

September 2017 post: A Framework for Managing Menses in Adolescents with Developmental Disabilities
(by Dr. Margaret Abraham)

Case: You are seeing an 11-year-old female with autism for a well-child visit. Mom shares that over the past year her daughter has become increasingly independent in her self-care. They found using [visual supports](#) tremendously helpful. She applies deodorant daily and recently started to wear a training bra. She's adapted well to these additions to her daily self-care routine. Mom is delighted with the progress but has concerns about managing future menstruation and inquires if it would be reasonable to prevent it from occurring. Mom expresses that her daughter's physical and emotional changes are out of sync with her social and academic development. While her daughter seems to be coping well with puberty thus far, mom admits to feeling apprehensive, not knowing what to expect in the next stage of her daughter's development.

You discuss with mom and daughter that menstruation can present challenges and provide reassurances. You explain that by allowing menarche to occur naturally, a patent genital tract is confirmed, full stature is obtained, and the maturation process is completed. Most adolescents who are able to use the toilet without assistance can learn to use pads or tampons appropriately. Initial expectant management allows them to determine their ability to cope with menses and develop strategies for success. Underwear with built-in pockets designed to keep pads in place, leak-proof as well as absorptive underwear are commercially available and help limit or eliminate the need for pads or tampons. For the first few menses some parents / guardians set an alarm to wake up before their child to change her menstrual pad.

It's important to continually assess the patient's knowledge of puberty, menstruation, sexuality, safety and consent and provide education accordingly. Anticipatory guidance is crucial in equipping both adolescents and their parent / guardian to navigate pubertal changes and adolescence well. Puberty books written for children with disabilities can be very helpful (refer to list of resources below for recommendations) and a referral to a gynecologist should be considered.

If menstrual intervention is warranted menstrual goals are established. Complete amenorrhea may be difficult to achieve and the goal in menstrual manipulation is optimal suppression, meaning a reduction in the amount and total days of menstrual flow. Treatment options include nonsteroidal anti-inflammatory drugs, which can decrease ovulatory menstrual bleeding by 30-40%, hormonal methods and surgical methods. Most methods of menstrual manipulation involve hormonal contraception and the [Center for Disease Control and Prevention's U.S. Medical Eligibility Criteria for Contraceptive Use](#) provides comprehensive, evidence-based guidance for prescribing. Hormonal options include combined oral contraceptives, ring or patch, which can be used continuously or for an extended period to attain optimal suppression. Daily oral progestins can be used but efficacy in achieving amenorrhea depends on dose and adherence to taking the hormone at a similar time every day. Use of depot medroxyprogesterone acetate (DMPA) results in approximately 90% amenorrhea by the fourth dose but has associated weight and fracture risks. The levonorgestrel intrauterine system should be considered for any adolescent patient. Irregular bleeding is common initially, but amenorrhea rates increase over time and overall blood loss is decreased significantly. Progestin contraceptive subdermal implants have a high incidence of unscheduled bleeding and are not considered a first line treatment option. It should be emphasized that while many hormonal methods serve a dual purpose of preventing unintended pregnancy, none will prevent potential sexual abuse. Surgical methods specifically a hysterectomy portend considerable procedural risks and may be considered only after other reasonable alternatives have been attempted. Furthermore, laws regarding sterilization, hysterectomy, and consent issues for minors vary from state to state.

Resources:

Puberty Books by Terri Couwenhoven (for developmentally delayed children)

- The Girls' Guide to Growing up

- The Boys' Guide to Growing up

- Teaching Children with Down Syndrome About Their Bodies, Boundaries, and Sexuality: A Guide for Parents and Professionals.

ACOG Committee Opinion No. 668 Menstrual manipulation for adolescents with physical and developmental disabilities. *Obstet Gynecol* 2016;128:e20-5