

Removing My Ovaries: Is Risk Reducing Salpingo-Oophorectomy (RRSO) Right for Me?

A Pamphlet for Women at Increased Risk of Developing Ovarian Cancer



Many women at increased risk of developing ovarian cancer think about having surgery to remove their ovaries to help prevent cancer. This pamphlet provides information about this surgery and shares the experiences of other women who have faced the same decision.

What is Risk-Reducing Salpingo-Oophorectomy (RRSO)?

RRSO is an operation in which a surgeon removes the ovaries and fallopian tubes to help prevent ovarian cancer in a healthy woman.

How likely am I to get ovarian cancer?

Most women face about a 2 percent risk of developing ovarian cancer during their lifetime. Women who have a family history of ovarian or breast cancer may be at much higher risk. For example, a woman who has a positive BRCA gene test has a 20-45 percent risk of developing ovarian cancer over her lifetime (the BRCA genes cause some cases of hereditary ovarian and breast cancers). A genetic counselor can review your family and medical histories to help determine your risk of developing ovarian cancer.

"I was worried about my family history of breast cancer. I never realized I should also be worried about ovarian cancer."

"When I found out that I had a positive genetic test, I was really depressed and worried. I watched my mother get treated for cancer and I didn't want my family to have to go through that. But I guess I'd rather know than not know."

How is ovarian cancer detected?

Ovarian cancer can be difficult to detect. Some women may have bloating, abdominal pain, or vaginal bleeding, but these symptoms are very common in healthy women and only rarely do they indicate cancer. When symptoms are the result of ovarian cancer, the disease can be at an advanced stage

An ultrasound study can detect changes in your ovaries that suggest cancer. However, worrisome ultrasound findings usually turn out to be less serious conditions like cysts.

Ovarian cancer may be detected through a blood test that measures a protein called CA-125. However, CA-125 levels can be normal when ovarian cancer is in the early stages. To complicate matters, CA-125 levels can be elevated for reasons unrelated to cancer, especially in pre-menopausal women. When a high CA-125 level is truly due to ovarian cancer, the cancer is often at an advanced stage.

The only way to definitively diagnose ovarian cancer is through surgery that allows a doctor to carefully examine your ovaries and fallopian tubes.



"I felt good when my CA-125 and ultrasound tests would come back normal. But maybe I wasn't being fully honest with myself."

"I was shocked when I found out that there is no easy way to test for ovarian cancer. With all they can do now, you would think that they'd have a good test."

Is ovarian cancer curable?

When ovarian cancer is detected at an early stage, the cure rate is high. Unfortunately, ovarian cancer is usually detected at later stages, when the cure rate is much lower.

"I was lucky. Mine was caught at an early stage. But it really gave me a scare."

"My friend looked perfectly healthy. She had just had a physical, and everything was normal. And now they tell her that that she has advanced ovarian cancer and may only live a few years."

How can I prevent ovarian cancer?

Currently, no changes in lifestyle or diet have been proven to prevent ovarian cancer. Some studies suggest that birth control pills can reduce the risk of ovarian cancer, though birth control pills may slightly increase the risk of breast cancer. The most effective way to reduce your risk of ovarian cancer is through RRSO.

"I thought I was doing everything right. I didn't smoke, I watched what I ate, and I worked out all the time. I couldn't believe it when my doctor told me I had cancer."

"I wanted to do something, anything, so that I didn't ever get ovarian cancer."

If I have an RRSO, does that mean I will never get ovarian cancer?

RRSO lowers your risk of ovarian cancer by at least 95 percent. There is still a small risk of developing cancer of the peritoneum (the lining of your abdomen). For reasons that are not clear, the peritoneum can develop cancer that is indistinguishable from ovarian cancer, but this occurs in less than 1 percent of women who have had RRSO.

Does RRSO protect me against other cancers?

If the surgery is done before menopause it can lower your risk of breast cancer by about 50 percent. Many cases of breast cancer result from natural estrogen produced by your ovaries. Removing the ovaries lowers estrogen levels, lowering your risk of breast cancer. The younger you are when the surgery is performed, the greater the protection against breast cancer. However, we recommend screening for breast cancer even if you have your ovaries removed.

What is the ideal age for performing RRSO?

RRSO provides protection against ovarian cancer at any age, but doctors recommend the surgery between ages 35 and 40, or once you have completed your child-bearing decisions. This provides you with maximum protection because the average age of developing ovarian and breast cancer is in your 40's and 50's if you have a BRCA gene mutation.

"I was only 32. Even though I had two kids, I didn't think I was ready yet to have that surgery."

"I was 45 when I found out my BRCA test was positive. At first, I didn't want to have my ovaries removed. But then I thought Well, menopause isn't far off anyway, and it's not like I'm thinking about having more children."

How is the surgery done?

The operation is performed under general anesthesia (you are not awake and your body has been completely numbed). There are two types of RRSO — laparotomy and laparoscopy.

In a laparotomy, the surgeon makes an incision, or cut, in your abdomen. After separating your abdominal muscles, your ovaries and fallopian tubes are removed through the incision.

In a laparoscopy, a small incision is made in or just below your navel (belly button) and a tiny camera is inserted that allows the surgeon to look at the inside of your abdomen on a TV screen. Harmless carbon dioxide gas is injected into your abdomen to expand it and give the surgeon more room to work in. The ovaries are removed through additional small incisions in the lower part of your abdomen.

A discussion with your surgeon about your past surgical history, your health, your weight and other personal factors can help you decide which surgery is most appropriate for you.

“The surgery and recovery weren’t too bad. I did have a minor complication, which scared me a little, but now I don’t worry so much about getting ovarian cancer.”

“I really trust my doctor, and she was so helpful when I made my decision about surgery.”

Will the surgeon just remove my ovaries, or are other organs also removed?

It depends on medical and personal factors in your situation. Most women should have their ovaries and fallopian tubes removed because BRCA gene mutations can cause ovarian and fallopian tube cancers. Some women also decide to have their uterus removed, depending upon medical and genetic factors. Your doctor can help you decide what is best for you.

How safe is RRSO?

The complication rates of laparotomy and laparoscopy are 1 percent or less, the most serious of which are infection, bleeding or puncturing an organ. The complication rate may be slightly higher if the uterus is also removed.

Because both procedures remove your ovaries, you will immediately become menopausal. This change in hormone levels can result in hot flashes, mood changes, decreased interest in sexual activity and other symptoms of menopause. For many women, this is the most difficult complication of the surgery. Prior to surgery, you and your physician should thoroughly discuss the risks and benefits of hormone replacement therapy.

“Even though I’d read a lot about it, I wasn’t quite ready for going into menopause so quickly. The hot flashes really took me by surprise. And the mood changes....it was like I was a different person.”

“For me, ‘instant’ menopause wasn’t that bad. I took hormones for awhile and that helped. But my sister had a harder time after her surgery.”

How long will it take to recover from my surgery?

After laparoscopy, a one to two day hospital stay may be necessary. Most women have minor discomfort and tiredness, and return to a normal schedule within a week after surgery.

Because laparotomy involves a larger incision, you should plan to stay in the hospital for a few days before going home. Full recovery can take two to four weeks.

"I just picked the wrong time of year to do it. I was so busy with work and my family that being out all that time was really stressful. I wish I had planned it better and wasn't so pressured."

"My surgery wasn't that bad. I'm never happy about being in the hospital, but I went home pretty quickly, and I was able to get back to normal sooner than I thought."

Will my ovaries be examined for cancer?

Yes. About 5 to 10 percent of women who have a BRCA gene mutation will have an early stage cancer when the ovaries, fallopian tubes and abdomen are carefully examined. These women may need treatment such as chemotherapy to make sure the cancer is entirely eliminated.

"I felt so good when my surgeon called to say that my ovaries looked clean and didn't have any cancer."

"They found a small spot of cancer in one of my fallopian tubes, so they decided to give me some chemotherapy and watch me closely."

Where can I get additional help in deciding about RRSO?

You should discuss your decision with:

- Your spouse or partner, your family, your friends
- Your primary care physician or gynecologist
- A gynecologic oncologist (a physician who specializes in treating ovarian cancer)
- Women who have had RRSO or declined RRSO

"Some of my friends had been through this, too. They all had different experiences, but it was good to talk with them, even the ones who were still not sure if they had made the right decision. Your friends will tell you things your doctor never would."

You can also contact support and research organizations:

- CONVERSATIONS: The International Ovarian Cancer Connection at www.ovarian-news.org
- National Ovarian Cancer Coalition (NOCC) at www.ovarian.org
- Ovarian Cancer National Alliance (OCNA) at www.ovariancancer.org
- The Ovarian Cancer Research Fund (OCRF) at www.ocrf.org
- The Marsha Rivkin Center for Ovarian Cancer Research at www.marsharivkin.org
- Team Survivor Northwest at teamsurvivornw.org
- FORCE (Facing Our Risk of Cancer Empowered) www.facingourrisk.org/
- Be Bright Pink www.bebrightpink.org/

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