What is endometriosis?
The endometrium is made up of cells that line the inside of your womb (uterus). These cells are shed every month when you have a period. Endometriosis is a condition where cells that are similar to endometrial cells are found outside of the normal location. These cells can implant on ovaries, fallopian tubes, ligaments that support the uterus, and tissues that cover the bladder and rectum. These implants respond to hormones from the ovary, which can cause scarring and pelvic pain.

What causes endometriosis?
It is not completely understood why some teens get endometrial-like cells implanting in their pelvis, and others do not. One theory is that during the period, some of the blood and endometrial cells that usually come out through the vagina can escape through the fallopian tubes and implant outside of the uterus. Those with endometriosis are not able to prevent these implants from growing and the body’s immune system cells cannot clean up these implants. Over time, these implants can cause bleeding, scarring and pain.

How common is endometriosis?
In adolescents with severe and lasting menstrual pain, more than half may have endometriosis. Endometriosis can run in families. Studies show as many as 10% of reproductive-age adults have endometriosis.

What are the symptoms of endometriosis?
Many will experience pelvic pain before and during their period. The pain can be crampy, dull, sharp, stabbing and can radiate to your back or down your legs. The pain sometimes gets progressively worse and can become present all the time. Interestingly, there is no relationship between the amount of disease and the level of pain. Some teens will have a lot of endometriosis and have very little pain, while others may have a small amount of endometriosis and experience severe pain. Teens with endometriosis can experience pain during sex, urination, and bowel movements.

Graphic showing possible locations of endometriosis in the pelvis:
How do you treat endometriosis?

The hormones in birth control can be used to block the effects of ovarian hormones on the endometrial implants. Commonly used methods include the birth control pill, patch, ring, shot, implant or progestin IUD. Norethindrone acetate is a very effective oral progestin used to manage endometriosis pain.

If you continue to have pain despite medical treatment, a surgical procedure, called laparoscopy may be performed for both diagnosis and treatment. During laparoscopy, the endometrial implants may be treated or removed. Medical treatments are usually prescribed once again after surgery to keep further implants from forming.

If endometriosis is diagnosed during surgery, and hormonal medications are not controlling symptoms, there are other medical options. These include gonadotropin-releasing hormone (GnRH) agonists, such as leuprolide (Lupron), or an anti-estrogen medication called elagolix (Orilissa) that lower ovarian hormones and reduce the pain from endometriosis. These are not usually first line treatments for young adolescents due to potential effects on bone density. When these medications are used, additional hormones may be prescribed for bone protection.

Early diagnosis, pain management and a long-term treatment plan help teens to continue to be active in their normal daily lives and preserve future fertility. Also, to help with pain or for additional support, many teens are referred for other services such as biofeedback, physical therapy, acupuncture, exercise programs and psychological counseling.

How does your healthcare provider diagnose endometriosis?

A detailed history of the timing of pain with periods is important. A physical exam will include an abdominal exam and may also include a pelvic exam (an exam of the vagina and uterus). A pelvic ultrasound is often done to exclude a mass or other abnormality. Other imaging studies, blood tests and cultures may be obtained to be sure there are no other causes of your pelvic pain. Many patients are asked to keep a detailed diary of pain, periods, diet, and bowel movements.

Unfortunately, there are no diagnostic blood tests, x-rays or imaging tests that confirm endometriosis. Your healthcare provider may suspect you have endometriosis based on your symptoms, but the only way to confirm the diagnosis for certain is with surgery. Usually, if there is no improvement after 3 to 6 months of medical treatment, a diagnostic laparoscopy can be performed to allow your doctor to look at your pelvic organs. A laparoscopy is a surgical procedure that is done in the operating room. A camera is inserted through the belly-button to search for endometriosis. Most people who have this procedure will not have to stay in the hospital and can go home the same day.