University of Michigan
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Managing Menstrual Cycles for Girls and Women with Developmental Delay

Many families of girls and women with developmental delay have questions about their options for managing menstrual cycles. In general, if you have been able to teach your daughter to use the toilet by herself you can usually teach her to manage her menstrual periods. Every young woman is unique and managing hygiene independently is not always possible. While it may be challenging to teach your daughter to manage her menstrual cycle, it is often possible with patience and time, as with toilet training.

It may be helpful to talk with other families you know for support and suggestions. However, you know your daughter's needs best. Some girls and women become frightened by the bleeding, while others may have behavioral changes that make menstrual periods difficult.

This material describes several options you can consider for managing or suppressing menstrual cycles in women with a developmental delay. We hope this information will help you make a decision that is comfortable for your family.

Why should I consider suppressing my daughter's menstrual periods?

Suppression of menstrual periods can help to:

- Avoid unsanitary behavior such as refusing to wear pads, smearing blood, or touching private parts in public.
- Help with mood swings or troublesome behaviors that come only in the week before menstrual bleeding starts.

- Reduce concerns about the possibility of an unplanned pregnancy
- Ease the strain on you or your daughter's caregivers who have to teach her how to handle her periods.
- Reduce menstrual pain, heavy menstrual bleeding or other menstrual symptoms.

Is it possible to suppress menstrual periods?

Yes, there are many options available, each with its own benefits and risks. It is not possible to immediately and completely "turn off" menstrual bleeding, like turning off a faucet. Menstrual suppression may take time--up to a year or sometimes more. Improvement in menstrual problems is almost always possible with treatment, although each option has its pros and cons.

Is it safe to suppress menstrual periods?

Yes, it is safe. Even though all medicine can have side effects, there is no evidence that menstrual suppression is harmful to a woman's health.

What are the options for suppression or control of my daughter's menstrual period?

There are several medications that contain hormones that suppress the menstrual period.

Progestin-only-pills (The "Mini-Pill" or other similar medicine)

Pros:

These pills do not include the hormone estrogen, and do not increase the risks of blood clots. These pills may be helpful for girls and women who have certain medical problems and should not use estrogen.

Cons:

Timekeeping is very important. Taking a pill **every** day at the same time every day is **more important** with these pills than with the combination pills. Irregular

bleeding is also common with these pills.

Combined oral contraceptives (“The Pill” & “The Patch”)

Pills can be given in the usual way in which 3 weeks of hormone pills are followed by 1 week of placebos (reminder pills) that do not contain hormones. There are many different pills that are currently available with slightly different hormones or slightly different dosing. She will have predictable menstrual bleeding during the week when the placebo pills are taken. Four weeks (28 day) is considered one cycle.

The weekly patch has medicine that is absorbed through her skin with similar benefits described below.

Pros:

Periods are very predictable. Natural menstrual periods are often somewhat irregular in the first few years. Many girls with developmental delay need routine and the pill can help with a regular cycle. Periods are also usually lighter and she will have fewer cramps.

Cons:

- She will have to swallow the pill every day, although there is one type of pill that can be chewed. Most can be crushed and given through a G-tube.
- The patch is changed once a week and some girls with developmental delay may pick at or scratch off the patch. We can usually get past this by placing the patch between the shoulder blades where she cannot reach.
- Irregular, “breakthrough” bleeding occurs in about 30-40% of girls (30-40 out of 100) in the 1st cycle. In the 2nd cycle, fewer girls have breakthrough bleeding—around 15-20% (15-20 out of 100). By the 3rd cycle only about 5% (5 out of 100) have irregular bleeding.
- Side effects are uncommon, but may include headaches, breast tenderness, nausea, or mood changes. Most of these side effects go away over time, but if they stay the same or make her “miserable,” a different pill or another method may be better for your loved one.

Does estrogen cause blood clots?

The answer is complicated. Medicine that contains estrogen, like birth control pills, increases the risk of blood clots in the legs (deep vein thrombosis) or clots that travel to the lungs. The risk for women who are not pregnant and do not use birth control pills to develop a blood clot in a one year period is between 1 and 5 in 10,000. In women using the combination pill the risk to develop a blood clot in a one year period is between 3 and 9 in 10,000. See table below.

Not taking Estrogen	Women taking Estrogen
1-5 women out of 10,000 will develop a blood clot	3-9 women out of 10,000 will develop a blood clot

Use caution with these pills if you have a strong family history of blood clots. In cases where there is no strong family history of blood clots, young women are less likely than older women to develop a blood clot.

Extended cycle oral contraceptives

With this method the women takes the hormonally active pills for more than 21 days and gets her period less frequently. For example, there are pills that are packaged as 84 days of hormonally active pills, followed by 7 days of placebos.

Pros:

There is less frequent menstrual bleeding and less frequent menstrual-related symptoms.

Cons:

Irregular, “breakthrough” bleeding occurs frequently, although this does tend to lessen with time.

Continuous combined oral contraceptives

This is the method in which the woman takes hormonally active pills every day without a break.

Pros:
About 60% of women (60 out of 100) have no bleeding by the end of 1 year of treatment.
Cons:
These are similar to cyclic pills or the patch. Almost everyone has irregular or "breakthrough" bleeding for the first 6-12 months.

Depot medroxyprogesterone acetate ("The Shot" or Depo-Provera®) or DMPA

In the past, this was the most common option parents chose for their daughters. This method has been used for menstrual suppression since the 1960s.

Pros:
Between 50%-60% of women (50 to 60 in 100 women) will have no bleeding by the end of 1 year of treatment. The shot is given every 12 weeks.
Cons:

- Almost everyone has irregular (breakthrough) bleeding in the first 6-12 months.
- Weight gain can occur. The average is 2-4 pounds per year, (although it can be more or less). Over time this weight gain accumulates.
- The shot slows the rate of growth in bone density. This will return toward normal after the shot is stopped. The decrease in bone density is a concern especially for women in wheelchairs or women taking seizure medications which also lead to low bone density.
- Other side effects can include acne, more oily hair and skin, and mood changes. Because this shot lasts for 12 weeks if side effects occur, they can't be stopped, but have to wear off.

Progestin-containing intrauterine system (Mirena® IUD)

This hormone-releasing intrauterine device (IUD) is a small plastic device that is placed within the uterus. Other methods can be used first and the IUD placed later.

Pros:

This is the **most effective** method of birth control. It works well to treat heavy bleeding and cramping. Mirena® lasts five to seven years. One year after insertion, many girls or women will stop having periods (50-60%, or 50-60 girls out of 100).

Cons:

Inserting the IUD can be painful and requires a pelvic exam. Many teenagers will need general anesthesia for the insertion. If the patient needs another exam that requires general anesthesia, like an MRI or an x-ray, the IUD may be placed at the same time.

Nexplanon®:

This is a small 4 centimeter long and 2 mm diameter capsule that is inserted just under the skin in the inner surface of the upper arm and slowly releases progesterone over 3 years' time. The insertion is very quick and can be done with local anesthesia in the office in several minutes.

Pros:

The procedure is quick, and the capsule lasts 3 years. It is highly effective for contraception.

Cons:

This may be less effective for patients with seizure disorders on certain types of seizure medications. Only 20% of women (20 out of 100) will have complete suppression of menses with this method.

Endometrial Ablation

This is a surgical procedure to burn or destroy the lining of the uterus to lessen or stop periods. Only 15% of women (15 out of 100) stop having periods completely with this method. The other 85% may have lighter bleeding. This procedure is not recommended for adolescents or young women. The procedure is not very effective in stopping periods long term for younger women.

Hysterectomy

This is a surgery to remove the uterus. It is considered a major operation. The current clinical guidelines for gynecologists and pediatricians state that hysterectomy done for the purpose of stopping menses or sterilization in adolescents or women with disabilities is **not** recommended.

What should I expect with all hormonal options?

You can expect irregular, unpredictable, and unscheduled bleeding during the first few months after starting these medications. Spotting - small amounts of blood between periods - may also occur. The blood may be dark brown.

- Write down dates of bleeding or spotting on a calendar or track in an app so you can tell your clinician what the bleeding is like.

When should I call the office?

Seek medical care as soon as possible if the woman or girl has any of the following symptoms that create the acronym A.C.H.E.S.

- **A**bdominal pain
- **C**hest pain
- **H**eavy bleeding

- **E**yesight or vision changes
- **S**evere leg pain

Call your clinician if she has unwanted side effects making her miserable. Most nuisance side effects resolve over the first 1-3 months. It is possible to change from one option to another, but an initial trial of approximately 3 months is a reasonable goal. Every patient is unique so please discuss any questions you may have with your clinician.

Keep in mind that costs of these options vary depending on your insurance coverage.

Where can I learn more?

The following websites have information about birth control options. These references are not specifically for girls with developmental delay:

- Understanding Menstrual Suppression: https://www.arhp.org/Publications-and-Resources/Patient-Resources/fact-sheets/Understanding-Menstrual-Suppression
- Center for Young Women's Health: http://youngwomenshealth.org/gynecology-index/

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