

## Puberty and Menstruation

In healthy girls as well as girls with RS, puberty begins around the age of 8 when the pituitary gland begins to secrete hormones. These hormones travel through the bloodstream to the ovaries, where they trigger growth and change. The first observable change is breast budding. One breast may start growing before the other, and they may grow at different rates so they may appear unequal in size at first. Eventually, they will be the same size. Next, she develops pubic hair, and later, underarm hair. She goes through a growth spurt and her hips and breasts become more rounded.

Menstruation (menarche) usually begins about two years after the breasts begin to bud. It is considered "normal" if a girl begins her period after 9 years and before 16 years. Most healthy girls begin menstruating around the age of 13. This is usually the case in RS, but menstruation is delayed in some cases when the girl is very thin. Before hormonal changes can begin, she must reach a critical body weight of around 106 pounds, which some girls with RS may never achieve. She must also have the right amount of body fat and body water for menstruation to begin. In spite of this, many girls with RS begin their menstrual cycles at the expected time. Others may begin their period earlier or later than usual. Some girls have noticeable pubic hair earlier than what is typical. The first few years after menstruation begins, it is normal for her cycle to be irregular. She may skip a period now and then.

When should she see a gynecologist?

The need for a woman with RS is the same as any other woman. Most maturing girls should have a physical every year after the age of 18, unless they are taking birth control pills, the use of which requires an examination regardless of age. She should see the gynecologist if a vaginal infection is suspected. The examiner should be gentle and patient, and the parent should stay with her, giving reassurance and comfort.

How can we maintain good hygiene?

Menstrual flow is odorless until it comes in contact with air and bacteria. Bathing and the use of disposable wipes are helpful. Sanitary napkins can be used in the panties or can be inserted in the diaper for extra protection.

Should she have a vaginal discharge?

The effect of increased estrogen in her system is a thin, whitish, mucus-like discharge. This causes no discomfort and should not have an odor, cause itching, redness or lesions on the skin.

How can a vaginal or yeast infection be recognized?

A vaginal infection will usually have an odor. It may be very white, thick and cottage cheese-like, or yellowish or greenish in color. It may cause itching and may produce redness. Yeast infections will usually cause a bright red diaper rash with itching. If she has any of these symptoms, her doctor should be contacted.

Can she have an infection or irritation of the vagina even before puberty?

Vaginal irritation is common in girls over 3 years for a number of reasons. Inadequate bathing, wiping from back to front or washing too vigorously may cause problems. Sitting on the ground without protection, using bubble baths, and high sugar diets may also contribute to difficulties, as well as wearing clothing that is too tight and does not let air circulate. Pinworms and anal scratching are other sources of vaginal irritation. To avoid these problems, change her diaper frequently, give warm baths (avoid using bubble baths) and use bland lotions or ointments to protect the skin.

Can she use tampons?

Slim tampons which have been developed for teens can be used, and are most easily inserted when she is lying on her side, legs drawn up. Be sure to insert the tampon completely into the vagina, as it will be uncomfortable if it is only partly inserted. If tampons are used, it is important to change them often. As with anyone who uses tampons, it is important to recognize the signs of toxic shock syndrome, which occurs most often in women younger than 30. TSS is a rare but potentially dangerous disorder which is caused by bacteria which find a breeding ground in the absorbent nature of the tampon and moisture of the vagina. Sudden fever of 102 or more, vomiting or diarrhea, dizziness and rash are the symptoms to watch for. A physician should be consulted immediately.

What medications work for menstrual pain?

If she seems uncomfortable, over-the-counter preparations for menstrual pain may be adequate. If these do not work effectively enough, her physician can prescribe a stronger medication to give relief. A hot water bottle on the tummy may help.

Will she get PMS (Pre-Menstrual Syndrome)?

PMS is a predictable pattern of physical and emotional changes that occur just before menstruation. Most women experience these changes from a mild to moderate degree. The symptoms can develop any time after the midpoint of the menstrual cycle, and usually end soon after the period starts each month. PMS may cause bloating, breast tenderness, weight gain, fluid retention, fatigue, nausea, vomiting, diarrhea, constipation, headaches, skin problems or respiratory problems. It may also cause emotional changes that include depression, irritability, anxiety, tension, mood swings, difficulty concentrating or lethargy. If your daughter has a period, you may notice some of these changes taking place. It helps to remember that these changes are predictable and short-lived. Seizures can become worse prior to onset of periods.

What are the options for managing her period

The birth control pill will reduce her menstrual flow. Other methods to eliminate her period altogether include shots of Depo-Provera and surgeries known as endometrial ablation and hysterectomy.

Does the birth control pill help?

Newer low dose oral contraceptives are more effective and have fewer risks. There are dozens of brands on the market today. Your daughter's physician should be consulted about the risks and benefits and the type of pill that is best for her. Possible side effects, which are usually minor, include nausea, breast tenderness, fluid retention, depression and nervousness. A sense of fullness maybe felt in the breasts or pelvis. Weight gain may occur, but in RS, that is usually a plus! Some beneficial side effects include lighter menstrual flow and fewer cramps, regular and predictable periods, and decreased likelihood to develop breast lumps, iron-deficiency anemia, ovarian cysts, endometrial or ovarian cancer, or rheumatoid arthritis. Birth control pills are usually taken for three continuous weeks and during the fourth week, no pill or an inactive pill is taken. The menstrual flow will then begin. If no menstrual flow is desired, the active pill is continued without interruption.

Will it harm her to take the pill without a break?

It is not harmful to her, and it will help you with hygiene problems by stopping menstruation. While she will not have a regular period, she may have some spotting.

What is Depo-Provera?

Depo-Provera, given by injection, is a long-acting form of progesterone, which is an ovarian hormone produced in small amounts during the second half of the menstrual cycle. Because it does not contain estrogen, it does not produce many of the side effects of birth control pills. Depo-Provera suppresses ovulation without completely suppressing production of estrogen, the other normal ovarian hormone. Depo-Provera produces changes in the endometrium (lining of the

uterus) so that menstruation is less likely to occur. The first shot is given immediately after a menstrual period and every three months thereafter.

What are the side effects of Depo-Provera?

A frequent side effect of Depo-Provera is irregular bleeding. After being on the shot for six or seven months, most women stop having periods altogether. Some studies have reported weight gain on the medication. Some women have had continued spotting and have discontinued the medication for that reason. Ovulation sometimes does not resume for a year or two after the medication has been discontinued. The American Academy of Pediatrics Committee on Drugs found no conclusive evidence that Depo-Provera is harmful to humans but it acknowledges that there is controversy about the potential undesirable long-term effects.

What is endometrial ablation?

Endometrial ablation is a laser procedure which is done on an In-Out Surgery basis, and is usually performed on women who have an abnormally high degree of bleeding. From one to three months before the procedure, the patient is given a drug to thin the uterus so that the laser can penetrate the endometrium (lining of the uterus). Under general anesthesia, the laser is introduced through the vagina to vaporize the endometrium. The laser has a small camera which projects the image on a screen, and the surgeon follows this image. The procedure requires no incision. Two out of three women have a permanent cessation of bleeding following the surgery. The endometrial ablation has advantages. It does not require hospitalization overnight, there is less pain because it is not an invasive surgery, and it requires less recovery time. Because the endometrium is a tough organ, however, when done in younger women it may grow back, causing the period to return and making it necessary to repeat the surgery.

What are the facts about hysterectomy?

Hysterectomy (removal of the uterus) is the most permanent and certain way to end her period. It requires surgery and removes the possibility of pregnancy, menstrual periods, and eliminates the potential for uterine cancer. Hysterectomy requires hospitalization for several days and a period of recovery is necessary. Each state has different laws and requirements, and most states have some procedural process to protect her rights. Getting permission can be a lengthy process, but hysterectomy is a final solution to menstrual problems.

Sexual Maturity

Parents often worry about the problems created by sexual maturity. Most are uncomfortable with masturbation. This kind of stimulation is not abnormal. It is a satisfying and natural part of sexual maturity. It can be embarrassing when it happens at inappropriate times, but it will not hurt your daughter. Learning to control the behavior in public places can usually be accomplished through behavior modification techniques.

How can I prevent her from being molested?

Most parents share this fear as we look down the road to when our daughters are no longer in home care. As difficult as it is to confront, protecting her against potential abuse is very important. Keep her away from risky situations, watch for the danger signs of molestation that will be seen in her behavior, and trust your instincts.

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