Recurrent Endometriosis After Hysterectomy

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Question:

I have been through several surgeries for endometriosis. The pain kept coming back, so my doctor told me I should have a complete hysterectomy. I had the hysterectomy, but now a lot of the same symptoms, including the pain, are back. My doctor says that since everything has been removed it can't be endo, and wants to send me to a bowel doctor and a psychiatrist. Can I still have endometriosis, even after having my uterus and both ovaries removed?

Answer:

Yes, you can. This can be one of the most difficult situations encountered with endometriosis. It is especially tough from the patient’s standpoint, because she is usually dealing with the medical profession, her family, and others who are starting to question the legitimacy of her pain. For a gynecologist this can be the hardest type of surgery as well, and thus the most likely to be incorrectly or incompletely treated. As a result the patient will be subject to “treatment failure,” and the unfortunate recurrence of her symptoms.

There is no question that endometriosis can be present in a woman who has undergone a hysterectomy and the removal of both ovaries (it’s even more likely if the ovaries remain). Performing a hysterectomy does not in itself treat endometriosis. It may reduce the chance of the future recurrence of endometriosis, and it may reduce non-endometriosis-related cramps, bleeding etc. But the key point is that endometriosis, for the most part, does not grow on the uterus: It grows behind the uterus, on the bowel, in the rectovaginal septum, in the pararectal spaces, under the ovaries, around the ureters, on the bladder, etc.

If a hysterectomy is part of the agreed-upon treatment plan between you and your physician, that's fine. But this is appropriate ONLY AFTER the endometriosis has been completely removed (removal of the endometriosis and a hysterectomy can be done during the same surgery) from all of the areas that will not be taken out with the uterus. If you have undergone a hysterectomy alone for the treatment of endometriosis (i.e., the endometriosis was not treated just prior to the hysterectomy), there is a good chance you will have persistent or recurrent symptoms. The most common symptoms include constant pain, pain with bowel movements, pain with intercourse (usually during deep penetration, as if your partner is "hitting" something inside) and occasionally, mid-back pain (secondary to ureteral involvement). You can also experience the fatigue and emotional changes we have seen with endometriosis, including moodiness, depression, etc.

Now, assume for a minute that everyone (such as your doctor, significant other, employer, etc.) understands your situation, and your gynecologist/surgeon is ready to go after the endometriosis. What are the pitfalls? In my experience, by the time a patient has gotten to this point she has undergone so many surgical procedures, it is virtually impossible to tell what is and what is not endometriosis. The anatomy is distorted, fairly extensive scar tissue and fibrosis (tough, leathery tissue) are present, and the endometriosis is often buried out of sight, especially in a patient who has had a hysterectomy performed. As the surgeon clamps, cuts and ties the tissue during the hysterectomy, the endometriosis gets “wadded up” and buried in the process. After this area heals following the surgery, it can be impossible to detect the endometriosis without dissecting the areas in which endometriosis is known to grow.

Another common area for residual endometriosis is the vaginal cuff. Unless all of the endometriosis is removed from the rectovaginal septum prior to the hysterectomy, it can be easily sewn into the vaginal cuff. We have seen and
treated more than 200 women who have had residual endometriosis after undergoing a hysterectomy. If you are experiencing this situation, you are not alone.

I believe there are several key factors in successfully treating this type of case: First, since this is probably the most challenging surgery a gynecologist will face, it is important to seek out a surgeon who is technically proficient and has had experience in dealing with this situation. Second, since it can be impossible to determine what is and what is not endometriosis, all abnormal tissue must be removed, and the areas in the pelvis where endometriosis is known to grow must be dissected. It is not uncommon for an area to look normal on the surface, but to have deep endometriosis when opened up. In my experience, all areas need to be dissected down to normal tissue (endometriosis until proven normal). Depending on the specific situation, a small portion of the vaginal cuff may need to be resected.

In summary, even if you have had a hysterectomy you can still have endometriosis and the associated symptoms and pain. Treatment of this condition is technically challenging, and requires that the surgeon have the ability, expertise, and equipment needed to dissect and remove all of the pelvic areas deep down to the normal tissue. In my opinion, a surgeon cannot remove all of the endometriosis and scar tissue by just spot-treating or selectively excising lesions. It has been my experience that once all of the pelvic area has been explored and all the abnormal tissue has been removed, the patient feels better.

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