

Your guide to the Hereditary Cancer Program

Providing support and knowledge to help you
choose your personal care plan



What's in the booklet?

The Hereditary Cancer Program	3
Can I have a video consultation instead of meeting in person?	3
What can I expect during my appointment?	4
How do I prepare for my first appointment?	5
What will the team recommend to help reduce my cancer risk?	6
What can I expect after my appointment?	7
What other Kaiser Permanente resources and support services are available?	9
What resources are available in my community?	10
Are there opportunities to volunteer or participate in clinical research studies?	11

Welcome

Learning that you've inherited a high risk of cancer may bring on a rush of emotions for you and your family.

The news might make you feel as if your whole world is changing. Or you may feel empowered – now that something you've suspected has been confirmed, you can take control of your health.

Your Kaiser Permanente care team understands these feelings and is committed to helping you through this journey. This booklet will help you understand what to expect from your first appointment, and the types of discussions you'll have with your doctors. These conversations will help you make informed decisions about the most appropriate care plan for you.

When it comes to managing cancer risk, one size doesn't fit all. Your lifestyle and your personal preferences will affect your care choices. We're here to help you work through these complex decisions so you feel comfortable with your care plan and ready to engage with your health.





The Hereditary Cancer Program

The program is designed for women who have a high risk for breast, ovarian, and uterine cancer – both those who've had a cancer diagnosis and those who haven't – and for those seeking follow-up care. You'll get coordinated care and save time by seeing many specialists during the same visit.

You and your family will work with our multidisciplinary team of medical professionals to personalize your cancer screening schedule and discuss your prevention options. These specialists concentrate on caring for people who face an inherited risk. They can provide valuable information about strategies that could help you reduce your risk or prevent cancer.

There are 6 Kaiser Permanente Hereditary Cancer Program locations in Northern California, which are located in Fresno, Oakland, Sacramento, San Francisco, San Jose, and Vallejo. You're welcome to go to the location most convenient to you.

Can I have a video consultation instead of meeting in person?

If you live far from the clinic or are already getting care at a different location, a video consultation may be a more convenient way to meet your needs.

In some cases, a physical exam might be necessary. If so, you may need to meet with your care team in person.

If you're interested in a video visit, please ask your program coordinator. The coordinator can help you decide what kind of consultation may be best for you.

What can I expect during my appointment?

Before your appointment, your specialists will meet to review your medical records, get input from your genetic counselor, and discuss your situation.



Checking in

When you get to the clinic or start your video visit, you'll check in with our friendly staff and go over the plan for your appointment.



Meeting with your care team

Based on your needs and preferences, you'll meet individually with members of your care team to discuss cancer prevention and risk-reducing strategies. You might be meeting with:



A gynecologist

who will discuss cancer screenings and risk-reducing options, which may include surgery. In-person visits may also include a pelvic exam.

A breast surgeon

who will discuss cancer screenings and risk-reducing options, which may include surgery. In-person visits may also include a breast exam.

A plastic surgeon

who will discuss reconstruction options if you're considering a mastectomy. In-person visits may also include a breast exam.

A genetic counselor

who will review your risk of cancer and explain how this risk can affect your family.

Other caregivers

who may include a nurse practitioner or medical oncologist.

All of these medical professionals have special knowledge and experience to help you make informed decisions about your individual care.



At the end of your visit

Your team will go over your customized cancer risk management plan, based on your conversations during the appointment. You won't have to decide about treatment that day, but you should have the information you'll need to begin thinking through your choices.

Depending on how many specialists you're scheduled to see, your appointments may last up to 2 hours in total.

How do I prepare for my first appointment?

When you schedule your appointment, your program coordinator will discuss any necessary preparations. You may be asked to get a baseline screening, which can include a breast MRI, a mammogram, a pelvic ultrasound, and a blood draw for CA-125. In some cases, these screenings will take place after your visit.

Here are a few other things you can do:

- Write down any questions you may have in the back of this booklet and have it with you during your appointment. You'll get additional information to review at home.
- Ask a support person to be with you during your visit, either at the clinic or during a video visit.
- If you're coming to the clinic, arrive 15 to 20 minutes early to allow time for parking and registration.

“Learning about my increased risk for cancer was difficult because it meant having to face my greatest fears. With Kaiser Permanente’s expertise and guidance, I felt empowered to take an active role in my health. Making decisions about how to deal with my harmful genetic mutation became easier once I had the commitment and support of my health care team.”

– **Kristi B.**, BRCA carrier and “previvor”
(survivor of an inherited risk for cancer)

What will the team recommend to help reduce my cancer risk?

While your care plan will be personalized for you, it's helpful to know some common recommendations from the Hereditary Cancer Program.

During your first appointment, you won't need to make any decisions about acting on these recommendations. There's a lot of information to absorb, so you may want to take time to consider your options before making a decision.

Typical recommendations include:

Screenings



- Breast cancer screening: mammogram and breast MRI
- Ovarian cancer screening: pelvic ultrasound and blood test
- Endometrial cancer screening: uterine biopsy

Lifestyle



- Exercise: 150 minutes per week (30 minutes, 5 times per week)
- Bone health: make sure to get enough calcium and vitamin D
- Alcohol use: no more than one drink per day
- Diet: high in vegetables and fruits, low in fats and sugars
- Weight: maintain a healthy weight
- Menopausal symptoms: how to manage hot flashes and changes in libido and sexuality

Medications (when appropriate)



- Tamoxifen may reduce the risk of breast cancer
- Oral contraception pills may reduce the risk of ovarian cancer
- IUD use may reduce the risk of uterine cancer

Surgery (when appropriate)



- Breast cancer: mastectomy with or without reconstruction
- Ovarian cancer: removal of the ovaries and fallopian tubes (salpingo-oophorectomy)
- Uterine cancer: removal of the uterus (hysterectomy)



What can I expect after my appointment?

At the end of your visit, your team will review your customized cancer risk management plan, based on your conversations during the appointment.

Your care plan will include:

- A personalized schedule for cancer screening
- Risk-reduction recommendations based on your needs and preferences
- Educational resources to take home
- Future appointment plans

Your personal doctor will also receive a summary of these recommendations.

If you wish, we can also refer you to a wellness coach, nutritionist, social worker, or financial consultant.

We want to help you get the support you need. Please see the list of additional Kaiser Permanente services on page 9, and community support resources on page 10.



“After I tested positive for a BRCA1 mutation, I was initially in denial and feeling scared about the future. Scheduling my first visit with the cancer risk clinic helped me feel more proactive about taking control of my health.”

– **Carol J.**, BRCA carrier and “previvor”
(survivor of an inherited risk for cancer)

What other Kaiser Permanente resources and support services are available?

You have access to a variety of resources that are available online and in person. The program coordinator or other members of your care team can help connect you with services, including:

The Kaiser Permanente Genetics Department

mydoctor.kaiserpermanente.org/ncal/specialty/genetics

Our Genetics Department in Northern California can help you understand the influence of genetics on your health. For hereditary cancer resources, click the “Hereditary Cancer Program” link in the Multi-Specialty Programs section.

Managing menopause symptoms

kpdoc.org/menopauseandcancer

Get information about managing menopause symptoms if you’ve had cancer or cancer prevention treatment, or if you’re at risk for cancer.

Health education and wellness resources

healthy.kp.org/northern-california/health-wellness

Choose from a variety of on-site classes, personalized coaching, and online programs.* They’re designed to help you increase your activity level, lose weight, lower stress, eat healthier, and more.

*Some classes may require a fee.

What resources are available in my community?*

Facing Our Risk of Cancer Empowered (FORCE)

facingourrisk.org

Provides support, education, and awareness to help those facing hereditary breast, ovarian, and related cancers. Has a free Peer Navigation Program that connects you with someone who shares a similar journey.

Bright Pink

brightpink.org

A national nonprofit organization focused on prevention and early detection of breast and ovarian cancer in young women. Bright Pink offers both one-on-one peer support and an online support community for cancer survivors and women at increased risk of cancer.

Bay Area Cancer Connections

bayareacancer.org

Offers one-on-one support, social activities, and a variety of support groups for people affected by breast or ovarian cancer, and provides access to breast-screening MRIs at no cost to income-eligible people in the Bay Area. The Buddy Program connects cancer survivors with someone who's had a similar diagnosis or treatment experience.

AliveAndKickn

aliveandkickn.org

A national nonprofit advocacy organization supporting individuals and families affected by Lynch syndrome. AliveAndKickn offers peer-to-peer support specifically for the Lynch syndrome community.

*Kaiser Permanente does not endorse the organizations mentioned. Any trade names listed are for easy identification only.

Are there opportunities to volunteer or participate in clinical research studies?

Research and clinical trials

When you volunteer for a research study, you may help deliver the many benefits of health research: discovering the causes of disease, developing new treatments, and improving the quality of medical care.

The Kaiser Permanente Hereditary Cancer Program is actively involved in research and clinical trials related to gynecologic and breast cancer. Many of the research studies include women who are at inherited risk for cancer.

A sample of research includes:

- MRI surveillance for women at increased risk for breast cancer
- Breast cancer in men
- Menopausal quality of life and other health outcomes in women with BRCA2 who undergo a risk-reducing salpingo-oophorectomy
- A national clinical trial involving removal of fallopian tubes with delayed removal of ovaries for ovarian cancer prevention in female carriers of BRCA1 mutations
- Novel method of biomarker sampling with uterine wash for early detection of ovarian cancer in women with BRCA1 and BRCA2 mutations

If you're interested in learning more about research studies, let one of your care team members know. Ask what's available within Kaiser Permanente. There are clinical trials for women with cancer as well as for cancer survivors. You can also search **ClinicalTrials.gov** to find trials for which you may be eligible.

Share your insights

Would you like to help us improve the care experience for Kaiser Permanente members with an inherited cancer risk? We're looking for patient advisors to:

- Help us ensure a compassionate approach to discussing treatment options
- Share perspectives as we design educational materials and support services
- Offer ideas on how we can best communicate with our members
- Support women who'd like to talk to someone who has walked this path before

We meet one hour per month in an online conference call. Contact your program coordinator to learn more.

Notes

A series of horizontal dotted lines for writing notes.

