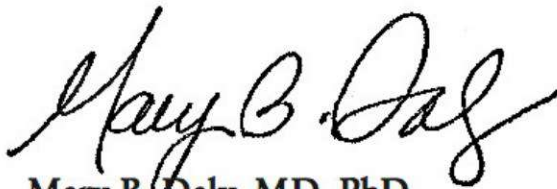




*Ovarian Cancer
Risk-Reducing Surgery
A Decision-Making Resource*

Preface

When we began counseling women about ways to reduce risk of ovarian cancer in the early 1990s, we knew very little about the long-term implications of removing healthy ovaries. But surgery was (and remains) the most definitive way to lower risk of this very frightening disease that is difficult to detect early given inadequate screening tests. Over time and with thanks to many who have shared their experiences, we have come to better understand the issues faced by women and their partners related to surgery. The decisions are complex and educational tools are lacking. Our hope is that this book will be a helpful resource for those who are considering ovarian cancer risk-reducing surgery.



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2006

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A Decision-Making Resource

Ovarian Cancer Risk-Reducing Surgery: A Decision-Making Resource

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Introduction

If you are using this resource, you probably have some sense that you are at increased risk for ovarian cancer. Perhaps you have family members with the disease or you have had a formal risk assessment, which may include testing for **genetic mutations** that increase ovarian cancer risk. (If you haven't participated in a formal risk assessment, you should do so before making any decisions about risk-reducing surgery. See the next section, "Understanding Your Risk of Ovarian Cancer," for more information.)

The surgery is technically called prophylactic bilateral salpingo-oophorectomy (which translates as "preventive removal of the **ovaries** and **fallopian tubes** on both sides"), although it is more commonly referred to as just prophylactic oophorectomy. Throughout this guide, we will refer to it simply as "risk-reducing surgery." Expert organizations such as the National Cancer Institute and the National Comprehensive Cancer Network traditionally recommended that high-risk women consider the option of having their **ovaries** and **fallopian tubes** removed by age 35, or as soon as childbearing is completed. Now, however, they qualify this recommendation by stressing that the decision should be made on a case-by-case basis, taking other factors into account.

Here are some important points about risk-reducing surgery:

- Research has shown that this surgery significantly reduces the risk of developing ovarian cancer.
- Ovarian cancer is difficult to detect at an early stage (before it has spread beyond the ovary and there's a better chance for cure).
- Studies have not been able to show that being followed closely by a doctor with regular exams and testing reduces a woman's risk of dying from ovarian cancer.
- Removal of the **ovaries** also can reduce the risk of breast cancer, which is reassuring to women who may be considering risk-reducing options for both breast and ovarian cancer.

While surgery has benefits, it entails some risks, many of which are not yet fully understood. Having your **ovaries** removed also means that your body will lose its main source of the female hormones **estrogen** and **progesterone**. Therefore, depending on your age, this surgery could suddenly put you into **menopause** 5, 10, 15, or even 20 years before you would go through it naturally. The medical community does not fully understand the long-term consequences of this “**surgical menopause**.” It almost certainly would increase your risk for osteoporosis (thinning of the bones) and potentially uncomfortable menopausal symptoms. These and other quality-of-life issues should be considered before choosing risk-reducing surgery.

Using This Resource

The Margaret Dyson Family Risk Assessment Program at Fox Chase Cancer Center has created this resource to help you learn about your options and use that knowledge to make a decision. The goal is to help you reduce your risk of getting ovarian cancer or find it early. This resource also:

- discusses risk-reducing surgery
- looks at options other than surgery
- explains the potential pros and cons of different choices
- discusses some recent research findings
- suggests questions that you can ask your health care team every step of the way
- lets you hear from women and their partners who have already been through the decision-making process

Understanding the layout of this resource



The colored flowers = women’s experiences



The gray flowers = partner’s experiences

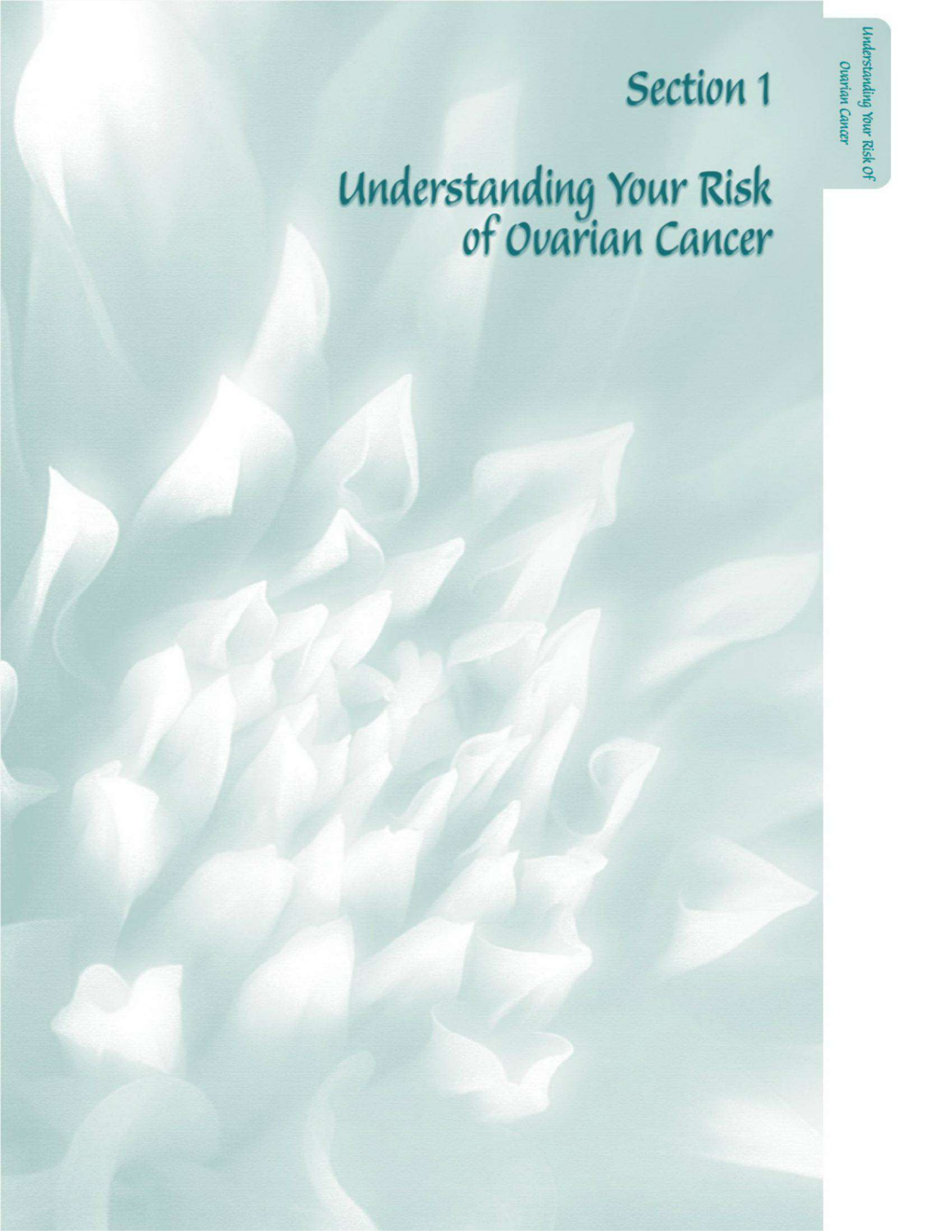
- Words that are **bold** are defined in the glossary (p. 135).

At the end of the guide, you will find a decision-making tool that can help you sort through the options. You might find it helpful to share this information with loved ones or health care providers who are helping you with your decision.

Remember, there is no absolute right decision – only a decision that's right for you. Be sure to take the time you need to sort through all of the issues and feel comfortable with your choice.

Section 1

Understanding Your Risk of Ovarian Cancer





Formal Risk Assessment

To fully understand your risk of ovarian cancer, you need to go through a formal risk assessment. This involves working with a genetic health professional. This person may be a nurse, doctor, or expert with a degree in genetic counseling, specially trained to provide information and advice about inherited conditions (diseases or health risks passed on through families). This genetic counselor charts your family history and explains genetic testing.

A formal risk assessment typically involves the following steps:

- Education about ovarian cancer and the factors that increase and decrease risk
- Individualized counseling with a trained genetic health professional
- Analysis of your family tree, showing the pattern of cancer in your family – who was affected and the ages at which they were diagnosed
- Education about **genetic testing** options
- **Genetic testing**, if appropriate
- Discussion of the genetic test results
- Further counseling about risk-reduction options, if you are found to be at high-risk.

For More Information

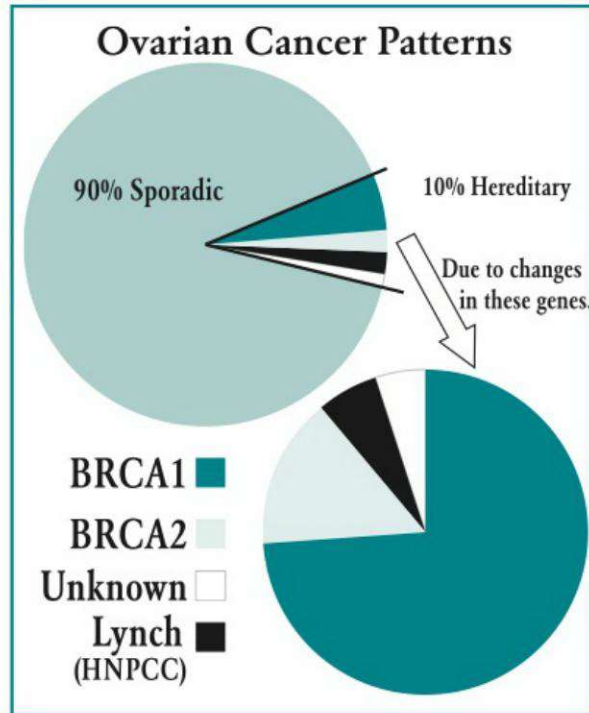
Here are some ways to find a genetic health professional:

- Search the National Cancer Institute's online directory at www.cancer.gov or call **1-800-4-CANCER**.
- Contact the National Society of Genetic Counselors (NSGC) at www.nsgc.org or call **312-321-6834**.
- Check with cancer centers in your area.

Factors That Increase Risk

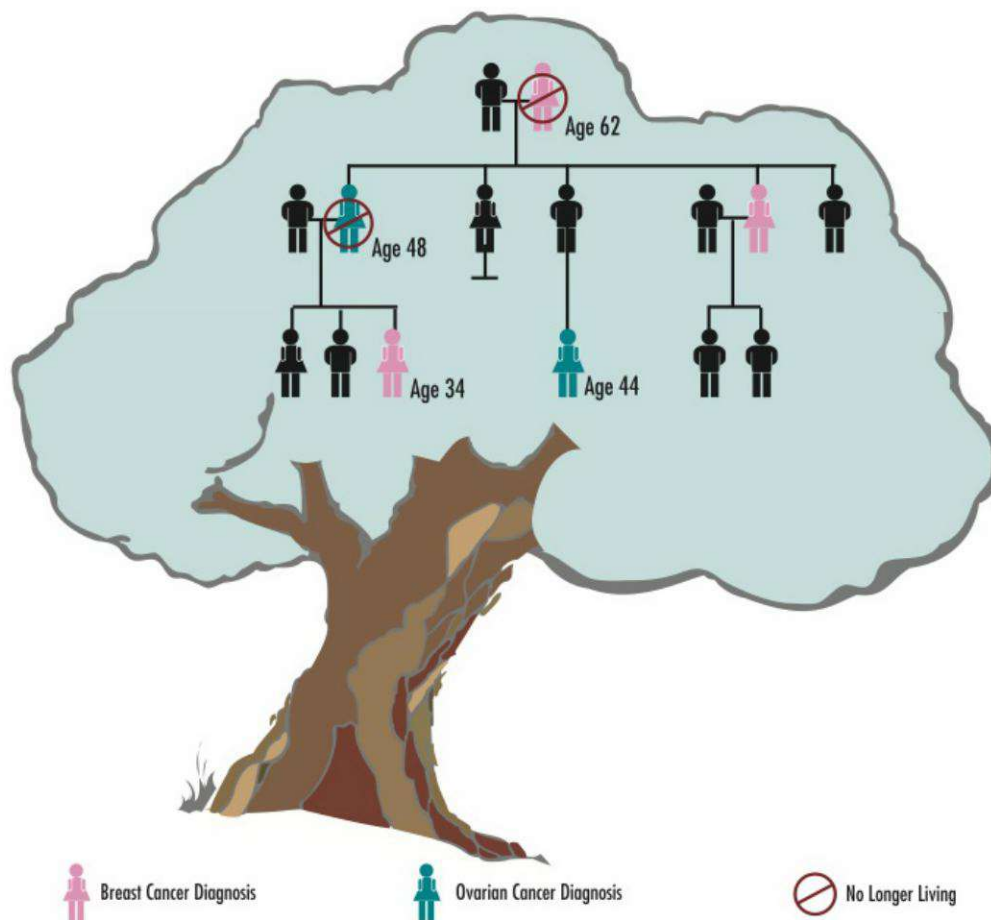
Most women first begin considering risk-reducing surgery because a formal assessment has indicated they are at increased risk of ovarian cancer. Usually this is based on a strong family history and/or a positive test result for an inherited **genetic mutation** that increases that risk. There are other factors that affect your risk such as age, number of pregnancies and infertility. But the effect of these factors on your risk is hard to measure.

Genes known as “*BRCA1*” and “*BRCA2*,” and the genes related to the Lynch Syndrome (also known as Hereditary Non-Polyposis Colorectal Cancer or HNPCC) affect ovarian cancer risk. Together, mutations in these genes account for five to ten percent of all ovarian cancer cases. This means the majority of all ovarian cancer cases are not caused by these mutations (sometimes being referred to as **sporadic**.)



BRCA1 and BRCA2

In their normal form, the *BRCA1* and *BRCA2* genes help to prevent cancer by producing a protein that stops cells from growing out of control. When these genes are mutated, however, their proteins cannot work properly, and this increases a woman’s risk of developing both ovarian and breast cancer. If you and/or some of your relatives have a mutation in either of these genes, your family tree may look like the one on page 5. There could be multiple cases of ovarian cancer alone or of both breast and ovarian cancer. Note that the cancers can occur at a young age – often before age 50 or at least before **menopause**.



This family tree shows a pattern of disease in a family with a *BRCA1* or *BRCA2* mutation.

Researchers are still learning more about how these mutations raise ovarian cancer risk. A recent article that looked at data from 22 different studies on this topic concluded that:

- Women with *BRCA1* mutations have approximately a 40-percent chance of developing ovarian cancer by age 70. (In individual studies, this chance ranged from 18 percent to 54 percent.)¹ Since a woman in the general population has just a two-percent chance of developing the disease, this means that a woman with a *BRCA1* mutation is about 20 times more likely to develop ovarian cancer.

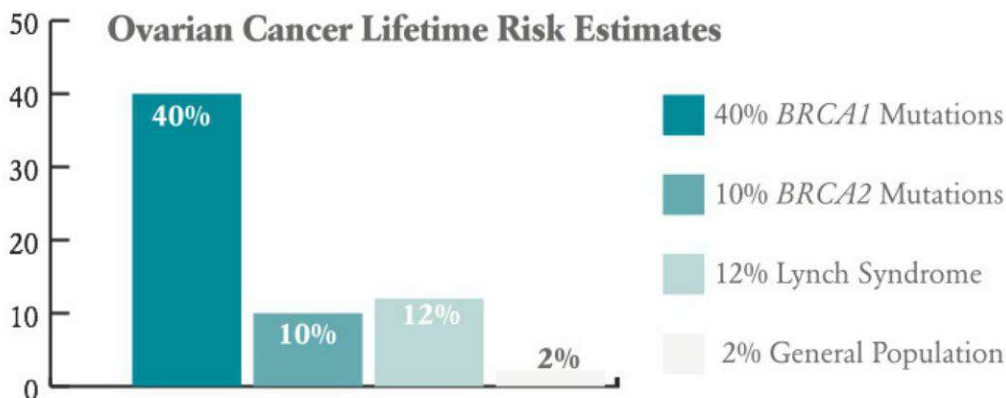
¹ Antoniou A, Pharoah PDP, Narod S, et. al. "Average risks of breast and ovarian cancer associated with *BRCA1* or *BRCA2* mutations detected in case series unselected for family history: A combined analysis of 22 studies." *American Journal of Human Genetics* 2003 May; 72(5): 1117-30.

- Women with *BRCA2* mutations have approximately a 10-percent chance of developing ovarian cancer by age 70. (In individual studies, this chance ranged from 2.4 percent to 19 percent.)¹ This means that a woman with a *BRCA2* mutation is about five times more likely to develop ovarian cancer than a woman in the general population.

Also, women with the altered *BRCA* genes tend to develop ovarian cancer at a younger age. While the average age of onset in the general population is 62, mutation carriers are more likely to develop the disease in their mid-40s and 50s – a full 10 to 15 years earlier.

Lynch Syndrome (HNPCC) Mutations

Another inherited syndrome known as Lynch Syndrome (or HNPCC) also raises ovarian cancer risk, although it is believed to account for less than two percent of hereditary ovarian cancer cases. HNPCC stands for Hereditary Non-Polyposis **Colorectal Cancer**: family members who inherit HNPCC-related **genetic mutations** are at significantly increased risk for colon cancer, typically at an early age. These mutations also increase risk for cancer of the endometrium (the lining of the **uterus**), ovary, stomach, and other organs.



¹ Antoniou A, Pharoah PDP, Narod S, et. al. "Average risks of breast and ovarian cancer associated with *BRCA1* or *BRCA2* mutations detected in case series unselected for family history: A combined analysis of 22 studies." *American Journal of Human Genetics* 2003 May; 72(5): 1117-30.

Estimates of Lynch Syndrome-related lifetime ovarian cancer risk vary, although one recent article estimates it at 12 percent.² This means that women with a Lynch Syndrome mutation are roughly six times more likely to develop ovarian cancer than women in the general population.



My Experience

“My mom was diagnosed with ovarian cancer in 1993. It was stage IIIc – pretty much a late diagnosis. She was one of a long line of people in our family to be diagnosed with and eventually die of cancer. It was within a few months of her diagnosis that I started thinking, ‘Hey, this might be something that I have within me, too.’”

Our history went back to a generation of people who did not have the benefits of the medical knowledge we have today. So there were many diagnoses of ‘cancer of the female parts’ and ‘cancer of the stomach.’ I think now that it was just that a lot of women had ovarian cancer-related ascites – buildup of fluid – and the doctors couldn’t tell where the cancer had originated.

It turned out that I have a BRCA2 mutation, just like my mom.” –Lisa

Other Genetic Mutations Yet to Be Discovered

Even if you have a strong family history of ovarian cancer, you can test negative for the *BRCA* or Lynch Syndrome mutations. If these mutations have been confirmed in your relatives who had ovarian cancer, yet your test is negative, then you did not inherit the mutation that runs in your family. Your risk is then considered the same as that of women in the general population.

However, if these mutations have *not* been confirmed in your family, you are still considered to be at higher risk of developing ovarian cancer than women in general, just based on your family history. Researchers believe that there must be other inherited **genetic mutations** (either on *BRCA1*, *BRCA2*, Lynch Syndrome or other **genes** yet to be discovered) that can raise ovarian cancer risk. Perhaps one of these unknown mutations is responsible for the cancer in your family.

2 Brown GJ, St John DJ, Macrae FA, Aittomaki K. “Cancer risk in young women at risk of hereditary nonpolyposis colorectal cancer: implications for gynecologic surveillance.” *Gynecologic Oncology* 2001 Mar; 80(3): 346-9.

Currently, this is an active area of research. You may want to keep in touch with your risk counselor from time to time as other gene tests may become available in the future.

My Experience

"It was not a hard decision for my family to get tested for the Lynch syndrome. Each generation seemed to have a person who had died of colon cancer at a young age: my grandfather, my father's sister and brother, my father. The family history was very strong. I developed colon cancer at age 43.

I think everyone was just assuming that we had the syndrome. My sister basically said, 'It is what it is.' And that is how we all felt. We weren't going to get upset about it. My sister and I both tested positive. She shares the same attitude as I do: 'Well, now I know, and now I can do something about it.'"
—Kelly



*"I have a family history of breast and ovarian cancer. My mom was diagnosed with stage III ovarian cancer a little less than five years ago, at age 70. She also had a bout with breast cancer 25 years ago. In addition to that, she lost a sister in her 30s to breast cancer, and she has another sister who has now survived two bouts with breast cancer. So we knew we were good candidates for **genetic testing**. We called everyone — my brother, my older sister, my cousins, my mother's brothers — and told them they potentially had a **genetic mutation** they could have passed on to their children.*

I think what scares me most is that my mom is a very healthy woman who, as far back as I can remember, always walked five miles a day, ate extremely well, never smoked, rarely drank, and took some dietary supplements. The choices she has made have all been good. So that fact that she could get cancer from this risk factor of a mutated gene really concerns me, since I have it [the mutated gene] too." —Donna

Interpreting Your Assessment Results

A positive genetic test result or a strong family history of ovarian cancer (where no confirmed **genetic mutation** has been identified) significantly increases your risk of developing the disease over the course of your lifetime. This is of particular concern because ovarian cancer is difficult to detect early, making it a serious and potentially life-threatening disease.

At the same time, however, a positive result does not mean that you definitely will develop ovarian cancer. For example, if your lifetime risk of ovarian cancer is estimated at 40 percent because you have the *BRCA1* mutation, there is still a 60-percent chance (better than one in two) that you will never develop ovarian cancer.

A positive genetic test result or strong family history significantly increases your risk of developing ovarian cancer, a hard-to-detect and potentially life-threatening disease, over the course of your lifetime. At the same time, however, this does not mean that you definitely will develop ovarian cancer.

This uncertainty may make it difficult for you to determine how you wish to act on the information. You have not been diagnosed with a disease, but with a lifetime risk of developing a disease. Not all experts care for women in this situation the same way. Therefore, as you consider the pros and cons of the courses of action discussed in this guide, you also need to think about how much risk you can tolerate as you go about your daily life. This is a truly personal choice.

If necessary, go back to your genetic counselor for more in-depth discussion of what your genetic test result and other risk factors indicate about your lifetime risk of ovarian cancer. If you have not already done so, you should consider meeting with a gynecologic oncologist, a doctor who specializes in cancers of the female organs. You can ask your primary care doctor or gynecologist for a recommendation.

For More Information on Genetic Mutations and Cancer Risk

American Board of Genetic Counseling

(913) 895-4617

www.abgc.net

Prepares and administers examinations to certify individuals who provide services in the medical genetics specialty of genetic counseling and accredits its training programs in the field. Also maintains a directory of board-certified professionals.

FORCE: Facing Our Risk of Cancer Empowered

(866) 288-7475

www.facingourrisk.org

A nonprofit organization for women who are at high risk of breast and ovarian cancer due to their family history and genetic status, and for members of families in which a *BRCA* mutation may be present.

Myriad Genetic Laboratories

(800) 469-7423

www.myriad.com

Myriad Genetics, Inc. handles testing for mutations that can increase cancer risk. Free educational materials are available.

National Cancer Institute

Cancer Genetics Services Directory

1-800-4-CANCER

www.cancer.gov

A directory of individuals who provide services related to cancer genetics (cancer risk assessment, genetic counseling, genetic susceptibility testing, and others). The NCI also offers a free brochure titled "Understanding Gene Testing."

National Society of Genetic Counselors

(312) 321-6834

www.nsgc.org

Offers a searchable database of genetic counselors and other information about the genetic counseling profession.

Women's Cancer Network

(312) 578-1439

www.wcn.org

Provides an online risk assessment survey for several women's cancers, including ovarian.

For More Information on Ovarian Cancer

American Cancer Society

1-800-227-2345

www.cancer.org

Association of Cancer Online Resources

www.acor.org

Best-known for hosting a number of electronic mailing lists designed to provide support and information for people who have or are concerned about cancer – including the Ovarian Problems Discussion List.

Cancer Care

1-800-813-HOPE

info@cancercare.org

www.cancercare.org

Johns Hopkins Ovarian Cancer Information

www.ovariancancer.jhmi.edu

National Cancer Institute

1-800-4-CANCER

www.cancer.gov/cancertopics/prevention-genetics-causes/ovarian

An information summary reviewed by experts on various aspects of ovarian cancer.

National Ovarian Cancer Coalition

1-888-OVARIAN

www.ovarian.org

Ovarian Cancer National Alliance

(202) 331-1332

ocna@ovariancancer.org

www.ovariancancer.org

QUESTIONS TO ASK . . . After a Formal Risk Assessment

- I feel that I need extra support in dealing with this test result. Do you know of any support counselors or women who have been through this that I could talk to?

- Is there a hospital or cancer center nearby that has a program for high-risk women that you would recommend? Are there any **clinical trials** available for me?

- [If **genetic testing** has taken place] Should my other family members get tested? What could this mean for my children?

Section 2

Considering Risk-Reducing Surgery

Considering Risk-
Reducing Surgery



Women considering risk-reducing surgery quickly discover that cancer experts and organizations vary in their recommendations. This is due to some uncertainty about the long-term health effects of removing a woman's **ovaries**.

For example, here are two different guidelines from expert groups, current at the time of this writing:

- **The Gilda Radner Familial Cancer Registry** at Roswell Park Cancer Institute in Buffalo, NY, recommends that all women with a family history of ovarian cancer in two or more **first- or second-degree relatives** should undergo risk-reducing surgery.
- **The National Comprehensive Cancer Network (NCCN)**, an alliance of 19 leading cancer centers, suggests a more individualized approach. They note that women at high risk for ovarian cancer because of a **genetic mutation** or strong family history should consider the surgery on a “case-by-case basis, including discussion of reproductive desires, extent of cancer risk, degree of protection for breast and ovarian cancer, and management of menopausal symptoms and related medical issues.”

Thus, this decision is not a simple one. It requires careful consideration of the potential pros and cons of risk-reducing surgery in relation to your situation.

For More Information

National Comprehensive Cancer Network

215-690-0290

www.nccn.org

Follow the link to the NCCN Clinical Practice Guidelines in Oncology to find the guideline titled *Genetic/Familial High-Risk Assessment: Breast and Ovarian*, which includes information on options for high-risk women.



Thinking about Your Own Situation

As you consider the potential pros and cons of surgery, you need to consider the particulars of your own situation, such as:

Age and menopausal status: If you are younger and potentially many years away from **menopause**, you may feel more strongly about avoiding surgery – and the menopausal symptoms it brings on – than if you are in your 40s or 50s and closer to **menopause**, or already experiencing it.

My Experience

“I had the testing for the BRCA1 and BRCA2 mutations and it came back positive. At around the same time, my mom died of ovarian cancer. That was what really prompted me to look into risk-reducing surgery – plus the fact that I knew there was a lack of reliable testing to catch anything that might be going on early. Also, what made it easier for me was that, at age 47, I was well into perimenopause, so the thought of becoming menopausal was almost a relief.” –Sarah

Desire to have children: If you want to have children, you should delay surgery for the time being.

The particular mutation you have: In some cases the level of ovarian cancer risk is related to the location of a particular mutation. Your counselor can help you understand this.

The particulars of your family history: Every family pattern is a little bit different. If many women in your family developed ovarian cancer in their 40s or 50s, you may be more concerned about your risk than if there is one relative who developed it at a later age.

Your gynecologic history: Having other gynecologic health issues, like bleeding from **fibroids**, **ovarian cysts**, or previous surgeries may make you more or less open to considering surgery.

Your feelings about being “high-risk”: Individuals vary in how they react to the knowledge that they are at higher-than-average risk for ovarian cancer. If this knowledge

causes you to feel a constant sense of anxiety or worry, then risk-reducing surgery may be the best choice for you. On the other hand, if you are more concerned about surgery's impact on your quality of life than about your elevated risk for ovarian cancer, surgery may not be the best choice for you right now.



My Experience

"Because I was still in my late 20s/early 30s when I found out I was high-risk, I thought about risk-reducing surgery for a time later in my life – maybe mid- to late 40s. I knew that the surgery would bring on menopause. But even more important, I wanted to have children – I had my first at 33 – and I delayed anything because of that.

I still might consider surgery down the road. I am 42 now, and in my last conversation with my doctor, I was told that you should look at a family member who had ovarian cancer and subtract ten years from their age at diagnosis and view that as your window for really needing to be vigilant. My grandmother passed away from ovarian cancer at 52. So I am starting to think more seriously about surgery." –Rose

Also, you should know that, while surgery is the only proven tool for reducing ovarian cancer risk significantly, it is not a perfect solution. A small number of women (approximately two percent, or one out of every 50) who undergo risk-reducing surgery still go on to develop a form of cancer closely related to ovarian cancer, known as **primary peritoneal carcinoma**. This cancer originates in the **peritoneum**, which is the membrane that lines the walls of both the **ovaries** and the **pelvic cavity**. The peritoneum cannot be surgically removed during risk-reducing surgery.

Women vary in how they react to the knowledge that they are at higher-than-average risk for ovarian cancer. If this knowledge causes you to feel a constant sense of anxiety or worry, then risk-reducing surgery may be the best choice for you. If you're more concerned about the potential impact of surgery on your quality of life, then it may not be the best choice for you.

The decision-making tool at the end of this book will help you to weigh all of these factors.



Why Do Women Choose Surgery?

Ovarian cancer is a serious disease that tends to be diagnosed at a later stage – that is, after it has already spread beyond the **ovaries** – when it is difficult to cure. The **ovaries'** location deep within the body makes it challenging for **imaging tests** and physical exams to diagnose early-stage tumors. There is a blood test for a protein called **CA125** that is often elevated when a woman has ovarian cancer. However, the test is not completely reliable: many women with ovarian cancers have a normal **CA125** result, and women can have an elevated **CA125** for other reasons.

My Experience

“I had had breast cancer already. And subsequent to that, I underwent genetic testing, because I’m the fifth woman in three generations to have breast cancer and I also had an aunt who had ovarian cancer. When my test came back positive for the mutations – one on BRCA1 and one on BRCA2 – I knew what the probability was that I would develop ovarian cancer. I thought to myself, ‘I’ve had my kids. These are optional organs at this point in my life.’” –Theresa

Women tend to choose risk-reducing surgery for two main reasons:

- It has been proven in research studies to be effective in reducing risk of ovarian AND breast cancer.
- It is a way of taking control of an anxiety-producing situation.

It’s a Proven Strategy

Over the past several years, a number of studies have shown that surgery reduces ovarian cancer risk. Generally, these studies have compared high-risk women who had the surgery with those who chose close follow-up (frequent exams and testing) by their doctors instead. For example:

- One study used registries of women with *BRCA* mutations to identify 259 women who had undergone risk-reducing surgery and 292 matched controls who chose close

follow-up instead, and then followed them for at least eight years. Only two women in the surgery group went on to develop peritoneal carcinoma (a form of cancer closely related to ovarian cancer), while 58 women in the non-surgery group received a diagnosis of ovarian cancer. Researchers concluded that the surgery reduced risk for ovarian cancer by 95 percent. They also found that the surgery significantly reduced breast cancer risk.¹

- Another study followed 218 mutation-positive women for an average of four years. Of the 145 women who had risk-reducing surgery, two developed **peritoneal cancer** and five developed breast cancer. Among the 73 women who chose close surveillance over surgery, eight were diagnosed with ovarian or **peritoneal cancer**, and 14 with breast cancer.²
- A study that compared 43 women with *BRCA1* mutations who underwent risk-reducing surgery with 79 mutation carriers who did not find a significant reduction in risk of breast cancer in the former group – a nearly 50 percent reduction.³

Furthermore, in the first two studies mentioned above, several women who underwent risk-reducing surgery – six in the first group, and three in the second – were found to have early-stage ovarian cancers at the time of surgery.

Many women are convinced by these and other studies' conclusions that risk-reducing surgery offers a clear advantage over close follow-up in high-risk women.

1 Rebbeck TR, Lynch HT, Neuhausen SL, et al. "Prophylactic oophorectomy in carriers of *BRCA1* or *BRCA2* mutations." *New England Journal of Medicine* 2002 May 23; 346(21):1616-22.

2 Yemel Y, et al. "Four year follow-up of outcomes following risk-reducing salpingo-oophorectomy in *BRCA* mutation carriers" [Abstract] 2005 American Society of Clinical Oncology Annual Meeting.

3 Rebbeck TR, et al. "Breast cancer risk after bilateral prophylactic oophorectomy in *BRCA1* mutation carriers." *Journal of the National Cancer Institute* 1999 Sep 1; 91(17):1475-9.



It Offers a Way of Taking Control

Many women choose risk-reducing surgery because it offers a way of taking control of their situation, both for their own sake and the sake of their loved ones. They see it as the best way to ease their anxiety about developing ovarian cancer and making sure they will be there for their families over the long term.

My Experience

“Even before I had genetic testing, I was considering prophylactic surgery for ovarian cancer. I decided that when I went through menopause, I would go ahead and do it. I knew that my cancer risk would increase anyway with age. But then I had a transvaginal ultrasound that showed an ovarian cyst, which I thought raised the possibility of ovarian cancer. At that point, I decided to have my ovaries out right away, rather than wait it out and see if the cyst resolved. As it turned out, my ovaries were healthy.

I knew that the disadvantage of having the surgery would be going through menopause at 48. The advantage would be that I could reduce my risk drastically. I felt from the beginning that the reduction in risk would outweigh any side effects or impact on my life.”

—Kelly

Often, women in high-risk families have watched their mothers, sisters, aunts, or other relatives go through the difficult experience of being diagnosed with and treated for ovarian cancer. Some feel a strong need to take whatever action is necessary to avoid going through the same experience. For many women, the desire to have surgery increases as they reach the age at which their relatives developed ovarian cancer.

Many women choose to have surgery because it is a proven strategy for significantly reducing their risk of developing ovarian AND breast cancer. Over the past several years, a number of studies have confirmed this benefit.

Why Do Women Not Choose Surgery?

Even though risk-reducing surgery is the most effective preventive tool that doctors have to offer high-risk women, some choose not to have surgery for a variety of reasons. This section explains the most common.

Concern about Side Effects

When a pre-menopausal woman has her **ovaries** removed, her **estrogen** level drops suddenly instead of gradually, as it would if **menopause** occurred naturally. As a result, she is likely to experience intense menopausal symptoms.

The most common symptoms are:

- Hot flashes/night sweats
- Vaginal dryness and irritation
- Lessened sex drive.

Some women have reported a wide range of other physical symptoms:

- Joint and muscle pain
- Fatigue
- Chest pain/heart palpitations
- Muscle spasms
- Insomnia (difficulty sleeping)
- Recurrent urinary tract and yeast infections
- Urinary incontinence (difficulty controlling the urge to urinate)
- Emotional effects such as anxiety, depression, and mood swings.

For women who have already gone through **menopause** naturally, losing the **ovaries** is typically less difficult than it is for younger women, both physically and emotionally. The **ovaries** already have stopped producing their usual level of **estrogen** and fertility (ability to have children) is no longer an issue. Since the **ovaries** do produce small amounts of **estrogen** and other hormones after **menopause**, however, there may be some side effects.



My Experience

"I had my surgery in early 2002, within a month after it was recommended to me. I had been waiting for my doctor to make a recommendation one way or the other. My dad is a pediatrician who worked in a teaching hospital, so I grew up around medical research and had utter faith in it. And the studies had definitely proven you can reduce your risk of cancer by taking this action, and I was ready to do it. I was 38 at the time. I also had had some problems with heavy bleeding, so I was ready to have those organs out.

I guess I was determined to avoid the path that my ancestors had laid before me: many had died of cancer. My husband was all for it. He did not want to see me go through what my mom had gone through. I had been my mom's primary caregiver so I really saw ovarian cancer up close and personal, and I did not want to go there." –Lisa

In short, the nature and intensity of symptoms vary from woman to woman, but there almost certainly will be some impact on quality of life. In the past, many doctors would have automatically prescribed **hormone replacement therapy** (HRT) to relieve these symptoms. However, a number of recent studies have raised new concerns about the safety of HRT, particularly for women who are considered to be at high risk of ovarian and breast cancer (see section 3 for more information about these studies). Some doctors believe that short-term use of HRT is still safe, while others disagree and steer women away from it. There are some non-hormonal approaches to managing **surgical menopause**, but none has yet proven as effective as HRT. This reality can sway some high-risk women – particularly those who are potentially many years away from **menopause** – to decide against surgery, despite its benefits in terms of ovarian cancer risk reduction.

The loss of **estrogen** has been found to increase a woman's risk for osteoporosis (thinning of the bones). Also, doctors do not yet have a complete understanding of how the loss of **estrogen** affects heart health, mental functioning, memory, and other aspects of women's health.

When a pre-menopausal woman has her ovaries removed to reduce ovarian cancer risk, her estrogen level drops suddenly instead of gradually, as it would if menopause occurred naturally. Doctors are not yet sure about the long-term health effects of this “surgical menopause,” nor are they certain about the best ways to help women deal with its symptoms safely.

It's Not the Right Time

Timing is often a key factor in a woman's decision not to have surgery. Here are some reasons why the timing may not be right:

- She wants to have children.
- Surgery may seem too disruptive to work life or family responsibilities.
- She's concerned about the effect of **surgical menopause** symptoms on her intimate relationship(s).

At least for now, these women are willing to cope with the knowledge that they are high-risk rather than cope with the surgery and its potential side effects.

A Strong Preference for Alternate Options

There are other options women can follow to reduce their risk of ovarian cancer, or at least try to catch it at an early stage if it does develop. Although none of these has proven as effective as surgery, they come with fewer physical side effects, if any. Their main drawback is that they may fail to ease a woman's anxiety about getting ovarian cancer as much as surgery does. Nevertheless, some women see them as a way of taking action without having to go so far as to have their **ovaries** and **fallopian tubes** removed.

Examples of these options include close follow-up (regular exams and testing by a doctor) and oral contraceptive use (birth control pills). Some women decide to enroll in **clinical trials** that are looking at new early detection methods for ovarian cancer. There have been some promising breakthroughs in the search for a more reliable blood test that could detect ovarian cancer at its earliest, most curable stage. More research is needed before such a test is commercially available. All of these options are discussed in the later section "If You Do Not Want to Have Surgery Now: What You Need to Know."

Your Perception of Risk (or How it Feels to You)

Everyone reacts differently to hearing they are "high-risk" for getting ovarian cancer. For example, there are different ways of looking at the risk related to *BRCA1* and *BRCA2* mutations.

Research suggests that a woman with a *BRCA1* mutation has roughly a 40-percent lifetime risk of developing ovarian cancer. One woman might hear this and reason that her risk is more than 20 times that of an average woman in the general population, who has a two-percent lifetime risk. To her, this feels like a drastic increase for a serious and potentially fatal disease. As a result, she may be more likely to choose surgery.



Two ways of hearing the same information – one woman bears “40% lifetime risk of cancer,” another woman bears “60% chance of not getting cancer.”

However, another woman might hear the same information and conclude that she still has a 60-percent chance of never developing ovarian cancer. She would be less likely to choose risk-reducing surgery, reasoning that she does not want to have surgery for something that may never happen. Or she may choose to delay surgery until she gets older and closer to **menopause**, since all women’s risk of ovarian cancer increases with age.

A woman’s perception of her risk can also be influenced by her family history. Even if she has a *BRCA* or Lynch Syndrome mutation, she may be less concerned about ovarian cancer risk if all of her relatives had other cancer diagnoses, such as breast and colorectal. Her perception of risk also may depend on how old her relatives were when they developed ovarian cancer. For example, if a woman is in her late 30s, and all of the ovarian cancer cases in her family occurred at age 55 or older, she may be less likely to have surgery right away. The same might be true of a woman in her early 40s whose relatives were diagnosed in their late 40s or early 50s.



My Experience

“At first I was very clear in my mind that, if I tested positive for a mutation, I was going to have risk-reducing surgery. But I was clear for the wrong reasons. My mother’s bout with ovarian cancer was fresh in my mind. And it is extremely hard to watch someone you love go through something so difficult. So my thought was, why wouldn’t I get an oophorectomy? How could I not get one? And then I thought, if I am going to do that, shouldn’t I get a mastectomy?”

Then I began to really struggle with the prospect of completely altering my body – physically, emotionally, everything. I did not feel I had enough information on the quality-of-life issues that I might face as a result of risk-reducing surgery. I was young – just 40 years old – and I was going to put myself into surgical menopause, which has lots of other health risks and issues associated with it. It also can be extremely difficult to manage from a relationship perspective. All of this had to go into my decision-making. I am now 42, and I am keeping my ovaries and keeping my breasts, at least for the time being.” –Donna



“Since I am finished having children, my biggest issue with the surgery now is being launched right into menopause. I feel it will be best to try to do it later, as close to the time of natural menopause as possible. ‘Later’ could be a year, could be two years, I don’t think it is going to be that far out. I have already experienced some perimenopausal symptoms. My husband and I have started the serious conversations.

Certainly I would like to lower my lifetime risk, if I can, and be here longer for my kids and my husband. But I will need to time the surgery so that it’s least disruptive. I am working full-time, my husband works and travels sometimes, the kids are in school. It may be that I decide to do it over a summer rather than a school year, which is less challenging in terms of schedules.” –Rose



Some Tips for Decision-Making

The rest of this guide will help you better understand the potential pros and cons of risk-reducing surgery. At the end there is a decision-making tool. It will help you put down your thoughts in writing. We offer these other tips as well:

My Experience

"I wish I had taken more time to make my decision to have surgery. In a manner totally unlike myself, I did not get on the Internet and start researching pros and cons. I didn't talk to anyone who had been through it. Had I done my normal course of research, study, and thinking, I might have made a different decision, given how much the surgery has impacted my quality of life.

I think it's important for women considering this procedure to know that they are absolute pioneers. Think of how differently the same medication can affect individual patients. The surgery can help you avoid cancer, but it also might change your life in ways you don't like or don't expect. You have to get all of the facts." -Lisa

- **Take your time:** Don't feel as if you have to make a decision right away, and don't feel pressured. You need to give yourself time to consider all of the pros and cons of various courses of action.
- **Realize that making this decision is a process:** Even if you decide not to have risk-reducing surgery right now, you may want to reconsider your decision over time. Changes in your own health, your family history or new research findings may affect your decision over the long term.
- **Get help:** You cannot make this decision alone. You may wish to consult with doctors, nurses, researchers, social workers and/or genetic counselors who specialize in working with high-risk women. It can also be helpful to talk to other women who have been through the decision-making process. Be sure to involve trusted family members or friends as well; their help can be invaluable in sorting through the information.
- **Do your homework:** Certainly, reading this guide is a start, but keep in mind that new research studies can change current medical thinking. You may wish to do research on your own, or at least make sure you have access to a health care team that can keep you up to date on the latest medical research.



My Experience

“Talking to other women is helpful. I went to a focus group of high-risk women, some who had the surgery and some who didn’t. I gathered a lot from listening to women who had had the surgery – what was good for them about it, what were the negatives. It was useful to hear the real-life negatives, not just read about them on paper.

I’d also recommend paying attention to the research. I think the only way you can have comfort in what you are doing is to know what is going on in the medical community. It is better to be armed with information and know ahead of time what could happen.

*Finally, I would recommend having a spouse or family member or friend you can talk this decision over with. No matter who you are, it is always better to have someone to bounce your ideas and thoughts off of. Somebody who is not living through the shock of knowing that they have this **genetic mutation** can perhaps be more objective and help you straighten it out in your mind, and think about what is the best path to take. I wouldn’t go it alone.” –Rose*



“I look at making this decision as a process. For now, at 42, I have decided not to have risk-reducing surgery, but I know I will have to evaluate my decision as I get older. I think I take care of myself, and make good choices about how I live my life, and I am not afraid I am making the wrong decision. I do not want to make a decision based on fear.

I have looked for research that has been done on women who have had oophorectomies, and quite frankly there is not a lot out there, because it is so new. I did talk to a number of doctors who are now performing studies on these women’s quality of life. But for now the information seems incomplete.” –Donna

SUMMARY | Reasons Women Do or Do Not Choose Surgery

Why Some Choose It

- It is a proven method for reducing ovarian cancer risk.
- It is a way of taking control, reducing anxiety, and reassuring oneself and one's family.
- It can reduce risk of breast cancer in women with *BRCA1* mutations.

Why Some Do Not Choose It

- They are concerned about potential side effects.
- It's not the right time in their lives.
- They have a strong preference for other risk-reduction and **screening** methods.
- For right now, they do not feel that their risk of ovarian cancer justifies going through with surgery.

The Partner's Experience

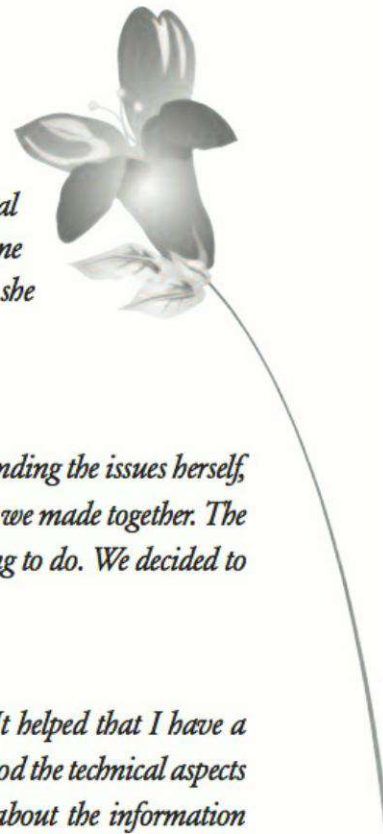
"I was there to give my wife emotional support, and to be someone she could bounce ideas off of. I'm not very well acquainted with medical terms; in fact, I get a little uneasy in the doctor's office. So she spared me a lot of the details, but I was there for moral support. And whatever she decided was going to be just fine with me." –Joe



"My wife was certainly very proactive about researching and understanding the issues herself, and understood a lot better than I did. But I felt like this was a decision we made together. The key for us was when her doctor came out and said this was the best thing to do. We decided to go in and do it." –Mark



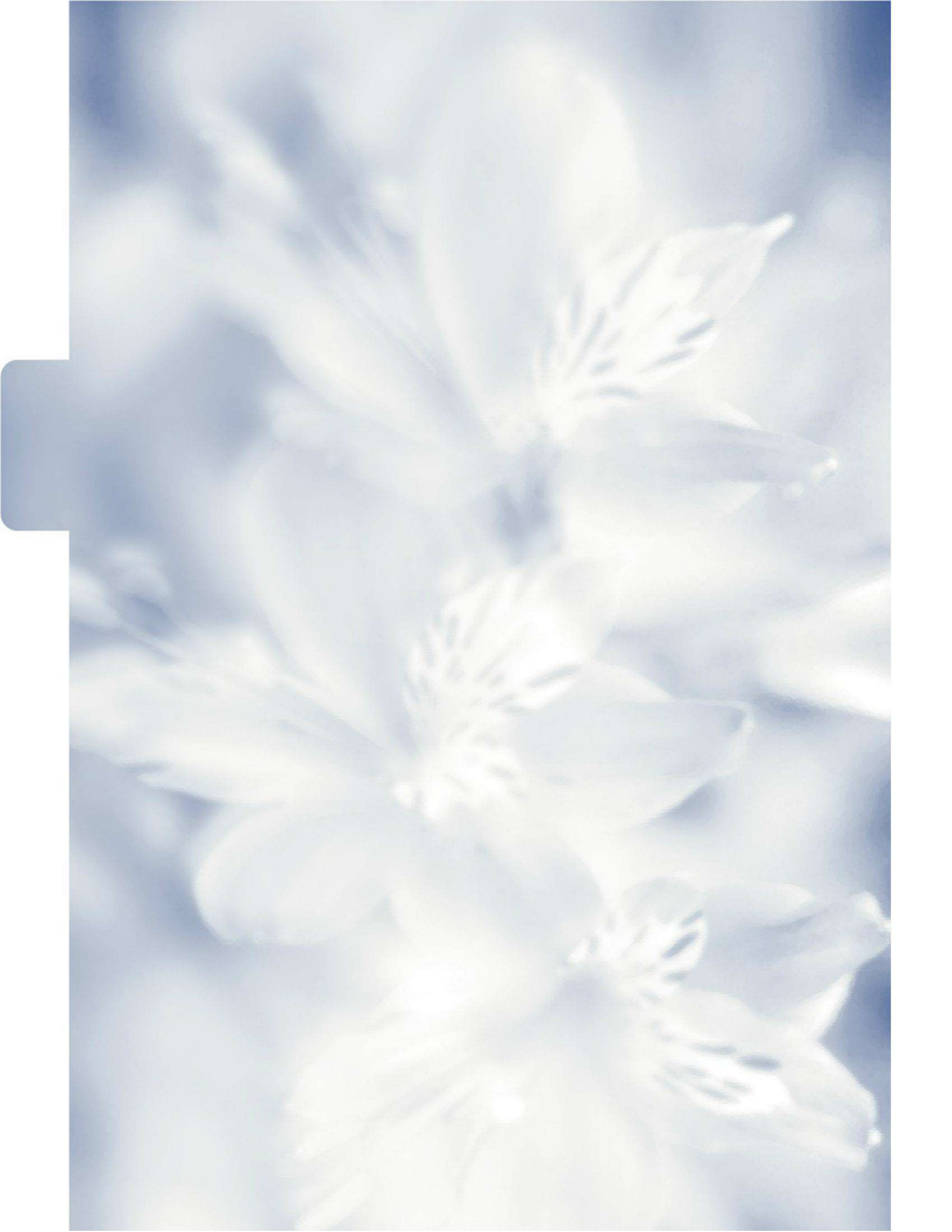
"My involvement was at all levels: research, reading, and listening. It helped that I have a fairly good science background. I wanted to make sure that she understood the technical aspects of what she was being told. I think it's easy to jump to conclusions about the information you're given, especially when you're feeling anxious. So I think my role was simply to try to get the facts straight." –Connie



Section 3

If You Want to Have Risk-Reducing Surgery: What You Need to Know

If Having Surgery
What You Need To Know



Do you feel that risk-reducing surgery is the right choice for you? Then your next step is to learn about the procedure, the recovery time, potential short- and long-term effects, and necessary follow-up care. This section can help you get the information you need to have the best possible experience. Also see Section 5, which focuses on the issues of sexuality and intimate relationships after risk-reducing surgery.

Before You Have Surgery

Risk-reducing surgery has clear pros and cons, many of which we have already discussed. It is important for you to understand all of them before moving ahead with the procedure. You also need to find a doctor (or doctors) who will do the surgery and manage all aspects of your follow-up care, which should include helping you to cope with side effects. Some women who have had risk-reducing surgery tell us they wished they had gone into surgery with a better understanding of what could happen and ways to deal with it.

Understand All of the Pros and Cons

The previous section, “Considering Risk-Reducing Surgery,” discussed surgery’s major benefits: significant ovarian cancer risk reduction, some reduction in breast cancer risk, relief from worry, and a sense of control. It also discussed drawbacks such as **surgical menopause** and possible impact on quality of life. There are some other important pros and cons to consider.

Pros

- **Availability of minimally invasive surgery:** Many risk-reducing surgeries can now be done through several small incisions in the abdominal wall, using a specialized instrument called a laparoscope. This lighted instrument has a fiber optic camera that allows the surgeon to view the **pelvic cavity** and operate on it without having to make a

large incision in the abdomen. Laparoscopic surgery is still a major procedure and it does require some time to recover. However, it tends to involve fewer complications, shorter recovery time, and less scarring than abdominal surgery. (Some women need to or wish to have more extensive surgery, however, and this will be discussed in the next section, “What Surgery Involves.”)

- **The end of monthly periods:** Some women, particularly those who have had difficult monthly periods with many symptoms, are relieved to have their menstrual cycles come to an end.

Cons

The major drawback is surgical menopause, which will be discussed in more detail later in this section. There are some other important drawbacks to be considered:

- **A small remaining risk of cancer:** Surgery cannot completely eliminate the risk of developing an ovarian-cancer-like illness. Even after you have your **ovaries** and **fallopian tubes** removed, you still will have a small risk of developing a disease called **primary peritoneal cancer**. This form of cancer starts in the peritoneum, the membrane that lines the **ovaries** and **pelvic cavity**, and it looks and behaves very much like a stage III ovarian cancer. It also is very difficult to detect early.

Over the past couple of decades, a number of studies have followed women after risk-reducing surgery and found this risk. Individual studies show that anywhere from two percent to five percent of women go on to develop primary peritoneal carcinoma.¹ Although more research is certainly

¹ Case MJ, et.al. “Intra-abdominal carcinomatosis after prophylactic oophorectomy in women of hereditary breast ovarian cancer syndrome kindred associated with *BRCA1* and *BRCA2* mutations.” *Gynecologic Oncology* 2005 97; 457-67.

needed, it is clear that this risk, while very small, is real.

Primary peritoneal cancer requires the same kinds of treatment as ovarian cancer, such as surgery and chemotherapy.

- **Continuing need for follow-up by a doctor:** Even after risk-reducing surgery, you will need to be followed closely by a doctor, mainly because of the risk of **primary peritoneal cancer**. And of course, you will need to start or continue routine **screening** for breast, colon, and other cancers.

You may be disappointed to learn that surgery is not always a perfect solution. However, keep in mind that the reduction in your ovarian cancer risk certainly will be much greater than your risk of ever developing primary peritoneal carcinoma.

SUMMARY | PROS and CONS of Risk-Reducing Surgery

Pros

- Provides the best chance for a high-risk woman to avoid ovarian cancer, a serious and sometimes fatal disease
- Reduces anxiety for a woman and her loved ones
- Often can be done through small incisions, reducing recovery time and the risk of complications
- Ends a woman's monthly menstrual cycle, which some women view as a benefit

Cons

- Does not reduce a woman's cancer risk to zero
- Brings on sudden **menopause**, and the effects of that are not fully predictable
- Requires time out from one's normal schedule, both for the surgery itself and recovery
- Involves short- and longer-term side effects

My Experience

“For me, having my ovaries out was such a relief. I had breast cancer when I was 29 and had already been through chemotherapy. So, the only emotion I experienced was relief to have this over with and not worry about the possibility of my ovaries becoming cancerous. I really did get an emotional lift. I felt good that I had done everything I could to control my fate.



At the same time, I must say that intellectually, I do know there is still a small chance of cancer. My mother’s ovarian cancer started in the pelvic lining, the peritoneum. I am vigilant about getting checkups – I have a CA125 test, pelvic exam, and Pap smears, along with follow-up for my breast cancer – and leading a healthy lifestyle. Still, the relief feels like one-hundred-percent relief, even though intellectually I know it’s not.” –Sarah



“Before I had risk-reducing surgery, I felt like my risk for ovarian cancer was a ten, on a scale of one to ten. Now I’d say I feel like maybe I’m a three. Even though the ovaries are gone, my doctor was very clear with me that there is still always a possibility of getting ovarian cancer, because of whatever tissue is left behind.” –Dora



“I have to say I was thrilled not to have my period anymore, or have to worry about getting pregnant! Those were important side benefits for me.” –Paula



“Even though I experienced terrible hot flashes after surgery, in some ways things were better. I no longer had the migraines that I typically got along with my periods, no backaches, no mood swings. I have enjoyed the freedom of not having that monthly period – that’s been a great physical comfort. And I like the peace of mind of knowing I have done something that reduces my risk dramatically – that’s the emotional comfort. I think it gave my loved ones some sense of control as well.” –Kelly

Choose a Surgeon

You also need to choose the doctor who will perform your surgery and provide your immediate follow-up care. Two kinds of specialists are qualified to perform risk-reducing surgery: gynecologists and gynecologic oncologists.

- A **gynecologist** is specially trained in matters related to women's health and the female reproductive tract. If a gynecologist delivers babies, he or she is also an obstetrician.
- A **gynecologic oncologist** has completed the same training as a gynecologist, along with more in-depth training in the diagnosis, surgical approaches, treatment, and management of gynecologic cancers, including ovarian cancer.

Working with a Gynecologic Oncologist

If you have had a formal risk assessment, you likely will have access to gynecologic oncologists who specialize in managing high-risk women and performing risk-reducing surgery. You also can seek one out on your own. One good resource for finding a gynecologic oncologist in your area is the Society of Gynecologic Oncologists, which can be reached by phone at 312-235-4060 or through its website at www.sgo.org (or access the Women's Cancer Network at www.wcn.org).

Working with such a specialist can be an advantage. Some studies of risk-reducing surgery have documented cases in which apparently healthy women were found to have an early-stage ovarian cancer during the procedure. Although this is not a common finding, many experts believe that it justifies working with a gynecologic oncologist. This surgeon has the training required to recognize the cancer, determine whether or not it has spread beyond the ovary (a process called staging), and if it has, remove as much of it as is possible (a process known as optimal debulking). Accurate staging and optimal debulking are proven to increase the likelihood of a long-term remission, which means that there is no evidence of disease.

After surgery, your **ovaries** will need to be examined closely by a **pathologist**, a doctor who evaluates the tissue for any evidence of disease. He or she should be informed that your **ovaries** were removed because you are at increased risk for ovarian cancer. Gynecologic oncologists at a cancer center or a hospital with a specialty cancer program are more likely to have access to **pathologists** with special expertise in evaluating gynecologic cancers.

Working with a Gynecologist

Even though there are many advantages to working with a gynecologic oncologist, you may prefer to work with a gynecologist. If you have established a good long-term relationship with your gynecologist, as many women have done through annual visits, you may feel more comfortable with having him or her do the surgery and providing your follow-up care.

As already mentioned, there have been some cases in which women were found to have ovarian cancer during risk-reducing surgery. You should discuss this possibility with your gynecologist before the procedure. If by some chance cancer is found, you will want a gynecologic oncologist to continue with the surgery. Such a specialist has much more experience operating on women with ovarian cancer and making sure that all of the cancer is removed. Your gynecologist may be able to have a gynecologic oncologist on call to step in if needed, or he or she may simply stop the surgery and reschedule it with a gynecologic oncologist at a later date. Also, make sure that your gynecologist works with a **pathologist** who has experience in gynecologic cancers.

Experience Matters

Whichever type of surgeon you choose, you need to make sure that he or she is experienced with performing risk-reducing surgery and at managing women's care after the surgery. Do not be afraid to ask specific questions about the doctor's level of experience in these areas. You want to work with someone who is already well versed in the special health issues you face. You may decide to work with more than one

doctor – a gynecologic oncologist and a gynecologist, perhaps – and help make sure they communicate with each other. The questions at the end of this section should help get the information you need.

Make sure that your surgeon is experienced with performing risk-reducing surgery in high-risk women and managing their long-term care after the surgery. To cover both bases, you may need to work with more than one doctor.

Make a Long-Term Care Plan

The doctor who does your surgery will follow you for a few weeks to make sure that there are no complications. You will also need to have long-term follow-up care because of a small remaining risk of cancer, and because of surgery's potential side effects, such as **surgical menopause**. (See the later section titled "Long-Term Considerations" for a discussion of what this care will involve.) As you consider doctors who might perform the surgery, it's important that you raise this issue. After risk-reducing surgery, some women have reported feeling unsure about where to turn for help with questions or problems.

Keep in mind that any long-term care plan should include **screening** for breast cancer and other gynecologic cancers, such as cancer of the **uterus**, or the **cervix** (the lower neck of the **uterus**, above the **vagina**). Removal of the **ovaries** and **fallopian tubes** does not protect you against these other gynecologic cancers. However, women are protected if they have a hysterectomy (removal of the **uterus** and/or **cervix**) as part of their risk-reducing surgery. The possibility of having more extensive surgery will be discussed in the next section, "What Surgery Involves."



My Experience

"I took about seven months to make the decision to have risk-reducing surgery. It wasn't something that was just presented to me, and then a month later I had it. Once I had the information, I checked it out with each of my doctors – gynecologist, primary care doctor, rheumatologist – over the course of a year. I also spent four or five months reading about it. I really took my time." –Sarah



Verify Health Insurance Coverage

Women generally have not had trouble getting their health insurance plans to pay for risk-reducing surgery. However, many plans do require precertification for major medical procedures (verifying in advance that it is covered), so you should check whether this is true for your plan – and follow its directions accordingly.

My Experience

“I wish I had thought more about who would manage my care after surgery and be able to tell me what I should and shouldn’t do. I felt like I was alone in dealing with all of the physical side effects that started to happen. There really is no one medical specialist who has a full picture of what removing estrogen can do to a woman’s body, and what to do about it. Women who are making the decision to have surgery really need to know this and plan ahead for it.” –Lisa



“I am being managed by my gynecologist now. From the beginning, I kept him involved and informed. I had to explain what the Lynch syndrome was, what it meant, what the risks were. I provided him with articles and pamphlets. I did that with my family doctor and my gastroenterologist as well. I felt comfortable with this. I like the sense of control that comes from being proactive.” –Kelly

You may be concerned about letting your health insurance company know that you have a higher-than-average risk of developing ovarian cancer. (Of course, if the plan has already paid for your **genetic testing**, it knows that you are concerned about your risk.) Some women express fears that their health insurance plans will try to drop them, or raise their premiums, once they have this information. If this concerns you, ask your doctor to indicate that a strong family history, rather than a positive genetic test result, is the reason for ordering the surgery. The results of your genetic test can be kept confidential.

Fortunately, we have not seen insurance companies discriminate against women on the basis of **genetic testing** results. Federal laws are helping. For example, the Health Insurance Portability and

Accountability Act (HIPAA) protects people in group health insurance plans from having genetic information considered as a preexisting condition and being used as a reason to increase rates. For the last several years, the U.S. Congress has been considering even better legislation, such as The Genetic Information Nondiscrimination Act of 2008. It forbids health insurance companies from refusing to enroll individuals because of their or their family members' request for or receipt of genetic services. It also forbids insurers from raising group premiums based on this information. This information will continue to change. You can find the latest update by checking the trusted sources listed below (see box below).

In short, the law is on your side, and you should challenge your health insurance plan if you encounter any difficulties related to **genetic testing** or risk-reducing surgery.

For More Information

National Society of Genetic Counselors

(312) 321-6834

www.nsgc.org

Visit the consumer area of the website for a brochure about genetic discrimination and related resources.

FORCE: Facing Our Risk of Cancer Empowered

(866) 288-7475

www.facingourrisk.org

Visit their website section on genetic information, privacy, and discrimination.

National Human Genome Research Institute

(301) 402-0911

www.genome.gov

Check their website's page on genetic discrimination in health insurance or employment.

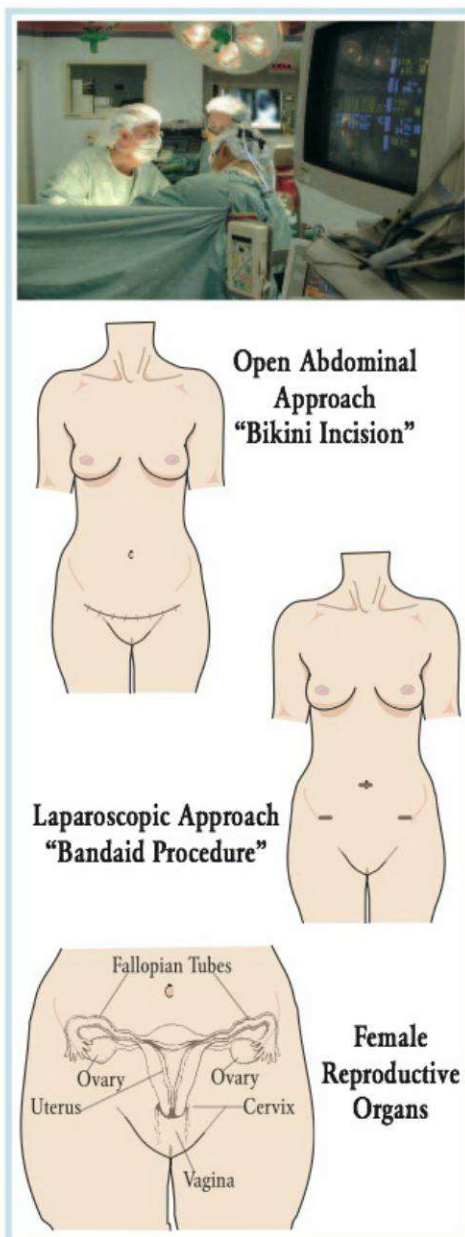
What Surgery Involves

Once you choose a surgeon, you will need to work with him or her to decide what type of surgery you are going to have. You also will need to schedule your pre-surgical testing and make any arrangements you need for assistance or time off during your recovery.

Types of Procedures

In many cases, risk-reducing surgery can be done **laparoscopically**, with the **ovaries** and **fallopian tubes** being removed through small incisions in the pelvic region. This is still considered major surgery. However, as compared with a larger abdominal incision, the laparoscopic approach may lower the risk of complications from the surgery itself, may shorten recovery time, and may cause less scarring. Furthermore, this procedure allows for the use of abdominal wall tissue for **breast reconstruction**, either at the same time or future time, if you decide to have **risk-reducing mastectomy**.

There are some cases in which the doctor recommends more extensive surgery that includes removal of the **uterus** and **cervix**. This is called a hysterectomy. Sometimes women choose a hysterectomy, usually because of health-related concerns. These concerns are described later in this section.



Women who undergo risk-reducing surgery have one of the following procedures:

- **Laparoscopic Bilateral Salpingo-oophorectomy (BSO)**

The surgeon makes several small incisions in the abdominal wall, and then uses a special device called a laparoscope to perform the procedure. First, a tube is inserted through the bellybutton to inflate the pelvis with carbon dioxide gas. Then the surgeon inserts a lighted fiber optic camera that allows for viewing of the internal organs on a television monitor. He or she uses special surgical instruments to remove the **ovaries** and **fallopian tubes** through the small incisions. If these organs and the surrounding tissue appear healthy, there is no need for the surgeon to go any further. He or she would send the tissue to a **pathologist** for close examination under a microscope, just to be certain that no early-stage cancer is present. Sometimes laparoscopic surgery is referred to as a “bandaid procedure” because the small incisions can be covered with a bandaid.

Laparoscopic BSO typically lasts about one to one-and-a-half hours.

- **Abdominal BSO**

There are some cases in which the surgeon needs to make a larger incision to perform BSO. If a woman has scar tissue (technically known as adhesions) from previous abdominal or pelvic surgeries, for example, it may be impossible to access the **ovaries** and **fallopian tubes laparoscopically**. The surgeon would need to make a bikini incision – a horizontal incision just above the pubic bone – to complete the surgery. The surgeon also might need to make a longer vertical incision down the abdomen if he or she sees something suspicious that may be suggestive of cancer. He or she would want to inspect the area thoroughly and send any suspicious tissue for immediate examination by a pathologist. This process is known as a “frozen section.” If the tissue were normal, no further surgery would be needed.

Abdominal BSO generally lasts about one to two hours, perhaps a bit longer if the surgeon needs to do some further exploration.

- **BSO with Laparoscopically Assisted Vaginal Hysterectomy (LAVH)**

The surgeon removes the **ovaries** and **fallopian tubes laparoscopically**, as already described, and begins the process of detaching the **uterus** and **cervix** (the neck of the **uterus**, which connects it with the **vagina**). The hysterectomy is completed through an incision in the **vagina**. This approach allows women to avoid the longer abdominal incision that was traditionally needed to perform a hysterectomy.

BSO with LAVH typically lasts about two to two-and-a-half hours.

- **Total Abdominal Hysterectomy/Bilateral Salpingo-oophorectomy (TAH/BSO)**

To perform TAH/BSO, the surgeon makes a four-to six-inch incision in the abdomen and removes the **ovaries**, **fallopian tubes**, **uterus**, and possibly the **cervix**. The surgeon would want to inspect the area thoroughly.

TAH/BSO typically lasts about two to four hours.

Why You Might Want, or Need, a Hysterectomy

There are a number of cases in which removal of the **uterus** and **cervix** may be warranted. You will need to talk to your doctor about each of these possibilities in advance and consider whether or not it makes sense to have the more extensive surgery.

Possible reasons for having a full hysterectomy in addition to BSO include:

- **You have a Lynch Syndrome (HNPCC) mutation.**
If you have tested positive for the **genetic mutation** that is linked with the Lynch Syndrome, you are considered to be at higher-than-average risk for cancer of the **uterus**.
- **You are concerned about a possible increased endometrial cancer risk linked to the *BRCA* mutation.**
The endometrium is the inner lining of the **uterus**. Some preliminary research has suggested that women with a *BRCA* mutation may also be at increased risk for a certain type of endometrial cancer (called papillary serous carcinoma of the endometrium) that is closely related to ovarian cancer.
- **You are concerned about increased uterine cancer risk associated with taking tamoxifen.**
Many women who are considered high-risk for ovarian cancer also take the drug tamoxifen to reduce breast cancer risk. While tamoxifen blocks the effect of the hormone **estrogen** on breast tissue, it actually raises its effect on uterine tissue, leading to an increased risk of uterine cancer.
- **You have a history of problems involving the uterus or cervix.**
Hysterectomy may be indicated for problems such as abnormal uterine bleeding, uterine **fibroids** (noncancerous growths that sometimes cause pain and/or heavy bleeding), abnormal PAP tests, or **endometriosis** (a condition in which tissue from the uterine lining grows outside the **uterus**).
- **You are considering hormone replacement therapy (HRT).**
Women choosing HRT after hysterectomy only need to take **estrogen**. Women choosing HRT who keep the **uterus** have to take both **estrogen** and **progesterone**. This combined therapy may be linked to increased risk of heart disease, **stroke**, blood clots, and breast cancer. For a more detailed discussion of HRT, see the later section “After Surgery: Managing Physical Consequences.”

- **You have a strong preference for the more complete surgery.**

Some women simply have a strong personal preference for undergoing hysterectomy along with the BSO. They reason that, if they are going to have surgery to have some of their reproductive organs removed, they might as well have all of them removed to guard against future problems. Also, some surgeons feel that the only way to be sure that all fallopian tube tissue has been removed is to remove the **uterus** (since the tubes are connected to the **uterus**).

- **You are approaching the age of menopause.**

If you are nearing natural **menopause** or already in **menopause**, you may have gotten used to the fact that your reproductive years are ending, and this may make the idea of a hysterectomy more acceptable to you.

- **Ovarian cancer is found during the surgery.**

Although this is rare, it can happen. There have been documented cases in which doctors have found ovarian cancer – typically early-stage cancer – while performing risk-reducing BSO in an apparently healthy woman with no signs or symptoms of ovarian cancer.

Why You Might Not Want a Hysterectomy

The decision not to have a hysterectomy as part of your risk-reducing surgery may be based on the following reasons:

- **Your uterus and cervix are healthy and not implicated in any future risk of disease.**

Research done to date has not established a definite connection between the risk of ovarian cancer and the risk of other gynecologic problems. Therefore, you may not see the sense in having these organs removed.

*My
Experience*

“The hardest decision was whether to have just the ovaries and fallopian tubes removed or have a full hysterectomy. The doctors wanted to remove everything, but I couldn’t decide whether or not there was a real benefit to that. Did I really need it? When I talked to more experts, I found that no one really went either way and said, ‘Yes, you should have this,’ or ‘No, you shouldn’t have it.’ Ultimately I decided just to have the ovaries and fallopian tubes removed, because that was where the risk of problems was.” –Dina



“I decided to have a total abdominal hysterectomy. What helped me make up my mind was, about a month before the surgery, my gynecologist tried to do a uterine biopsy (removal of cells from the uterus for examination). Because I have stenosis (narrowing) of the cervix, she wasn’t able to do the test. That was what made me go from just having the ovaries out to having everything removed. She said it wouldn’t be easy to check my uterus, and that just sort of pushed me over the edge to having everything taken out and not needing to worry about it again.” –Sarah

- **You want to avoid more invasive surgery and the potential side effects of hysterectomy.**

Laparoscopic BSO is a major procedure, but the smaller incisions generally mean a faster recovery time, lower risk of complications, and less disruption in your life. Having BSO alone also eliminates the risk of additional side effects from a hysterectomy.

- **You have a strong personal preference to keep your uterus and cervix.**

Often this decision comes down to strong personal preference. For many women, surgery to remove the reproductive organs is an emotional experience as much as it is a physical one. And some simply prefer to have the least amount of surgery possible.

Practical Planning Before Surgery

Even though you are not sick, you are about to have major surgery. Whether you have laparoscopic surgery or a larger incision, you will need to give yourself time to recover and rely on the help of others. It is a good idea to prepare for this in advance. Some practical steps you can take include the following:

- **Determine who is going to accompany you to your surgery, talk with the doctor after it's over, and generally act as your advocate.**

It's important to have a trusted family member or friend act as your advocate while you can't do so yourself. The nurses and other medical staff members who will care for you after surgery will be responsible for many other patients, too. So it's always wise to have someone with you who can ask questions and get their attention.

- **Prepare a space at home for your recovery.**

Make sure you're well stocked with books, magazines, a television, a radio – anything you feel you might need. Keep in mind that it may be difficult for you to climb steps and lift things during the first several days after your surgery.

- **As much as possible, delegate some of the tasks that you are used to handling at home and at work.**

Plan for who will take over your responsibilities. For laparoscopic surgery, it may be three or more weeks before you have all your energy back, and for abdominal surgery, about four to six weeks.

- **If you live alone, try to have some one come stay with you after your surgery.**

This is especially desirable if you are going to have major abdominal surgery, as opposed to laparoscopic surgery. See if you can get a relative or close friend to stay with you for at least part of that time.



My Experience

"I had a laparoscopically assisted vaginal hysterectomy. Actually I had the ovaries, fallopian tubes, and uterus above the cervix. I have my cervix, but everything above it is gone. The reason I chose to do that, besides just having the ovaries removed as I had originally planned, was that my gynecologist noted that taking tamoxifen increased my risk of uterine cancer. She said, 'Once you don't have your ovaries, you really don't need the uterus. We might as well take both.' And I thought there was some sense in that, so that's what I did."
–Theresa

Even though you are not sick, you are about to have major surgery. Whether you have laparoscopic surgery or a larger incision, you will need to give yourself time to recover and rely on the help of others.

My Experience

"I had my ex-husband keep our two kids for the first couple of days while I was recovering. I did talk to my children a little bit about the fact that I was having an operation, but I made sure they knew I was OK.

My dad stayed with me for the first couple of weeks until I was able to be up and driving again. He took care of me and made sure I had meals to eat. He also left my freezer stocked before he left, which really helped.

I also was very thankful that my gynecologist, knowing that I was going to have extensive surgery, signed me out of work for eight weeks. She knew that, once I went back to work, I wasn't going to get any rest, since I am a single parent. She said, 'You need as much time at home to recover before you have to go back into full swing.' I thought she was very wise in that." –Theresa



"My sister came with me for the surgery and stayed a few days. My oldest daughter also came up from college, about an hour away, for a couple of days to help me. Then my friends were also there, in case I needed them." –Dora



"Go out and find a pair of pants with a waistband that doesn't rub, like sweatpants. I am perfectly serious. That was one of the biggest challenges I faced after surgery." –Penny



Pre-surgical Procedures and Testing

All medical centers have set procedures for surgical patients to follow. Generally, you can expect to meet with an **anesthesiologist** in advance of your surgery and have some standard pre-surgical tests. These may include:

- Electrolytes (measures blood factors like sodium and potassium)
- Complete blood count (measures blood parts like red and white blood cells)
- Coagulation studies (measures how well your blood clots)
- Chest x-ray (an image of the organs in your upper body, like your lungs)
- Electrocardiogram, or EKG (a test that records the electrical activity of the heart)
- Pregnancy test, if you are premenopausal.

Your doctor should also perform a **CA125** test and a **transvaginal ultrasound**. In some cases, another imaging test like a **CT scan** will be ordered. These are done to make sure that the **ovaries** are healthy.

You will go through an informed consent process at some point before your surgery. This means your doctor should explain the surgery and its risks and then give you a written form to sign that explains them. He or she also will give you instructions for the day of your surgery, or arrange for a staff member to contact you with that information.



The Partner's Experience

"I offered to take care of everything for a while – the kids, the house, meals. I told her to focus on getting better. I think it lifted a real burden from her to know that. I tried to give her a shoulder to cry on when she needed it, and to reassure her that I was there for her and would still love her when this was all over." –Joe



"I tried to give emotional support but also help with all of the mundane, day-to-day stuff. I was also kind of surprised at how long it took her to recover from the surgery. It certainly was no minor deal." –Mark

You should tell your doctor about any medications you are taking, including aspirin and aspirin-containing drugs, nonsteroidal anti-inflammatory drugs (NSAIDs, such as ibuprofen), blood thinners, and any vitamin or herbal supplements. Some of these medicines can cause bleeding and may need to be stopped before surgery.

Recovering from Surgery: What to Expect

The length of your hospital stay depends on the type of procedure you have, as shown in the following table:

<i>Type of Procedure</i>	<i>Length of Stay</i>
Laparoscopic BSO	One night, or released same day
BSO with LAVH	One night
Abdominal surgery (BSO or TAH/BSO)	1-2 nights

During your stay, nurses will monitor you for any signs of infection, such as a fever or unusual redness and drainage from your incision. You may be given a patient-controlled analgesic (PCA) pump that allows you to give yourself pain medication when you need it. As you recover, you also will take some pain medications by mouth, immediately and for a few weeks after your surgery.

The same day or the very next day, you'll be expected to get up and walk around. This may be painful at first but it's important to your recovery. At first, you may not be allowed to take any food or drink by mouth. After that, you'll probably be restricted to a diet of fluids until your doctor is sure that your bowels are working normally. The **digestive system** is the last part of the body to recover from the effects of **general anesthesia**.

Side Effects

In the days and weeks after surgery, you could experience any or all of the following side effects.

- **Pain:** If you had laparoscopic surgery, your pelvis and abdomen were inflated with carbon dioxide, and this can cause some pain that may radiate to your shoulder. You also may experience some pain at the site of the incision(s). Your doctor will likely order pain medication to be taken during the first week or two after surgery.
- **Fatigue:** Fatigue is common after the surgery. You may find that you feel tired sooner and you require more rest. Generally, it takes three to four weeks after laparoscopic surgery to resume your usual activity level, and up to six weeks for surgery that involves the longer abdominal incision.
- **Changes in your digestive system:** You may find that you have less of an appetite than normal in the days after surgery. Some women find it helpful to eat more frequent, smaller meals instead of three large meals. You may have less frequent bowel movements until your **digestive system** gets back to normal. Your doctor may recommend that you take a stool softener.
- **Surgical menopause:** Within days or even hours of surgery, you may begin to experience side effects related to the loss of **estrogen**. These effects are likely to be more pronounced if you had not yet started the process of natural **menopause**. They can include intense hot flashes,



My Experience

"When I was in the hospital, I did not do very much. When I got home, although I was still weak, I tried to do the stairs at least once a day, take a short walk to the mailbox. I also had someone take me somewhere every day, just so I would get out of the house. Soon enough, I was able to get back to my regular routine." –Dina



"As far as recovery goes, the biggest thing for me was just listening to my body. When it said, 'Go lie down,' I would listen to it and do that." –Theresa

fatigue, mood swings, and vaginal dryness and irritation. Because these side effects will require management over the long-term, we will discuss them in the next section, “After Surgery: Managing Side Effects.”

Limits on Physical Activity

The following are typical recommendations for resuming normal activities. Be sure to check with your doctor for specific instructions:

<i>Activity</i>	<i>Time before resuming</i>
Driving a car	2 weeks
Heavy lifting	2 – 6 weeks
Exercise	6 weeks

My Experience

“It was not an easy surgery, but I had adhesions from my previous abdominal surgery, so I think that made it more difficult for me. And after the surgery, my colon decided it just wasn’t going to work. So I had to spend some additional time in the hospital. After that, it took about three weeks for me to feel really well, and I was back at work in six weeks. I arranged for that time off in advance.” –Kelly



“What helped me the most was just taking time off after surgery and having absolutely no obligations whatsoever. It doesn’t ever happen in my life, so just allowing myself that time was nice. Letting myself just read or relax with a cup of tea, just giving myself the chance to recover, made a big difference.” –Dora



“I didn’t find that I really needed emotional support after surgery. I had an awful lot of help from my husband and a few close friends, who would have been there for me emotionally if I had needed it. But just physically they helped me out a lot. I had friends dropping by casseroles for dinner and my husband was doing everything around the house. So that made it very easy for me to focus on my recovery.” –Sarah



When to Call Your Doctor

You should call your doctor if you experience any of the following symptoms:

- A temperature over 100.4 degrees. For at least a couple of weeks, you should take your temperature in the morning and evening
- Increase in swelling or redness at your incision(s)
- Any drainage from your incision
- Pain not relieved by your pain medicine
- Vaginal discharge with itching or a bad-smelling odor
- Nausea, vomiting, or abdominal pain
- Any difficulty with urinating, such as pain, burning, urinating often, or being unable to reach the bathroom in time.

Follow-up Visits with Your Doctor

The doctor who performed your surgery may see you for an office visit at about two weeks and again at about four to six weeks after surgery. He or she will want to check to make sure your incision(s) is healing properly. If you had a hysterectomy as part of your risk-reducing surgery, you can expect to have a pelvic exam at about four weeks.

Regardless of who is going to provide your long-term care (your surgeon or another doctor), make sure you have some plan in place to get the help you need in coping with side effects. Talk about these issues ahead of time. One plan is to schedule more frequent office visits during the first year after surgery. At the very least, be sure you know how to contact your doctor when you have a problem or question.



My Experience

“My advice after surgery would be to walk, walk, walk. It is amazing what that will do for you. It helps with a lot of things. It helps you feel like eating and sleeping, it helps you gain strength, and emotionally it just helps to get outside and feel better. You don’t have to run a marathon. Just do what you can, day by day.”
–Kelly

After Surgery: Managing the Physical and Emotional Impact

Just as individuals can experience different effects when taking the same medication, you have no way of knowing exactly how risk-reducing surgery will affect you. Women tend to fall along a broad spectrum: at one end are those who experience few or no effects, while at the other are those who experience many effects that impact their quality of life. Most fall somewhere in between. Researchers are now working to build a more complete understanding of how removing the **ovaries** impacts a woman's health and well being.

If you are pre-menopausal, you are likely to experience effects of early **menopause** due to surgery, or "**surgical menopause**." The most common are hot flashes, night sweats, and vaginal dryness. Others include headaches, fatigue, and sleep problems. Some women report having mood changes, such as anxiety and depression, and changes in thinking, such as forgetfulness and loss of mental sharpness. Still others have reported effects like weight gain, change in body shape, and joint pain. Also, women who have the surgery are at greater risk of osteoporosis (thinning of the bones), and possibly of heart disease as well. Women can experience sexual side effects and a lessened libido (sex drive), which will be discussed in Section 5.

If you already are experiencing natural **menopause**, you may find that your menopausal symptoms do not change, or you may find that they intensify or that you experience some new symptoms.

There are some things you can do to manage these effects. **Hormone replacement therapy** (HRT) is one option, but some studies have raised questions about its potential health risks. More research on HRT is needed for women in general, for those who are considered to be at higher-than-average risk of breast and ovarian cancer, and for those who have already had breast cancer. Other options include non-hormonal medicines, natural remedies, and lifestyle changes such as diet and exercise. Just how effective these options are is still being studied. You will need to work with your health care team to make a plan that works for you.

In spite of the physical effects of risk-reducing surgery, many women report one very positive effect: the relief that comes from significantly reducing their risk of ovarian cancer.

Just as individuals can experience different effects when taking the same medication, you have no way of knowing precisely how the removal of your ovaries will affect you. Women can fall anywhere along a broad spectrum: at one end are those who experience a few or no effects, while at the other are those who experience many effects that impact their quality of life. Most fall somewhere in between.



My Experience

“I wish my health care team had talked more about the potential after-effects of being thrown into menopause. Everybody knows you are going to have night sweats and hot flashes, but there are other things that can happen afterwards that aren’t expected. I never would have guessed that I would have insomnia and joint pain. Also, I always had 20/20 vision, and within a year after surgery, my vision started to go downhill rapidly. I spoke with some doctors and they said that this could be a side effect. I guess a more detailed discussion before surgery of what could happen would have made me feel better prepared.” – Anne



“No one ever said to me, ‘You may feel a lot better emotionally when this is done.’ What they tended to focus on was how I could feel worse emotionally. No one said that I might feel like a weight had been lifted from my shoulders. I think women need to know that.

I am very happy with my decision. It was the best thing I ever did.” – Kelly

My Experience

*“My health care team covered most of the symptoms I might experience after surgery. I think what was lacking was a full explanation of the big difference between **surgical menopause** and **natural menopause**. I really thought that **surgical menopause** would be more gradual, but it is much more pronounced and they didn’t tell me that.*

At the same time, surgery was not as scary or horrible as I thought it might be. I had never had surgery before and I was pretty frightened about it, but my recovery was good. I felt great afterwards. It took such a weight off my mind. I have many of the symptoms I read about, but they don’t really interfere with my life. And surgery has brought such a sense of relief that any of the symptoms are still worth it.” –Paula



*“There was little talk of possible side effects or drawbacks of the surgery. I knew about hot flashes and all of the common effects that could happen. We talked about different ways of dealing with them. So I felt pretty much like, ‘Oh, those common things that happen to women in **menopause** will be no problem, because there are ways to combat them.’ But it’s really been much so much worse than I ever imagined.” –Lisa*

The Partner’s Experience

*“My partner was already having menopausal symptoms, so we had already gone through a lot of the issues related to **menopause**. So the surgery really didn’t present us with any additional challenges. Overall, the quality of life is basically the same as before, so I think it was a good decision and the right decision.*

The greatest benefit is that she is not obsessing about this anymore. It’s just one less thing she has to worry about. At the time she was contemplating surgery, she had several family members who were dying of cancer. Her doctor told her, ‘I can protect you pretty well from breast cancer, but I cannot protect you from ovarian.’ I’d rather have my partner with me for a lifetime than take the risk of not having her.” –Connie



The Partner's Experience

*"My wife was not even close to **menopause** when she had the surgery. So we found ourselves there all at once, almost overnight. For her it was very intense and physically uncomfortable, and she was very unhappy. We hadn't really expected this and probably would have benefited from knowing more about what could happen. The surgery was presented to us as something we had to do, given her risk, and the quality-of-life piece never really made it to the table. That might be because the effects weren't really understood when we made our decision, which was a few years ago now.*

Despite that, I know my wife went to her doctor the other day and met a woman her age who also had the surgery and was found to have ovarian cancer, and now she is going through chemo. So I guess you could say there's diminished quality of life, on the one hand, and then there's being alive, on the other."
—Mark



"My wife was certainly pre-menopausal and the reactions to surgery were extreme for a long time. It was almost a year before the physical side of it became less complicated. The emotional side still exists today and it's almost five years later.

*I would advise a pre-menopausal woman to carefully consider and talk about the changes that could occur once surgery is completed. I think it's easy for a positive genetic test result to override any rational conversation about what the consequences of surgery could be. My wife's immediate reaction was, 'Well, I am not having any more children, I don't need that body part,' and she was ready to have surgery right then and there. Given the side effects she has had, my wife might have waited a little bit longer to have surgery, until she was closer to **menopause**, but I think ultimately she would have gone through with it. Of course, because there is no accurate early diagnosis test for ovarian cancer, waiting to have surgery does mean that you are taking the risk that the cancer will sneak up on you." —Timothy*

Loss of Estrogen

Removing the **ovaries** removes the body's source of **estrogen** and **progesterone**. **Hormone replacement therapy (HRT)** was once viewed as an excellent solution for women who wanted to relieve menopausal symptoms due to **estrogen** loss and reduce their risk of heart disease and osteoporosis. In the past, it was routinely given to women who had risk-reducing surgery before **menopause**. HRT involves using a pill, patch, or implant that contains the hormone **estrogen** alone or a combination of **estrogen** and **progestin** (a synthetic, or man-made, form of the hormone **progesterone**) to replace the hormones that are no longer present in the body naturally.

Over the last few years, however, a number of studies have suggested that HRT has some risks that women should consider when deciding whether or not to take it.

Recent Research Findings

In 2002, the Women's Health Initiative, a large-scale clinical trial by the National Institutes of Health, suggested that the risks of HRT might outweigh the benefits. More than 16,000 post-menopausal women participating in the study were randomly assigned to take either **estrogen-progestin** HRT or a **placebo** (inactive pill). After about five years of follow-up, the HRT group had 26 percent more cases of breast cancer, a 29 percent increase in heart attack rate, a 41 percent increase in the rate of **stroke**, and double the rate of blood clots in legs and lungs. They had fewer cases of hip fractures and colon cancer. The trial was stopped early as a result.¹

Other studies have raised specific concerns about HRT in relation to the risk of cancer. A British study of more than one million women found that those who took **estrogen-progestin** HRT were more likely to

1 Rossouw JE, Anderson GL, Prentice RL, et. al. "Risks and benefits of estrogen plus progestin in healthy postmenopausal women: principal results from the Women's Health Initiative randomized controlled trial." *Journal of the American Medical Association* 2002 Jul 17; 288(3): 321-33.

develop and die from breast cancer. Women who were using this HRT at the time of enrollment were 50 percent as likely to develop breast cancer, while women taking **estrogen** only were 30 percent more likely to develop it.²

Interpreting the Findings

While these percentages are significant, it is very important to keep the actual numbers in perspective. In the Women's Health Initiative study, for example, 38 out of 10,000 women taking HRT developed breast cancer annually, versus 30 out of 10,000 in the no-HRT group. These eight additional breast cancer cases account for the 26 percent increase in risk reported by the study.

According to the American College of Obstetricians and Gynecologists, which in fall 2004 published its *Task Force Report on Hormone Therapy*, these study results do not mean that taking HRT should be off-limits for all women. Rather, these results suggest that all women need to consider the potential risks of HRT before taking it to relieve menopausal symptoms. In addition, the report stresses that:

- Women should not take HRT to prevent cardiovascular disease, given the results of the Women's Health Initiative study.
- The average age of women in the study was 63 – about ten years older than the typical woman seeking relief at the onset of natural **menopause**. This is also considerably older than most women are when they are making decisions about risk-reducing surgery.

All women need to make the decision about whether or not to use HRT in close consultation with their doctors, carefully weighing the potential benefits and risks.

2 Beral V, Million Women Study Collaborators. "Breast cancer and hormone-replacement therapy in the Million Women Study." *Lancet* 2003 Aug 9; 362(9382): 419-27.

There is particular concern about the use of HRT by women who are considered high-risk for ovarian and/or breast cancer, or who have already had breast cancer, whether due to a *BRCA1* or *BRCA2* mutation, a strong family history of disease, or both. This concern is relevant to women who undergo risk-reducing surgery for ovarian cancer. Doctors' recommendations tend to vary:

- Some doctors definitely would not recommend HRT for these women, particularly in light of the possible increased risk of breast cancer.
- Some doctors feel that short-term HRT is acceptable. One study has shown no increase in breast cancer risk among women using short-term (2-3 years) HRT after risk-reducing surgery.³
- Still others feel that low-dose HRT (which is lower than the normal amount your **ovaries** make) is acceptable until age 50, the time at which a woman is likely to go through natural **menopause**.

Considering HRT as an Option

Given these concerns, it is most important to discuss these issues in advance of your surgery. If you are very concerned about the effects of **surgical menopause**, you may plan to start HRT right after surgery, and then gradually wean off it as your body adjusts to the significant drop in natural **estrogen** levels. On the other hand, you may want to wait and see how your body reacts to the surgery, perhaps trying other options for relief from menopausal symptoms. Or, you may decide to avoid HRT entirely, no matter how you feel after surgery, because of its potential risks. The key is to work with your health care team to find the best possible plan for you.

NOTE: While there is increasing interest in “**bioidentical hormones**,” most of these custom-made compounds of hormones made from plants have not been tested for safety and effectiveness.

³ Rebbeck TR, et al. “Effect of short-term hormone replacement therapy on breast cancer risk reduction after bilateral prophylactic oophorectomy in *BRCA1* and *BRCA2* mutation carriers: The PROSE Study Group.” *Journal of Clinical Oncology* 2005 Nov. 1, 23(31): 7804-10.

There is particular concern about the use of hormone replacement therapy in women who are considered high-risk for ovarian and/or breast cancer, or who have already had breast cancer, whether due to a BRCA1 or BRCA2 mutation, a strong family history of disease, or both. However, for some women, the impact of surgical menopause on quality of life may justify short-term use of HRT at the lowest dose needed to offer relief.



My Experience

“I wish I had known that doctors do not yet really have a clear understanding of the role of estrogen in the body. I have yet to find a doctor who really understands, at least in my body, what estrogen is responsible for. I wish I had known the limits of modern medicine. I wish I had known that when you basically go cold turkey to having no estrogen in the body, you might suffer repercussions. I have had a wide range of side effects. About six months after the surgery, my joints started swelling – all of my major joints, shoulders and knees and hips – and I still have this. The hot flashes weren’t as upsetting to me as the fact that I was hobbling around like a person twice my age. I also had chronic urinary tract infections and kidney infections. I have had hair fall out. My body shape has changed – I gain weight without eating very much. I forget things easily; I seem to have lost a lot of memories formed before my surgery. I often struggle to find the right word. My stamina is very low. My allergies are worse. None of these things were anything I had expected to happen.” –Lisa



“My gynecologist went over the possible side effects of surgery with me, such as the fact that my hot flashes would certainly continue or possibly worsen, I’d have vaginal dryness, etc. I was already familiar with these symptoms because I had been perimenopausal for about five years, but I was still worried about how bad they could get. Actually, the effects after surgery were not as bad as I had expected, and that was such a relief. If I had known that would be the case, I wouldn’t have worried as much. Of course, I have since found out that this is not true of all women. Other people have had much worse times after surgery than I had.” –Sarah

You will be living with the knowledge that you remain at higher-than-average risk for ovarian cancer. Your anxiety may be intensified by knowing that ovarian cancer is very difficult to detect early, even when a doctor is following you closely. Also, if you undergo regular CA125 testing and ultrasounds, you could at some point receive a false positive result – a result that suggests the possibility of ovarian cancer even when it really is not present. This is likely to cause you and your loved ones a significant amount of anxiety. You also could receive a false negative result: that is, everything seems normal on testing, even when an early-stage cancer is present. This realization also may cause you some anxiety.

In addition, your partner, family members, other loved ones, and even your doctor may disagree with your decision. Naturally, these people want to protect you from ovarian cancer, and they may see risk-reducing surgery as the best option for doing so. They may not be as convinced as you are by your reasons for deciding against surgery. Also, you may have relatives who are also high-risk and have decided to go ahead with the surgery – and this may cause some tension in your relationships.

Of course, every woman's situation and feelings can be a little bit different. You may find it helpful to talk to your health care team about these issues, or ask them to put you in touch with a social worker or mental health provider who can help you sort through them.

You also may wish to talk with other women who are going through the same experience. If you are participating in a program for high-risk women, you may have access to a support group of women who have had risk-reducing surgery, or at least to women who might be willing to talk about how they coped. Another option is to turn to the website of an organization called FORCE, or Facing Our Risk of Cancer Empowered (www.facingourrisk.org), which is designed specifically for women who are considered to be at higher than average risk for breast and/or ovarian cancer. An online message board allows women to share their experiences.

SUMMARY | PROS and CONS of Not Having Risk-Reducing Surgery

Pros

- Women who choose not to have risk-reducing surgery maintain their fertility and avoid sexual side effects and **surgical menopause** (see Section 5 for more on this).
- Women also avoid the short-term pain, inconvenience, and risk of complications associated with any surgical procedure.

Cons

- Women will need to consider other options to reduce their risk of, and screen for, ovarian cancer. All of these options have limitations.
- Not having surgery may mean living with more cancer-related anxiety.



My Experience

"I have to say I can count on two or three fingers any times when I have felt panicked or scared about my decision not to have risk-reducing surgery. I don't spend a lot of time thinking that way — it's just not healthy. I will admit that there was a time when I was frantic about all of this, and I don't know why I kept doing that to myself.

I feel so good that it is so hard for me to imagine going through an elective surgery that could potentially worsen my quality of life. Even though I might change my decision at some point, for right now in my life I have made the right decision for me. And that gives me the most satisfaction."

—Donna



Section 5

*Sexuality and Intimate
Relationships After
Risk-Reducing Surgery*



It is important to give some thought to how risk-reducing surgery could affect you sexually and impact your relationship with a current – or future – partner or spouse. In general, the issues are similar whether you are in a relationship with a man or a woman. They are also relevant to women without partners. Certainly, the reduction in cancer-related anxiety can benefit physical and emotional relationships, freeing you and your partner to focus less on the question of “What if?” and more on your future plans and your life together. Some women in heterosexual relationships find that freedom from not having to worry about getting pregnant also improves their sex lives.

At the same time, many women who have risk-reducing surgery report that they experience sexual side effects such as vaginal dryness and discomfort, as well as a decrease in their libido, or sex drive. They find that intercourse is uncomfortable, unappealing, or just “different” than it used to be. Other physical effects of surgery, such as fatigue and hot flashes, can interfere with sexual desire.

Before considering the potential impact of risk-reducing surgery on sexuality and intimate relationships, however, it’s important to think more broadly about your own sexuality. This is a complex subject, and there are many factors involved in intimacy besides hormones and sex organs.

Thinking about Sexuality

When you hear the word “intimacy,” it may bring to mind images of warm affection, closeness, and caring – perhaps in the context of lovemaking but perhaps not.

Your sexuality certainly has a physical component influenced by hormones and body image – how you see your body and how satisfied you are with it. But sexuality is much more than the experience of orgasm or intercourse. The physical part is balanced by your emotional health, which is influenced by current or past issues and events. Your concern about your risk of cancer could be one of these issues. Factors

such as your feeling of well being, sense of usefulness and meaning in life, and the depth of commitment and support in close relationships can all have an impact. Just as these factors can vary over time, variations in sexual interest occur normally over our lifetime and don't necessarily mean there's a problem. (See the boxed information below if you wish to read more on this topic.)

It's also important to realize that many people and their healthcare providers don't feel comfortable discussing sexual issues. You may find that it is sometimes awkward and embarrassing to bring up these private topics with your healthcare team and your partner. It also may require the patience to start slowly and work on these issues at a pace that feels right to you. While it can be difficult, talking about potential sexual side effects of ovary removal sooner rather than later is likely to help. Things may not be exactly the way they were, but you can find a "new normal" that satisfies you and your partner. This section is designed to help get you started.

For More Information about Sexuality

Reclaiming Desire: 4 Keys to Finding Your Lost Libido

Andrew Goldstein, M.D. and Marianne Brandon, Ph.D.

Emmaus, PA: Rodale Press, 2004.

National Women's Health Resource Center, Inc

Healthy Women

www.healthywomen.org

Get Educated and Plan Ahead

You can certainly have an enjoyable sex life again after risk-reducing surgery. Whether you had just your **ovaries** removed, or you had your **uterus** and/or **cervix** removed as well, you still have your **vagina** and **clitoris** – both of which play a central role in sexual pleasure and functioning. The breasts, skin, and brain are other organs that contribute to arousal and pleasure.

For those of you who are sexually active, we encourage you to spend time thinking about the sexual practices of you and your partner. Consider what aspects of your life affect your interest in sexual activity now. These might include a busy schedule, family and work demands, fatigue, and side effects of medicines, like antidepressants. Then consider the possible sexual side effects of surgery in the following section. Think about the adjustments you may need to make, how that may make you feel, and what support you might need.

The Impact of Surgery on Your Sex Life

Depending on the extent of your surgery and your own doctor's recommendations, you'll need at least two to four weeks for healing before having intercourse/vaginal penetration. More details about types of surgery and the recovery period are found in Section 3.

Like the symptoms of **surgical menopause** already discussed, sexual side effects are due, at least in part, to the sudden drop in hormone levels that occurs when the **ovaries** are removed. In addition to producing **estrogen** and progesterone, the **ovaries** produce testosterone. People may think of testosterone as only a male hormone, but it is also present in women and thought to play an important role in sexual desire.

This drop in hormone levels can cause some physical changes in pre-menopausal women. Blood flow to the **vagina** and **clitoris** decreases, and this in turn decreases vaginal lubrication. There's also a thinning of the tissue lining the **vagina**. These changes can make intercourse/vaginal penetration uncomfortable. There also can be decreased sensitivity and lessened quantity and strength of orgasms.

Wrapped up with the physical changes you may experience is the potential impact of your surgery on your libido or sex drive. This is a challenging subject because women's sexual desire is quite complex. In a special issue of the National Women's Health Report focused on women's sexual health (National Women's Health Resource Center, April 2005), Sheryl A. Kingsberg, Ph.D., a reproductive biology and

psychiatry professor at Case Western Reserve University, notes that women’s libido involves three components:

- The physical or biologic part
- Social beliefs and values
- Motivation.

Risk-reducing surgery can affect all three areas in different ways. For example, lower levels of hormones can lessen sex drive, as can physical side effects such as vaginal dryness and discomfort. These also can make you feel less motivated to have sex. If you have always thought of menopausal women as “non-sexual” (a social value), then being in **menopause** may lead you to think of yourself that way. And if you are feeling sad, anxious, or fatigued after surgery, certainly this can affect your motivation to have sex. On the other hand, you may experience an emotional lift after surgery, and this can improve sexual motivation.

When it comes to research, relatively little is known about how to improve a woman’s libido – and even less is known about how to improve it after **surgical menopause**. Because this field of study is so new and not often discussed openly, many of the potential treatments discussed in this section have neither been tested rigorously nor approved by the Food and Drug Administration. Low libido is one of the sexual side effects that are addressed below.

Managing Sexual Side Effects

There are a number of different options that have helped women to manage the physical changes after ovary removal. We discuss them below in no particular order of preference.

Hormonal Treatments

Section 3 discussed **hormone replacement therapy** (HRT) as a possible treatment for symptoms of **surgical menopause**. HRT also can help with the vaginal dryness and discomfort that make sex

uncomfortable for some women. However, as already noted, research has raised some concerns about giving HRT to women who are considered high-risk for developing breast and ovarian cancer. This decision needs to be made on a case-by-case basis and requires close consultation between a woman and her doctor.

Other hormonal options include:

- **Estrogen creams, tablets, or rings:** Estrogen applied directly to the **vagina** can help make vaginal penetration more comfortable and pleasurable. Estrogen is available as a cream (Estrace®), as a tablet that can be inserted into the **vagina** (Vagifem®) once daily for two weeks and then twice a week thereafter, and as a ring that can be placed in the **vagina** for up to three months (Estring®). The tablet and ring products are considered safer than HRT because the estrogen does not travel throughout the body. Small amounts of Estrace cream have been shown to be absorbed into the bloodstream.
- **Testosterone patch:** The hormone testosterone is made by the **ovaries** and thought to play a role in a woman's sex drive. Some women have been helped by using a testosterone patch placed on the skin to deliver low doses of the hormone to the body. A patch called Intrinsa® underwent review by the Food and Drug Administration in 2004, but the FDA concluded that the product needed more safety data before it could be approved. There have been reports that some women experience side effects such as facial hair growth, acne and voice changes. Nevertheless, many doctors will make the patch available to women complaining of low libido. Testosterone also comes in the form of a gel or cream that can be applied directly to the skin.

Lubricants and Moisturizers

Applying lubricants and moisturizers outside and inside the **vagina** can help to relieve the problems of vaginal discomfort and dryness. Water-based lubricants such as Astroglide® and K-Y Liquid® are intended to be used during intercourse/vaginal penetration to replace diminished vaginal secretions. Some brands offer a version that provides a warming sensation on contact, which may further help with sexual stimulation. Vaginal moisturizers such as Replens® and Lubrin® are used on a regular basis to keep the **vagina** moist for a longer period and relieve ongoing irritation. These too can help to prevent discomfort during intercourse.

A newer product called Zestra®, which is advertised as “feminine arousal fluid,” consists of a blend of botanical oils. It is designed to increase lubrication and intensify a woman’s climax. Other creams such as Viacreme®, Vigel®, and Femore® also claim to increase feelings of arousal, although none has undergone rigorous clinical testing. Your healthcare professional may be able to give guidance on use of these products, as the safety profile is not well established.

Alprostadil, which traditionally has been used in men to increase blood flow to the penis, is being studied in women. In research studies it increased feelings of arousal and pleasure when applied to the **clitoris** and **vagina**.

External and Internal Devices

Some women find that the **vagina** shrinks after surgery, making vaginal penetration uncomfortable or even painful. Regular use of a vaginal dilator or a dildo (an object shaped like an erect penis) can help to widen the **vagina**.

Other devices can be used to increase blood flow to and stimulation of the **clitoris**, which can produce more vaginal lubrication and feelings of arousal. One is the EROS Clitoral Therapy Device, a vacuum-pump device applied directly to the **clitoris** and **vagina** to increase blood flow to the area. It is approved by the FDA and available by pre-

scription. Another is the standard vibrator, which is used to stimulate the **clitoris**. If you feel uncomfortable purchasing a vibrator, take a friend with you for moral support or try shopping online. Many online stores will send the item to you in discreet packaging that gives no indication of the contents.

Medicines

No medicines have been approved yet to treat problems with arousal in women. Some studies have suggested that medicines used to treat impotence in men, such as Viagra®, also can help women become more sexually aroused. Just as they increase blood flow to the penis in men, they also increase flow to the **clitoris** in women. Pills with names such as ArginMax® and Avlimil® are advertised with claims that they can improve sexual function in women, but these have not been proven in scientific studies.

Be sure to check with your doctor before taking any medicine that wasn't prescribed for you.

Changing Your Sexual Routines

When it comes to sexual behavior, many couples tend to fall into routines, especially if they have been together for a long time. You may need some adjustments to help you feel more inclined toward reestablishing your intimate relationship and becoming sexually active again.

Little advice has been written specifically for women undergoing risk-reducing surgery. More has been written for survivors of breast and ovarian cancer, whose libido is often affected by chemotherapy and/or surgical removal of the **ovaries**. In her book *Sexuality and Fertility After Cancer*, for example, Leslie R. Schover, Ph.D., recommends abandoning what she calls the “performance model” of sex – that is, the image of easy, perfectly satisfying sex perpetuated on movies and television. She stresses that intimacy can take a range of forms, from a romantic dinner or dancing to kissing and touching. These activities can help to reestablish a sense of intimacy.

My Experience

*"I was very concerned about the sexual changes I was going to face from my oophorectomy. I was only 48 and not through **menopause** and I was worried that our relationship would be different and not fulfilling if my sex interest or ability changed. My husband assured me that sex was only the icing on the cake of our relationship. His telling me how important I was in his life built a stronger bond of intimacy. Our facing this together brought us so much closer."* –Grace



"I'm a divorced mother of two and I don't really have a significant other, nor am I looking for one. Raising my kids is my first priority, so loss of libido and vaginal dryness are not things I have really worried about at this stage in my life. Ten years from now when they are grown and out of the house, maybe I'll be thinking about it, but not right now." –Theresa



*"The potential impact of **surgical menopause** on intimate relationships was definitely a factor in my decision not to have the surgery right now, at age 42. I may change my mind later in life, but for now I am keeping my ovaries."* –Donna



*"I had gone through **menopause** before I had the oophorectomy. My husband and I had already faced some changes in our sex life just from my **menopause**. I saw that I was not as interested in sexual intercourse as often as he was. We worked things out between us, trying different things besides sexual intercourse to meet both our needs. So when it came to having the oophorectomy, I had no problem."* –Sally

You also may have to ask your partner to spend more time on foreplay. This helps to bring about the sense of arousal that causes the **vagina** to relax, widen, and lengthen, and also become more lubricated. You also may find that manual or oral stimulation of the **clitoris** and vagina is more pleasurable than vaginal penetration – or perhaps helps foreplay.

If you had a hysterectomy in addition to oophorectomy, you may find that sex feels different because your body structure is different now. You will no longer have a **uterus** and, in many cases, a **cervix**. Some women report that orgasms feel different as a result; the contractions of the uterus that may have been part of the experience may no longer be there. You will still have your **clitoris** and vagina, however, and these can become more central to your sexual experience than they were before.

Involve Your Partner

If you are currently in a relationship, spend some time talking with your partner. Talk about how things are going now and what changes risk-reducing surgery might cause – both in your sexually intimate relationship and your relationship overall, since these tend to go hand-in-hand. A healthy day-to-day relationship, which includes good communication often, translates into a healthy intimate relationship, and vice versa.

Some questions you may wish to discuss together include:

- **How have we weathered other difficulties in our relationship?** If you have a good track record, then the same skills will prove useful at this time. On the other hand, if you find it hard to deal with other sources of stress besides those of everyday life, you may need to work on improving this aspect of your relationship before having surgery.
- **How is our relationship right now?** Whatever is going on right now could be compounded after risk-reducing surgery. If you are having problems, particularly in areas such as communication and sexual intimacy, these could worsen after surgery.

- **Is the timing right for us as a couple?** If you have young children, demanding jobs, or other commitments, you will need to consider these in making your decision. Can your partner take on more responsibilities at home while you recover? Will he or she do this willingly, or will this become a source of resentment?
- **How is our sex life now and how will we deal if it changes?** Will you be able to discuss this with each other, and get additional help from a counselor or therapist if you need it? Are you willing to express intimacy in other ways and/or change your sexual routine, if needed?

These are intended only as a starting point. Brainstorm your own list of questions and share them with your partner. If you're not accustomed to communicating in this way, break the ice by sharing this booklet – especially the parts about the potential consequences of surgery. Let your partner know you understand that surgery will impact both of you as a couple, and make it clear that you want to deal with these issues up front.

If you are not currently in a relationship, you can adapt these questions to your situation now:

- How have you weathered difficulties on your own?
- How central is sex to your life?
- Are you dating now or do you wish to date in the future, and how will you cope with possible sexual side effects as you do so?

Ask for Help

Many people have difficulty talking about issues related to sexuality and intimacy. Nevertheless, raising sexual concerns before risk-reducing surgery will make it much easier to discuss them afterwards. The questions at the end of this section are designed to get you started.



The Partner's Experience

"Surgery has definitely affected our relationship. Immediately after surgery, she found that her sex drive decreased. A little while ago, she switched a medication that she's on, and that decreased her desire even more. But we're working through it together, even though the desire for sex isn't always there."

-Eric



"We're having less intimate contact than we had earlier in our relationship, but it's hard to tell whether that's due to the surgery or 20 years of marriage! We try to keep the lines of communication open." -Joe



"Our sexual relationship has always included a lot of touching, kissing, and holding each other. None of that has changed since my partner went through menopause as a result of the surgery." -Connie



*"The surgery has affected our relationship on many different levels. The physical consequences have tied up a lot of time and energy and attention and such, so that affects us in all sorts of ways. And some of those consequences affect our sex life pretty directly. My wife just had trouble with chronic **urinary tract infections**, and that certainly interfered with things."* -Mark

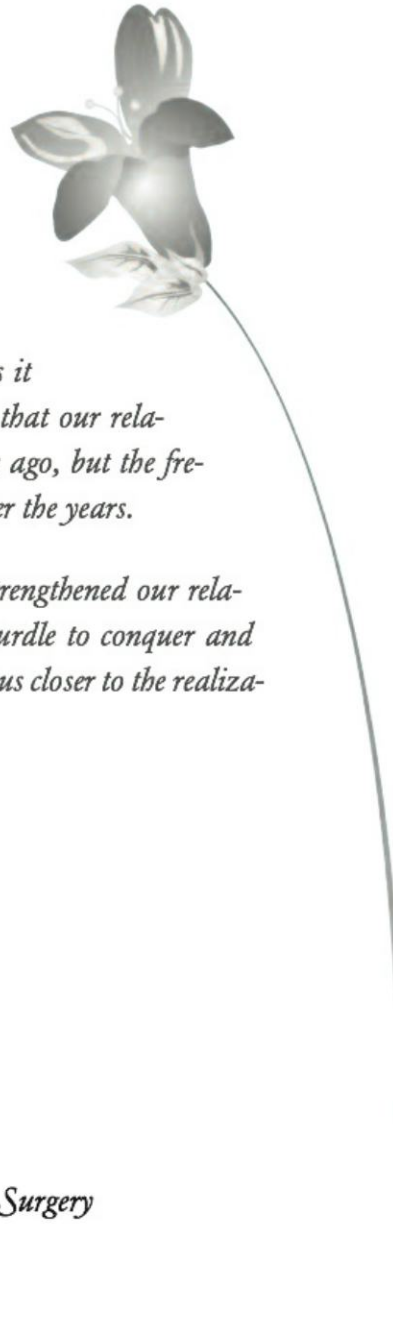
If necessary, consider the possibility of seeking professional help from a social worker, psychologist, psychiatrist, relationship therapist, or other type of relationship counselor. Your doctor or nurse may be able to make recommendations. Also, the boxed resources list at the end of this section features contact information for a number of organizations that may be able to connect you with a qualified professional.

One other note: If you have been a victim of sexual abuse or other sexual trauma, you should consider seeking help from a mental health professional, such as a social worker, psychologist, psychiatrist, relationship therapist, or other type of counselor. Invasive surgery could cause unexpected feelings of vulnerability.

The Partner's Experience

"The effect on our intimate life wasn't a huge problem because sex wasn't playing as important a role in our relationship as it had when we were younger. I would say that our relationship is as intimate as it was 20 years ago, but the frequency of sex has certainly diminished over the years.

In a larger sense, I think the experience strengthened our relationship. It was our first really serious hurdle to conquer and instead of being negative, it really brought us closer to the realization of how human we are." –Timothy



For More Information about Sexuality Organizations & Websites

American Association of Sex Educators Counselors & Therapists (AASECT)

1444 I Street NW, Suite 700
Washington, DC 20005
(202) 449-1099
Email: info@aasect.org
www.aasect.org

American Association for Marriage and Family Therapy

112 South Alfred Street
Alexandria, VA 22314-3061
(703) 838-9808 • www.aamft.org

Association of Reproductive Health Professionals-East

1901 L Street, NW, Suite 300
Washington, DC 20036
(202) 466-3825
Email: ARHP@arhp.org
www.arhp.org

“Nurture Your Nature: Inspiring Women’s Sexual Wellness” Website

Available at: core.arhp.org
An informational resource developed by the Association of Reproductive Health Professionals and the National Women’s Health Resource Center “in response to the gap in education about women’s sexuality.”

The Sexual Health Network

3 Mayflower Lane
Shelton, CT 06484
www.SexualHealth.com

Books

Reclaiming Desire: 4 Keys to Finding Your Lost Libido.

Andrew Goldstein, M.D. & Marianne Brandon, Ph.D. Emmaus, PA: Rodale Press, 2004.

The following resources were written for persons with cancer, but have information that may help you:

Sexuality and Fertility After Cancer

Leslie R. Schover, Ph.D. New York: John Wiley and Sons, 1997.

Living Beyond Breast Cancer: A Survivor’s Guide for When Treatment Ends and the Rest of Your Life Begins

Marisa C. Weiss, M.D., and Ellen Weiss. New York: Random House, 1997. See Chapter 12, “*Intimacy, Sex, and Your Love Life.*”

Ovarian Cancer Sexuality and Intimacy

Pamphlet available from the National Ovarian Cancer Coalition, Inc.
1-888-OVARIAN, www.ovarian.org



Appendix

A Decision-Making Tool

Appendix
A Decision-Making Tool



This worksheet is designed to help you move forward in making your decision about whether or not to have risk-reducing surgery for ovarian cancer, based on the information provided in this booklet. If you have already made your decision, it may help you to clarify the reasons behind it. You may find it useful to discuss your answers with your healthcare team and with loved ones who are assisting you with your decision.

I. Personal Information

This section is a place to record information about yourself that may help you do the following:

- Define your risk of getting ovarian cancer
- Think through the implications of surgery related to fertility and **menopause**.

Defining Your Risk of Ovarian Cancer

For more information on defining your risk, see Sections 1 & 2 of this booklet.

Genetic Test Results

Fill in the appropriate boxes in the following chart to reflect your experiences with **genetic testing** to date.

Genes Tested	Date test done	Result? (check one)	Your understanding of what the results mean
<i>BRCA1</i>		<input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Inconclusive <input type="checkbox"/> Don't Know	
<i>BRCA2</i>		<input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Inconclusive <input type="checkbox"/> Don't Know	
Lynch Syndrome		<input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Inconclusive <input type="checkbox"/> Don't Know	

If you tested negative for the **genetic mutations** known to increase ovarian cancer risk, has your counselor said that you are at higher-than-average risk of ovarian cancer due to a strong family history?

Yes

No

Don't Know

(If you're uncertain, speak with your counselor.)

What This Means: A Note about Genetic Mutations, Family History, and Ovarian Cancer Risk

- **Women with *BRCA1* mutations** have approximately a 40-percent chance of developing ovarian cancer by age 70. (In individual studies, this chance ranged from 18 percent to 54 percent.) Since a woman in the general population has just a two-percent chance of developing the disease (1 in 50), this means that a woman with a *BRCA1* mutation is 20 times more likely to develop ovarian cancer.
- **Women with *BRCA2* mutations** have approximately a 10-percent chance of developing ovarian cancer by age 70. (In individual studies, this chance ranged from 2.4 percent to 19 percent.) This means that a woman with a *BRCA2* mutation is five times more likely to develop ovarian cancer than a woman in the general population.
- **Estimates of Lynch Syndrome-related lifetime ovarian cancer risk** vary, although one recent article estimates it at 12 percent. This means that women with a Lynch Syndrome mutation are roughly six times more likely to develop ovarian cancer than women in the general population.
- **Women who do not have a mutation** but do have strong family history (defined as one or more relatives who developed the disease) have a lifetime risk of developing ovarian cancer that ranges from 5 to 11 percent.

Age and Family History

Your age: _____

What was the earliest age that ovarian cancer developed in one of your family members? _____

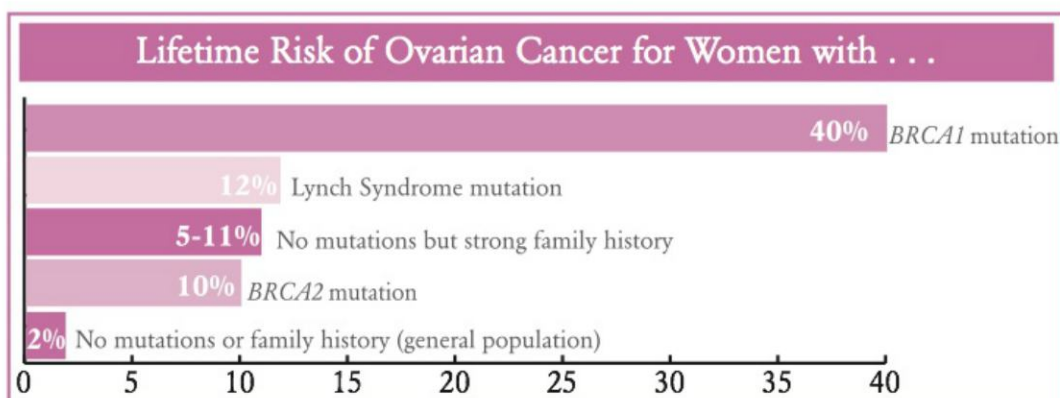
List here the names of family members with known or suspected ovarian cancer and the ages they were diagnosed.

Name	Relation to You	Age at Diagnosis

What This Means: A Note about Age and Family History as Risk Factors

- Simply getting older increases a woman's risk of ovarian cancer. In the general population, most cases are diagnosed after menopause (average age: 62). Women who are considered high-risk are more likely to develop the disease in their mid-40s and 50s – a full ten to 15 years earlier.
- For a woman with a strong family history, experts generally recommend that she compare her own age with the age at which her youngest relative developed ovarian cancer. While she always needs to be vigilant about her risk, it becomes especially important as she approaches that relative's age (within 10 years). For example, a woman in a family where ovarian cancer appeared at age 45 would want to step up her vigilance beginning at age 35.

- The greater the number of relatives diagnosed—and, more specifically, the greater the number of first-degree relatives (mother, sister, daughter) affected—the greater the risk.



Effect of Surgery on Fertility and Menopause

Fertility

Do you want to have children/ more children? _____

If “yes,” you should give very serious thought to weighing this desire against the compelling reasons to have surgery. Removing your **ovaries** will take away your ability to get pregnant.

Menopause

Are you still having menstrual periods? Yes No

Having your **ovaries** removed before going through natural **menopause** (defined as being without menstrual periods for 12 months or longer) will cause immediate **menopause** with a number of possible physical and emotional effects. To read more about these effects, please see Sections 3 & 5.

II. Weighing the Pros and Cons of Risk-Reducing Surgery

The following questions are meant to correspond with the information provided in Sections 2 and 5. You should review those sections if you require more background information about the reasons for and against having risk-reducing surgery for ovarian cancer.

The Status of Your Decision-Making

How soon would you like to make your decision?

(Often there is no definite deadline, but you may wish to set a date with your healthcare team if this is helpful to you.)

Which of the following statements best describes you at this point?
Underline the best choice.

- I have decided to have risk-reducing surgery for ovarian cancer.
- I am pretty sure I will have risk-reducing surgery.
- I am still unsure of my decision, but I am leaning toward risk-reducing surgery.
- I am completely undecided about whether or not to have risk-reducing surgery.
- I am still unsure of my decision, but I am leaning toward not having risk-reducing surgery.
- I am pretty sure I will not have risk-reducing surgery.
- I have decided not to have risk-reducing surgery.

In the space below, write down your most important reasons for this choice.

Reasons for Having Risk-Reducing Surgery

This guide has discussed a number of reasons why women choose to have risk-reducing surgery for ovarian cancer. **Read through the following statements and decide how closely each one applies to you.** Check the most appropriate box for each reason.

Considering your reaction to these statements may help you make a decision. If you find yourself agreeing with most of these statements, you may be leaning toward having surgery.

Reason for having surgery	Agree strongly	Agree	Neither agree nor disagree	Disagree	Disagree strongly
I want a proven strategy for reducing my risk of developing ovarian cancer.					
Worrying about developing ovarian cancer is impacting my quality of life.					
I am more concerned about developing ovarian cancer than I am about the potential consequences of risk-reducing surgery, such as menopausal symptoms, sexual side effects, and increased osteoporosis risk.					
No matter what physical symptoms I may experience after surgery, I am confident I can manage them.					
Risk-reducing surgery will give me peace of mind.					
Risk-reducing surgery will give my loved ones peace of mind.					

Do you have any other reasons for having risk-reducing surgery? List them here.

Reasons for Not Having Risk-Reducing Surgery

This guide has discussed a number of reasons why women choose not to have risk-reducing surgery for ovarian cancer. **Read through the following statements and decide how closely each one applies to you.** Check the most appropriate box for each reason.

Considering your reaction to these statements may help you make a decision. If you find yourself agreeing with most of these statements, you may be leaning away from having surgery.

Reason for not having surgery	Agree strongly	Agree	Neither agree nor disagree	Disagree	Disagree strongly
I prefer to use non-surgical options, such as birth control pills and regular follow-up by my doctor, even though their risk-reduction benefit is not as great as that of surgery.					
I am not worried about developing ovarian cancer, or if I am, it is not impacting my quality of life.					
I am more concerned about the potential consequences of risk-reducing surgery, such as menopausal symptoms, sexual side effects, and increased osteoporosis risk, than about my risk of developing ovarian cancer.					
I am not confident about my ability to manage the symptoms of surgical menopause.					
I am concerned about the impact of risk-reducing surgery on my relationship(s) with my spouse or partner and other family members.					
I prefer to delay risk-reducing surgery to a future date.					

Do you have any other reasons for not having risk-reducing surgery right now? List them here.

III. Next Steps: Putting It All Together

Has considering all of these issues helped you clarify your decision? Explain.

What else do you need before you can make a decision or implement the decision you've made? List your needs here. Examples might include the following:

- Talking with a trained genetics professional again about your family history
- Learning more about the possible effects of risk-reducing surgery
- Doing your own research
- Talking with other health care professionals
- Talking with other women who have had surgery.

What steps do you plan to take now?

IV. Considering the Opinions of Others

Ultimately this is your decision to make, but you may find it helpful to enlist the help of others, if you have not already done so. Consider sharing this worksheet with them as a basis for discussion.

Who is playing an important role in your decision (your doctor, spouse, partner, other relatives, friends)? List them here, and indicate what you believe their current opinions to be:

(1) you should have risk-reducing surgery

(2) you should not have risk-reducing surgery

(3) undecided.

Person's Name	Their opinion about the decision (check one)	Reason(s) behind their opinion (if known)
	<input type="checkbox"/> Have surgery <input type="checkbox"/> Don't have surgery <input type="checkbox"/> Undecided	
	<input type="checkbox"/> Have surgery <input type="checkbox"/> Don't have surgery <input type="checkbox"/> Undecided	
	<input type="checkbox"/> Have surgery <input type="checkbox"/> Don't have surgery <input type="checkbox"/> Undecided	
	<input type="checkbox"/> Have surgery <input type="checkbox"/> Don't have surgery <input type="checkbox"/> Undecided	

V. Case Studies

Below are two case studies, based on real women's stories, which resulted in different decisions about risk-reducing surgery. Although each woman is an individual with her own set of unique circumstances, these stories may help you with your own decision-making.

Case #1: A Decision Not to Have Risk-Reducing Surgery

Donna

Age: 40

Family History: Donna's mother was diagnosed with **stage IIIc ovarian cancer** at age 75 and with breast cancer at age 50; her maternal aunt died of breast cancer in her mid-30s; another maternal aunt is a two-time survivor of breast cancer that occurred before age 50.

Genetic Testing: *BRCA1*-positive

Donna discovered that she carried the *BRCA1* mutation soon after her mother had finished treatment for **stage IIIc ovarian cancer**. She immediately decided that she would have risk-reducing surgery to protect herself against what she had seen her mother go through. She was extremely concerned that her mother, an otherwise healthy woman who always ate well and exercised, had developed ovarian cancer—and breast cancer, earlier in her life—as a result of a **genetic mutation**. Donna was determined to avoid the same experience.

As time passed, however, and Donna's mom finished treatment, her initial certainty about having surgery began to weaken. She reasoned that, if she were going to have surgery to prevent ovarian cancer, she also should consider having surgery to prevent breast cancer (mastectomy, or removal of the breasts), since her family history of that disease was even stronger. However, this was not an option she was willing to consider.

In addition, as she learned about the pros and cons of risk-reducing surgery for ovarian cancer, she began to worry about the effects of **surgical menopause**—especially because she was only 40 and potentially several years away from going through **menopause** naturally. She feared the physical and even emotional effects that such an early **menopause** could cause.

She was also concerned about the impact on sexual intimacy. Donna checked into what medical experts have to say, and she became concerned that there was not enough known about the long-term effects of removing the ovaries before menopause. She went so far as to call some researchers in the field to ask them their opinion on quality-of-life issues after risk-reducing surgery. She also talked to someone close to her age who had undergone the surgery.

Based on her fact-finding, Donna has decided not to have risk-reducing surgery in the near future. While she plans to rethink her decision periodically, she is comfortable with her choice not to have a procedure that may impact her quality of life. Instead, she has chosen to have regular screening as part of a risk reduction study at a major cancer center with a risk assessment program. She understands that the ultrasound and CA125 tests are not perfect, but she likes being followed closely and knowing that she is helping research that could one day benefit her children.

Case #2: A Decision to Have Risk-Reducing Surgery

Ann

Age: 43

Family History: Ann's mother and grandmother had been diagnosed with advanced ovarian cancer in their late 40s; her maternal aunt had breast cancer in her early 50s. Ann was in her mid-20s when her mom was diagnosed.

Genetic Testing: *BRCA2*-positive

Ann was just beginning to start her own family when her mother developed and eventually died of ovarian cancer. She soon found out that her grandmother, who had died of a so-called "stomach cancer," also likely had ovarian cancer. Her mother's sister, with whom she remains close, is a breast cancer survivor.

Given this pattern, Ann decided to have genetic testing at age 41 and discovered that she carries a *BRCA2* mutation. This fact, combined with the experience of losing her mother at such a young age, made her very interested in having risk-reducing surgery. Her daughters were 15 and 13, and she had no plans to have any more children. In fact, she was starting

to look forward to getting them through high school and having more time to spend with her husband. They had often talked about how much they wanted to travel once the kids were in college.

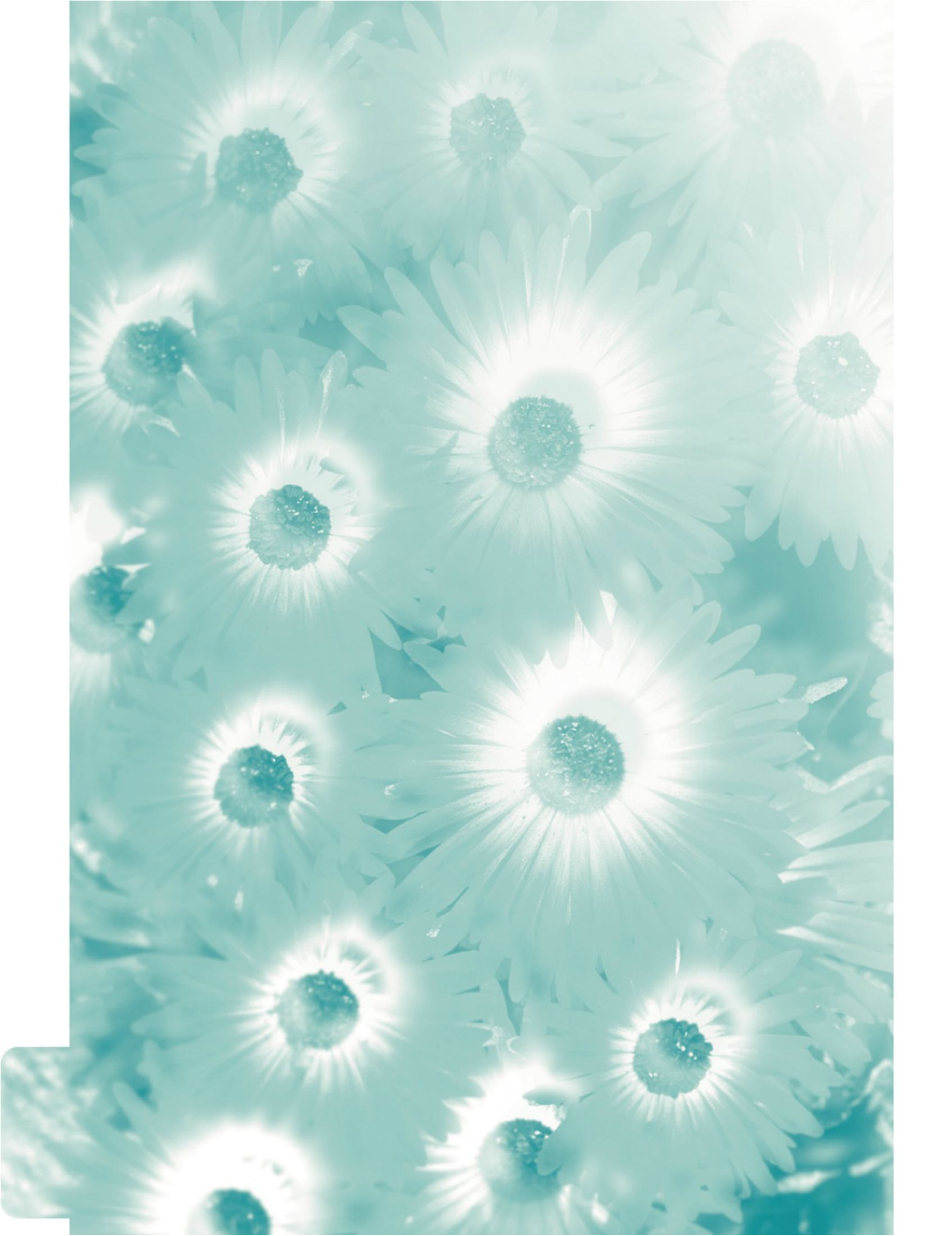
For nearly two years, Ann carefully weighed her decision whether or not to have risk-reducing surgery. She knew that she wanted to be free of the worry she felt over developing ovarian cancer, and she also knew surgery would be the best solution for reducing risk. Seeing her doctor for regular testing, as she was now doing, only seemed to increase her anxiety, not lessen it. At the same time, though, Ann was concerned about the potential effects of surgical menopause. She was already tired from working part-time and raising two children. She was concerned that these effects could disrupt her daily life and her relationship with her husband.

The more time passed, however, the more anxious Ann became over her risk of ovarian cancer—especially because both her mother and grandmother had been diagnosed in their late 40s. In addition, one of her cousins had recently been diagnosed with breast cancer, which made her feel even more anxious. After a number of conversations with her doctor, her husband, and two other women who had undergone surgery, Ann decided to go ahead and have the surgery. She planned it for the summer, just after her oldest child graduated from high school. She reasoned that she would have her energy back in time to help her daughter pack up and move to college. Summertime was also less demanding at work and her daughters' schedules were much lighter, too.

After having risk-reducing surgery, Ann found that she experienced most of the side effects her doctor had warned her about, including pretty intense hot flashes, fatigue, and vaginal dryness. Because she was prepared for them, however, they were not as upsetting as she had imagined. She worked with her doctor to find ways to cope with them. Even more importantly, she felt as if a weight had been lifted off her shoulders. Ann spent less time thinking about ovarian cancer and worrying about whether or not to have surgery. Although she was still concerned about breast cancer risk, she felt comforted by the fact that the surgery also helped to reduce that risk—and that breast cancer was easier to detect at an early stage if it should develop. She finally felt like she could plan for the future without having to look over her shoulder all of the time.

The background of the page is a dense, repeating pattern of daisy flowers. The flowers are rendered in a monochromatic teal color, with lighter shades for the petals and darker shades for the centers. The overall effect is a soft, textured floral pattern.

Glossary



Aerobic exercise: Physical activity intended to increase the heart and breathing rate, which over time makes the body more efficient in absorbing and transporting oxygen. Examples include jogging, swimming, and dance.

Anesthesiologist: A doctor who is specially trained to give anesthesia, a general term for medications that block the sensation of pain and, in some cases, cause a person to become unconscious. During surgery, anesthesiologists are responsible for giving anesthesia and for managing vital life functions, including breathing, heart rhythm, and blood pressure.

Bioidentical hormones: A custom-made formula of various hormones made by a pharmacist that mixes compounds according to a doctor's order. These products come in different forms, like liquid drops, creams, pellets placed under the skin, and in nasal sprays. They are not approved by the Food and Drug Administration, so their safety is not known.

Breast reconstruction: Surgery that rebuilds the breast after mastectomy, either by using a woman's own tissue from elsewhere in the body, or by using an implant.

CA125: A protein found in the blood that is often elevated above usual levels when a woman has ovarian cancer.

CT scan: An imaging test that involves taking multiple x-rays and then reassembling them with a computer to create cross-sectional images of the inside of the body. Also referred to as "computerized axial tomography."

Cartilage: Flexible connective tissue that covers the surfaces of joints, such as the knees, ankles, and elbows. It is also found in the nose, ear, voicebox, windpipe, and some other areas of the body.

Cervix: The narrow, neck-like passage at the bottom of the uterus. It connects the uterus with the vagina, which opens to the outside of the body.

Cholesterol: A soft, waxy substance found among the lipids (fats) in the bloodstream and in all of the body's cells. It is produced by the body and is also present in many foods. Cholesterol is important because it is used to form cell membranes and some hormones, and it is needed for other bodily functions. But a high level of cholesterol in the blood is a major risk factor for heart disease.

Clinical trials: Research studies that involve patients. Generally they are used to evaluate new ways of treating and detecting disease, which may be better than current standard practice.

Clitoris: A pea-shaped structure made up of nerves, blood vessels, and erect tissue that plays an important role in women's sexual arousal. It is partially hidden by the lips of the vagina.

Colorectal cancer: Cancer that starts in the colon or rectum. The colon is the large intestine; the rectum is the lower part of the large intestine. Both play an important role in collecting waste for elimination from the body.

Digestive system: The entire system of organs involved in the digestion of foods. These include everything from the mouth, esophagus (the tube that connects the mouth to the stomach), and stomach to the small and large intestine.

Endometriosis: A condition that occurs when the same type of tissue that makes up the uterine lining (endometrium) starts growing outside of the uterus, attaching itself to other organs or structures in the pelvic region. Symptoms of endometriosis can include pelvic and abdominal pain and heavy and/or unusual uterine bleeding.

Estrogen: A sex hormone found naturally in a woman's body that is produced by the ovaries, the adrenal glands above the kidneys, and other tissues. Estrogen plays a key role in maintenance of many tissues throughout the body. It also plays a role in menstruation (monthly periods) and fertility (the ability to have children).

Fallopian tubes: The two tubes on either side of the uterus that connect it with the ovaries. In premenopausal women, the egg that is released by one of the ovaries each month travels through this tube into the uterus.

Fibroids: Balls of muscular tissue that can grow inside the uterus, on its surface, or inside the uterine wall. In most cases fibroids are not cancerous and require no treatment, and they tend to subside as a woman approaches menopause.

First-degree relative: A term used to describe an individual's parents, siblings, or children—the people who are most closely related to him or her.

Fracture risk: An estimate of how likely a person is to experience the bone breaks that are often a result of osteoporosis, or thinning of the bones. It is typically based on the results of bone density testing and other risk factors for osteoporosis, such as family history, ethnic background, and a thin body frame.

General anesthesia: Giving medication that makes a person unconscious during surgery or some other major medical procedure.

Genes: The units that carry physical characteristics from parent to child. Genes are part of a person's DNA, the chemical that carries instructions for nearly everything cells do and how they develop.

Genetic mutation: An unusual change in a gene that can affect how it functions. Mutations can be inherited (passed down from parent to child) or they can occur spontaneously on their own. Cancer develops when a mutation affects the genes that regulate the growth of cells and keep them healthy.

Genetic testing: A process that involves examining a person's DNA—typically taken from cells in a sample of blood—for mutations linked to a certain disease or disorder.

Hormone replacement therapy: Therapy that gives estrogen alone, or a combination of estrogen and progesterin (an artificially made form of the hormone progesterone), to replace the hormones lost after menopause. Typically it is taken in the form of a pill or of a patch placed on the skin. HRT can reduce menopausal symptoms such as hot flashes, mood changes, insomnia, and lessened sex drive.

Imaging tests: Tests that create images of the body's internal images and structures. Examples include CT scans and ultrasound.

Laparoscopically: Performing a procedure with the aid of a laparoscope, a flexible lighted tube with a fiber optic device that allows the doctor to view inside the abdominal area through small incisions. Surgery performed in this way requires smaller incisions than traditional surgery.

Mammogram: X-ray screening for diagnosis of breast problems, including cancer. It is used to create images of the soft tissues of the breast.

Menopause: When a woman's monthly menstrual periods end permanently, signifying the end of her childbearing years. Menopause typically occurs naturally around the age of 50. However, some women experience menopause earlier due to natural causes or as a result of surgery, illness, or other treatments that lessen ovarian function.

Ovarian cysts: A fluid-filled sac that forms on the ovary. Many ovarian cysts go away on their own. Others can grow large and cause pressure and pain, in which case treatment is needed.

Ovaries: The pair of female reproductive glands in which the ova, or eggs, are formed. The ovaries are located in the lower abdomen, one on each side of the uterus. These 1-inch long, walnut-shaped organs also release hormones that help to control the menstrual cycle.

Pap smear: A test that involves collecting a sample of cells from the cervix to detect the presence of cancer, inflammation, or infection.

Pathologist: A doctor who is specially trained to examine bodily tissues under a microscope for evidence of disease.

Pelvic cavity: The lower part of the inside of the abdomen, which contains the organs that play a role in sex and fertility, such as the uterus and the ovaries, as well as in the collection and discharge of urine, such as the bladder and urinary tract.

Perimenopause: The time before natural menopause, usually beginning three to five years before a woman's final menstrual period. A woman may begin to experience mild menopausal symptoms, such as hot flashes during this time.

Peritoneum: The membrane (thin layer of tissue) that lines the wall of the pelvic cavity next to the ovaries.

Placebo: An inactive pill that is given to one group in a research study in order to measure and compare the effect of medicine given to another group.

Primary peritoneal cancer: Cancer that begins in the peritoneum.

Progesterone (progestin): Produced by the ovaries, rising levels of this hormone signal the body to prepare the uterus with a lining of tissue in preparation for a fertilized egg. If no egg is fertilized, levels of this hormone fall, signaling the body to shed the lining and menstruation to take place.

Randomized trial: A research study where people are assigned by chance to a group, in order to prevent bias.

Risk-reducing mastectomy: Surgery to remove the breast(s) done to reduce the risk of getting breast cancer.

Screening: The practice of regular testing in order to detect a disease such as cancer early, when treatment is more likely to be successful. Examples include mammography for breast cancer, Pap smears for cervical cancer, and colonoscopy (examination of the colon with a small lighted tube) for colorectal cancer.

Second-degree relative: A term used to describe a set of relatives one step beyond the immediate family. Examples include aunts and uncles, nieces and nephews, grandparents, and half-siblings.

Sporadic: A cancer case or pattern of cancer in a family that has no obvious connection to an inherited genetic mutation.

Stage IIIc ovarian cancer: Ovarian cancer that has spread beyond the ovaries and fallopian tubes to form growths on the peritoneum that are larger than two centimeters, and/or has spread to nearby lymph nodes (small oval structures that filter the clear fluid called lymph, help the body fight infection, and form white blood cells).

Stroke: A blood clot or bleeding in the brain that interrupts the flow of oxygen to brain tissues. It can cause permanent damage such as memory loss, trouble speaking, and/or paralysis.

Surgical menopause: Menopause that occurs as the result of surgical removal of the ovaries.

Thyroid gland: Located at the front of the neck, this gland releases the thyroid hormone, which affects the rate at which the body carries on many different important functions. These include the release of growth hormones, heart rate and output, and the processing of proteins, fats, and carbohydrates.

Transvaginal ultrasound: An imaging test that involves placing a probe into the vagina, where it emits high-frequency sound waves. The reflected waves are translated into images of nearby structures on a specialized monitor.

Urinary tract infection: An infection that affects the structures of the urinary tract, such as the bladder, urethra (the tube that carries urine out of the bladder), kidneys, or ureters (tubes that connect the kidney to the bladder). It is caused by bacteria and often produces symptoms such as pain, burning, and urinary urgency (the constant feeling of needing to go).

Uterus: The pear-shaped reproductive organ that carries the fetus during pregnancy.

Vagina: The canal that joins the cervix, or lower part of the uterus, to the outside of the body.

NOTES



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