant. This could include teaching him to plan ahead, ask quietly, or use picture cards or gestures.

Touching Private Parts

All kids at some point will discover their private parts. Every family has their own values and beliefs about this behavior, and it is okay to teach your child what your family believes. It is a normal part of development for boys and girls to touch themselves at times, and it is almost impossible to stop this behavior completely. Teaching your son when and where this behavior is allowed may be the best option. Punishing, shaming, or giving it a lot of attention may actually make it happen more. It also may make your child less likely to ask you or the doctor important questions.

It is important to know the facts. Touching private parts does not cause blindness, make you “go crazy,” stunt growth, or damage your body parts. It is not always associated with thinking about sex, either. Some young people touch themselves because it is a calming sensory experience. Some children might touch their private parts because they itch or hurt, which could be a sign of an infection. If your child is touching so much that it gets in the way of doing other activities, you notice irritated skin, or you have other concerns, talk to a doctor.

You can teach your child which parts of the body are “private parts” by describing them as the parts of the body covered by a swimsuit or underwear. You can find examples of visuals and social stories to talk about private parts and about touching in *Private Parts Appendix*.

If your son is touching his private parts in public, you will want to stop the behavior quickly and quietly. You can use a visual to remind him of the rule, such as “No Hands in Pants” or a visual to cue a behavior that he can’t do at the same time, such as “Hands on Table.” Use a First/Then Visual of “Wash Hands” then “Reward” to interrupt the behavior. Before going out, consider bringing activities that will keep his hands active, like a fidget or a handheld game. If you are at home, you may want to use a visual to give him a choice of “No Hands in Pants” or go to a “Private” place. ■



Puberty can be hard for all children. Friends, social skills, and appearance matter more. Your son may need help handling stress and fitting in with other peers. As children move from elementary to middle and high school, clothing, dating, and driving become more important. Developmental differences may become more noticeable. Think about the social situations your son will face and how things like clothing, haircuts, and age-appropriate interests can impact his “social world.”

How You Can Help Your Son Socially

Get him involved in activities he enjoys with other peers. Find groups that do things your son enjoys, such as individual or team sports, a club that fits with his interests, or a youth group. Talk to the group leader about your son’s needs and ideas about how to include him. Contact local advocacy groups to learn more about what is available in your area. If no appropriate group exists, consider starting one.

Talk to your son’s teacher or school counselor about peer sensitivity training. Programs exist to help other children understand your child’s strengths and challenges. Teaching peers about why your son has differences in his communication, learning, and/or mobility can increase empathy and understanding. Many groups provide “toolkits,” websites, and lists of local resources to help promote peer sensitivity and inclusion. See the resources listed on page 15.

Hair. Take your son to get an age-appropriate haircut. Part of growing up is having clothing and hairstyles like your peers. Although this may not be your top priority, it may be important to your son and his peers.

- Look at magazines and talk to other parents to get ideas for styles. Think about haircuts that are easy for him to maintain. Let him choose pictures of haircuts he likes and share them with the barber.
- Set the appointment for a time when the shop is not as busy and consider asking for a longer appointment time in case your son needs a break. Take distractions, like an electronic tablet or a game to help him tolerate the haircut.
- Talk to your son’s occupational therapist about self-care skills (such as brushing and styling hair) and adaptive equipment that can help him be independent.

Clothes. When shopping for clothing for your son, it is important to recognize age-appropriate clothing trends. What are other children wearing when you visit your child at school? To find out where other teenagers get clothes, you can look at magazines, talk to other parents, or take an older sibling or cousin with you when you shop.

If your son is able to make choices, give him different clothing options. You can take him shopping, buy and lay out several shirts to pick from, or use a choice board with pictures. If your child has strong clothing preferences, or trouble with buttons, zippers, and snaps, and you would like him to consider other options, try slowly introducing new shirts or pants. Keep in mind comfort, fit, and your son’s favorite colors and textures. Use a social story to explain about how children, teenagers, and adults dress differently. For example, switching from velcro shoes to slip-ons or covering elastic wastebands with untucked shirts can help your son dress more like peers. Work with your occupational therapist on dressing skills.

What if my son doesn't care?

Puberty and being a teenager are about increasing independence and expressing individuality. Even if clothing does not seem to matter to your child, small things like a different style of pants or a new haircut can go a long way toward helping him feel included and preventing him from being teased. Helping him look and dress his age may make it easier for peers to get to know how great your son is on the inside too!



Augmentative Communication Devices. If your son uses a communication device with voice production, make sure that the voice matches his age and gender.

Moods and Feelings

Moodiness can be normal during puberty. You can teach your child to express these feelings. If your child is verbal, use your words to label feelings (“It sounds like you’re feeling angry,” or “So when he did that, it made you sad.”) If your child is less verbal, use visuals like cartoons, photos, sign language, or word cards. *Moods and Feelings Appendix* includes pictures of emotions your son can use to let you know how he feels. Consider getting support from a counselor or therapist who is familiar with your child’s diagnosis and can give you other strategies.

More Than “Moody”

Sometimes mood changes can be caused by something more serious, like medical problems. For example, thyroid problems (which are common in children with Down syndrome) can look like depression by affecting mood, appetite, and activity level. Mood changes also can be a symptom of depression or anxiety. Children with disabilities can have typical teenage moodiness, but they also can develop other mental health problems that should be treated. Watch for **changes** in their typical behavior like the ones listed below.

- **Emotions:** Crying, shouting, laughing for no clear reason
- **Behavior:** Pacing, rocking, rubbing hands together, picking at skin
- **Aggression:** Hitting, biting, scratching, head-banging, throwing items
- **Appetite:** Eating more or less
- **Wellness:** Complaining about headaches, stomach aches, or other body aches
- **Sleep:** Sleeping more or less, trouble falling or staying asleep, nightmares
- **Thinking:** Seeming confused, having trouble focusing, seeing things that are not there
- **Energy:** Moving more or less, acting withdrawn, not doing things they used to enjoy

Talk to your child’s doctor about any changes that you see. Keep track of them using a diary, data sheet (see *Diary Appendix*), or an electronic phone or tablet application. Write down what you see and when you see it. ■

Nocturnal Emissions

Many teen boys ejaculate while sleeping when they enter puberty. This is called a nocturnal emission. Some people may refer to this as a *wet dream*. The penis will release semen, a fluid that contains sperm. **This is a normal process that is not in your son's control.**

Nocturnal emissions may appear as a wet, sticky spot on his underwear, pajamas, or sheets. Nocturnal emissions usually start between ages 13 and 17, with an average age of around 14. It is very important to prepare your son for this event so that he does not think he has done something wrong. This is a natural part of puberty.

Preparing My Son for Nocturnal Emissions

- **Know the difference.** Your son may think he wet the bed after a nocturnal emission. He may hide it from you or be afraid to tell you about it. Explain to him what has happened and that it is normal.
- **Make connections.** It may help to link nocturnal emissions to other changes in your son's body during puberty, such as hair growth, becoming taller, and testicles and penis growth.
- **Encourage independence.** Nocturnal emissions cannot be prevented. Teach your son what to do after they happen. This may include changing sheets, putting underwear in a laundry basket, and washing his private parts with a wipe or wet cloth.
- **Use visuals.** Use a visual schedule to help your son clean up after a nocturnal emission. This may include cleaning up with tissues, stripping the bed and placing the sheets in a laundry basket, or starting the laundry. See *Teaching About Erections Appendix* for pictures you can use to help your son be more independent in cleaning up. If your son is unable to change the sheets or clean himself independently, find a way for him to let you know that he needs help. One option is using a cue card or a door hanger to communicate with you.

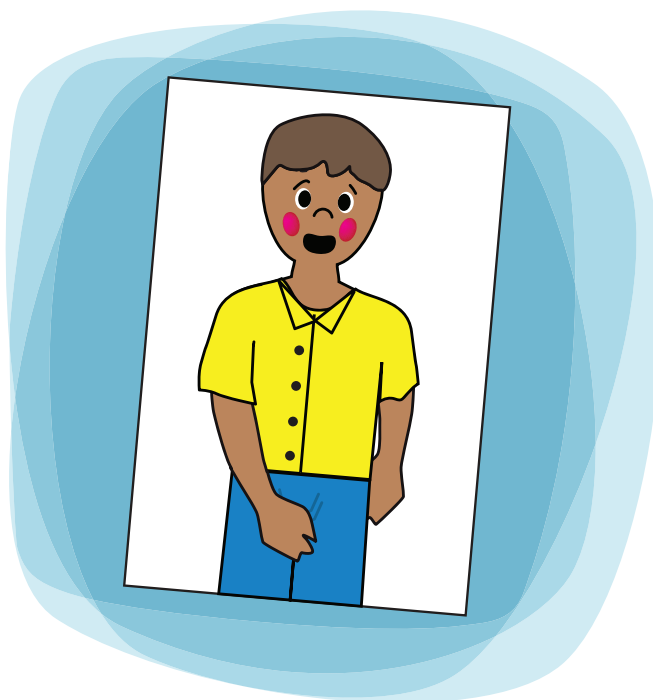
A door hanger can be found in *Teaching About Erections Appendix*. Just cut it out and laminate it for regular use.

- **Keep it private.** Nocturnal emissions are a private matter. Teach your son that he can talk about it with parents, doctors, or the school nurse only. Teach your son that he should not discuss it with friends, teachers, or strangers.
- **Stay positive.** Nocturnal emissions are a natural part of puberty. **Reacting negatively (shaming, laughter, punishment) will not stop them.** Instead, respond in a calm, matter-of-fact way, and focus on teaching your son how to handle it.
- **Ask.** Ask your son's doctor for help teaching him about puberty and body changes.



Erections

During puberty, most teenage boys have several erections throughout the day. This is a normal part of puberty for boys and often not within their control. Erections can happen for many different reasons. At this age, they can happen from something as simple as pants rubbing against the body, or just “out of the blue.” Because they may be out of your son’s control, erections in public can be unavoidable and embarrassing for him.



Things That May Help

- Create or use the social story in *Teaching About Erections Appendix* to talk to your son about erections.
- Remind him that this is one of those things he can talk about with his doctor and you, but not with friends, teachers, or strangers.
- Give him some ideas about what to do when it happens in public:
 - Stay seated, and eventually it will go away
 - Carry his books low to block his private area
 - Tie a jacket around his waist
- Well-fitting briefs may make erections less obvious and keep everything in place. Avoid sweatpants and other loose-fitting pants.

Boxers or Briefs

Helping your son choose boxers or briefs depends on what issue is most important to you and your son. Boxer shorts may be easier to pull on and off. Briefs may provide more support. Take your son with you to the store to pick out a few different types. Let him try them out at home to see what he likes best. ■



**Appendix and visuals
can be found online at:**

**[kc.vanderbilt.edu/
HealthyBodies](http://kc.vanderbilt.edu/HealthyBodies)**

Organizations

- Vanderbilt Kennedy Center:
kc.vanderbilt.edu
- Autism Society of America
www.autism-society.org
- Autism Speaks:
www.autismspeaks.org
- Easter Seals:
www.easterseals.com
- National Down Syndrome Society:
www.ndss.org
- National Parent Technical Assistance Center:
www.parentcenternetwork.org
- American Society for Deaf Children:
www.deafchildren.org
- United Cerebral Palsy:
www.ucp.org

Visual Support Resources

- <http://card.ufl.edu/content/supports/start.html>
- www.kidaccess.com/index.html
- Do 2 Learn:
www.do2learn.com
- Visual Aids for Learning: www.visualaidsforlearning.com/adolescent-pack-learning.htm

Websites

- National Information Center for Children and Youth With Disabilities. *Sexuality education for children and youth with disabilities*. Available at <http://nichcy.org/schools-administrators/sexed>
- Parent Advocacy Coalition for Education Rights' National Bullying Prevention Center:
www.pacer.org/bullying
- www.autismspeaks.org/family-services/tool-kits/dental-tool-kit
- kc.vanderbilt.edu/kennedy_files/OralHealthTips.pdf
- http://kidshealth.org/teen/sexual_health/#cat20015
- www.freewebs.com/kidscandream/main.htm

Social Stories—Information and Examples

- Gray, C., & White, A. L. (2002). *My social stories book*. Philadelphia, PA: Jessica Kingsley Publishers.
- www.thegraycenter.org/social-stories/what-are-social-stories
- www.bbbautism.com/pdf/article_27_Social_Stories.pdf

Books

- Gravelle, K., Castro, N., & Castro, C. (1998). *What's going on down there? Answers to questions boys find hard to ask*. New York: Walker and Company.
- Wrobel, M. (2003). *Taking care of myself: A hygiene, puberty, and personal curriculum for young people with autism*. Arlington, TX: Future Horizons.
- Eckenrode, L., Fennell, P., & Hearsey, K. (2004). *Tasks galore for the real world*. Raleigh, NC: Tasks Galore.
www.tasksgalore.com
- Bellini, Scott, *Building social relationships: A systematic approach to teaching social interaction skills to children and adolescents with autism spectrum disorders and other social difficulties* (2006). Autism Asperger Publishing Co., Shawnee Mission, KS.
- Middleman, A. B., & Pfeifer, K. G. (2006). *Boy's guide to becoming a teen: Getting used to life in your changing body*. American Medical Association.
- Madaras, L., & Madaras, A., Sullivan, S. (2007). *What's happening to my body? Books for boys: A growing-up guide for parents and sons*. Newmarket Press.
- Baker, Jed (2009) *Social skills picture book for high school and beyond*.
www.mayer-johnson.com/the-social-skills-picture-book-for-high-school-and-beyond
- Meehan, Cricket, *The right to be safe: Putting an end to bullying behavior* (2011). Search Institute Press.

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