Endometriosis: A debilitating condition that sometimes takes years to diagnose

By ACSH Staff — March 31, 2015

[1] A recent New York Times Well article [2] tells the stories of three women who all experienced almost exactly the same problem. As teens and pre-teens, they had agonizingly painful periods, accompanied by nausea, constipation, and exhaustion. Multiple doctors told them that what they were experiencing was a normal part of being a woman or that it was all in their heads. And it wasn’t until these women were in their twenties that they finally got a diagnosis they had severe endometriosis.

Endometriosis is a hormone and immune system disease in which tissue that normally lines the inside of the uterus grows outside of the uterus. The displaced uterine tissue acts as it normally would thickening, breaking down, and bleeding with every menstrual cycle. Lesions can form in the ovaries, fallopian tubes, abdominal lining, bowel or bladder. Endometriosis not only causes debilitating pain, but also may cause fertility problems. An estimated 89 million women worldwide have endometriosis, and more than 10 million women in the U.S. are known to have endometriosis.

A delayed diagnosis, even after visits to several doctors, is unfortunately not uncommon. The Endometriosis Association estimates that it can take up to 10 years from the onset of pain for a doctor to give an endometriosis diagnosis. The problem is that many physicians are not educated about the disease in adolescents, and often believe the disease does not affect teenagers.

Many times, we hear that girls are told they’re too young to have the disease, they’re trying to get out of school, or that they’re exaggerating, said Mary Lou Ballweg, the president and executive director of the Endometriosis Association.

There is no known cure for endometriosis, and experts say there is not a one-size-fits all solution. Treatment for endometriosis depends on the severity of symptoms and whether the patient hopes to become pregnant. A hysterectomy (surgical removal of the uterus) may sometimes help. Ms. Byrne, one of the three women with endometriosis who were interviewed for the story, decided to have a hysterectomy after being told she was infertile. But even after the surgery, although she had initially experienced pain relief, her symptoms started to come back a few years later.

If the doctors had taken me seriously at 15, she said, who knows [what] would have happened to
me at 22?

ACSH’s Dr. Gilbert Ross adds, This illustrates the need to educate doctors and healthcare providers about this condition. The belief that endometriosis does not affect teenagers is clearly incorrect. Furthermore, early treatment could reduce the chance of potentially irreversible conditions, such as infertility, as a result of this disease, and thus the earlier this disease is treated, the better.

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