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PATIENT & CAREGIVER EDUCATION

# Managing Hereditary Breast and Ovarian Cancer (HBOC) Syndrome

This information will help you manage HBOC syndrome (often simply called HBOC).

## About HBOC Syndrome

HBOC is a condition that's caused by hereditary mutations in your *BRCA1* and *BRCA2* genes. A hereditary mutation is a gene change that one or both of your parents passed down to you before you were born.

Normally, your *BRCA1* and *BRCA2* genes help keep your cells from growing and dividing too quickly. They also help fix damaged DNA. When there's a mutation in your *BRCA1* or *BRCA2* gene, DNA damage in your cells might not be repaired. This increases the chance that you'll develop some types of cancer.

## What's my risk for cancer if I have HBOC?

HBOC increases your risk of developing:

- Cancer at an early age
- Breast cancer
- Ovarian cancer
- More than one type of cancer in your lifetime

Breast and ovarian cancer are the most common cancers linked to HBOC. But HBOC can also increase your risk for prostate cancer, male breast

cancer, pancreatic cancer, and skin cancers, including melanoma.

Your cancer risk may depend on which mutated gene is causing HBOC in your family. The type of cancer and the age at which you may get it is different for everyone who has HBOC, even people in the same family.

## **What's the recommended cancer surveillance plan for people with HBOC?**

In general, the best way to protect yourself from cancer is to have regular cancer screenings. This is called a cancer surveillance plan. Following a cancer surveillance plan helps you and your healthcare providers notice the cancer as soon as possible after it develops, while it's easier to treat.

The following information is not a cancer surveillance plan. It's general information about common ways to screen for cancers linked to HBOC. It's very important to talk with your healthcare provider to create a cancer surveillance plan based on your individual needs.

### **Breast cancer**

There are several ways to screen for breast cancer and they may differ depending on your age. Talk to your healthcare provider about when to start breast screening. They include:

- Checking your breast tissue for changes every month. Generally, it's best to check at the same time each month. If you have menstrual cycles (get your monthly period), check at the end of your period.
- Visiting your healthcare provider for breast exams.
- Having breast magnetic resonance imaging (MRI) scans.
- Having mammograms (breast x-rays) or tomosynthesis (special breast imaging scans).

You can also talk with your healthcare provider about having risk-reducing treatment for breast cancer. Risk-reducing treatment is treatment to lower your risk of getting a disease. Risk-reducing treatments for breast cancer include:

- Having a mastectomy. A mastectomy is a surgery to remove your breast tissue.
- Taking selective estrogen receptor modulators (SERMs). SERMs are a type of medication that change how estrogen works in your breast tissue. Estrogen is a female hormone, a chemical that helps different parts of your body know how they should work.

## **Ovarian cancer**

There's no effective screening test for ovarian cancer. Instead of screening for ovarian cancer, talk with your healthcare provider about risk-reducing treatments, and when is the best time to have them. Risk-reducing treatments for ovarian cancer include:

- Taking a combined oral contraceptive (birth control pill with estrogen and progestin).
- Having a bilateral (on both sides) salpingo-oophorectomy (surgery to remove your ovaries and fallopian tubes).

You should also look out for:

- Any unusual bloating.
- Swelling in your abdominal (belly) area.

## **Prostate cancer**

There are several ways to screen for prostate cancer. They include:

- Having a prostate-specific antigen (PSA) blood test every year.
- Having a digital rectal exam (DRE) every year. A DRE is when your healthcare provider feels the surface of your prostate for lumps.

## **Pancreatic cancer**

Generally, people don't need to screen for pancreatic cancer unless one of their family members has had it. If any of your family members have had pancreatic cancer, talk with your healthcare provider.

## **Skin cancers, including melanoma**

There are several ways to screen for skin cancer. They include:

- Looking out for any unusual skin changes, such as:
  - New moles or skin lesions
  - Changes in a mole or skin lesion's shape, color, size, or texture
- Trying not to spend too much time in direct sunlight.
- Protecting yourself from the sun when you're outside (such as by wearing hats, using sunscreen, and wearing sun-protective clothing).
- Visiting a dermatologist (skin doctor) for a total body skin exam every year.

## **What else can I do to lower my risk of getting cancer?**

Following a healthy diet, getting enough exercise, quitting smoking, and reducing the amount of alcohol you drink can help you stay healthy and lower your risk of getting cancer. Talk with your healthcare provider for recommendations to help improve your lifestyle.

Having HBOC means you're at high risk for cancer. It's important that your healthcare team is highly experienced at managing hereditary cancer risk.

## **About MSK CATCH**

MSK CATCH is a clinic for people living with a hereditary cancer syndrome such as HBOC. Our name stands for Comprehensive Assessment, Treatment, and Prevention of Cancers with Hereditary Predispositions, and we're here to be your partner in managing your HBOC while helping you live your best life.

You're only eligible for MSK CATCH if you've already had genetic testing and counseling, so we know surveillance is right for you. To learn more about MSK CATCH, talk with your healthcare provider or read *MSK CATCH: Expert advice on hereditary cancer syndromes*

([www.mskcc.org/pe/msk\\_catch](http://www.mskcc.org/pe/msk_catch)).

If you have questions or concerns, contact your healthcare provider. A member of your care team will answer Monday through Friday from 9 a.m. to 5 p.m. Outside those hours, you can leave a message or talk with another MSK provider. There is always a doctor or nurse on call. If you're not sure how to reach your healthcare provider, call 212-639-2000.

For more resources, visit [www.mskcc.org/pe](http://www.mskcc.org/pe) to search our virtual library.

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