

ASK ESIG

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Empowerment through expertise

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ALL ABOUT ADENOMYOSIS

QUESTION 1: I was diagnosed (via a biopsy) with adenomyosis when I had my hysterectomy 7 years ago. My endo has just returned, despite a subsequent oophorectomy. My question is - is it possible for adenomyosis to return post-hysterectomy (in places other than the uterus)?

Michael East: “Although adenomyosis is a term generally reserved for endometriosis like deposits found within the wall of the uterus, similar ‘lesions’ can be found in other places (see below). The term adenomyosis contains 3 parts, adeno (meaning glandular tissue, in this case similar to endometrial tissue), myo (meaning smooth muscle) and sis (coming from the Greek ending to indicate ‘a condition’). The uterosacral ligaments that run from the cervix to the lower spine (sacrum) can also contain adenomyosis like tissue, as can the rectovaginal septum (wall between the rectum and vagina). Both of these structures contain smooth muscle and both can have endometriosis (known in these places as adenomyosis) within them, that can survive after hysterectomy. If it is suspected at the time of hysterectomy that the uterosacral ligaments and rectovaginal septum contain adenomyosis / endometriosis, then it is usual for the surgeon to try to remove that as well. It is still possible for some to survive even then after hysterectomy, and cause ongoing pain. I would like to stress however that pelvic pain persisting after hysterectomy is more likely to be due to other causes than adenomyosis (for example musculoskeletal pain). Ongoing pain is best helped by a team of health professionals consisting of a physiotherapist, gynaecologist, chronic pain specialist and a clinical psychologist.

Sometimes further surgery can help, but equally it may fail or even make the pain problem worse! It is important to remember that every woman's situation is slightly different and what may have helped a friend may not be the best option to help you. Talking about your options with the health team members mentioned above is often the next best step."

QUESTION 2: Following a pregnancy, with C-section delivery, is there any indication of the time period over which the adenomyosis worsens? Does the data suggest adenomyosis gets worse soon after pregnancy and delivery?

Michael East: "How adenomyosis occurs is still an unanswered question. The suggestion that pregnancy causes adenomyosis is probably a medical myth (other than after C-section which I will come to later). Before ultrasound scans had been invented adenomyosis was only diagnosed in women who had undergone hysterectomy and the majority of those had borne children. Even when ultrasound scans became available the appearance on scan thought to indicate adenomyosis, was only seen in older women. Now that ultrasound scans offer much higher definition the appearance of adenomyosis can be seen as early as age 14 years. It is important to remember that adenomyosis can't be diagnosed by an ultrasound scan or even an MRI scan. It can only be suggested by such scans, as tissue under a microscope is the only sure way to make the diagnosis.

"To answer the question above more specifically however, I am not aware of any good evidence that adenomyosis becomes worse after a pregnancy. The exception to that is in the case of C-section where the very cut into the wall of the uterus may become a site of adenomyosis due to faulty healing where the womb lining can become caught up within the wall of the uterus. This is one of the reasons why women who have experienced a C-section delivery are at greater risk of having a hysterectomy in later life."

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Neil Johnson: "Adenomyosis should not return after a hysterectomy (as long as it wasn't a subtotal hysterectomy and the cervix has also been surgically removed). Endometriosis associated with it can occasionally return after hysterectomy and oophorectomy ... unfortunately.

"Data are very sparse on whether adenomyosis gets worse soon after pregnancy and even more sparse than the sparse data indication on the length of time for recurrence of endometriosis and related problems after pregnancy. Adenomyosis remains much less well researched than endometriosis. We can often apply the same lessons that we learn from endometriosis research to adenomyosis (in fact we often have to, otherwise there is an information vacuum regarding adenomyosis). It is largely based on experience/anecdote rather than primary research data, but this experience tells us that endometriosis (and

adenomyosis) problems often resolve during pregnancy and for a variable time afterwards. In fact, there are some women whose endometriosis/adenomyosis-related problems do not recur after pregnancy. Unfortunately, there are also many women whose problems do recur, sometimes a short time (months) or a long time (up to many years) after having a baby. The length of time that women remain free from endometriosis problems after pregnancy is unpredictable. Having a caesarean section, rather than a vaginal delivery, has sometimes been claimed to be associated with earlier recurrence or more likely occurrence of endometriosis (www.hormonesmatter.com/endometriosis-vaginal-birth/). Probably the strongest study in the literature to support this was a Swedish cohort study (ref: Andolf E, Thorsell M, Kallen K. Caesarean section and risk for endometriosis: a prospective cohort study of Swedish registries. BJOG. May 13, 2013. doi: 10.1111/1471-0528.12236.)

FURTHER INFORMATION FROM ENZ:

Mr Michael East and Professor Neil Johnson have given a helpful response to these questions. ENZ recommends the gold standard approach to managing pelvic pain through multi-disciplinary teams at Centres of Expertise. If such a centre or clinic is not available near you, look at the ASK ESIG files about pain management and ask your GP or specialist about a referral.

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