



Talking with Your Genetic Counselor

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KNOW BEFORE YOU GO

Keep in mind that a genetic counselor's role is to help you make decisions that are both right for you and fully-informed. What does this mean?

- You won't be getting clear-cut directives—instead you'll get guidance based on the information you provide, which might include referrals to specialists.
- When it comes to recommended medical care, the counselor will likely refer you to a physician (for instance, a breast surgeon or a gynecologic oncologist).
- You can expect to talk about how certain medical decisions will mesh with your lifestyle, personality and individual circumstances.

WHAT IS YOUR EXPERIENCE WITH PATIENTS LIKE ME?

- Are you accredited by the American Board of Genetic Counseling (ABGC)?
- How long have you been a genetic counselor? Do you specialize in cancer genetics?
- Have you worked with other women who are at high risk for breast and/or ovarian cancer?

HOW DO I GET STARTED?

- How can I make sure I have the most helpful information about my family's medical history? What specific questions should I ask them?
- Do you have any good ways to spark discussions with my relatives about our medical history?

WHAT DOES MY FAMILY TREE SAY ABOUT ME?

- Based on my family history, what's my projected risk for developing breast and/or ovarian cancer? How does this compare with the average woman?
- If someone in my family has tested positive for a known genetic mutation, what are the chances that I'm also a carrier?
- What plan would you recommend for me, based solely on my family history? If I test positive for a genetic mutation, would that change your recommendation?
- Is DNA banking something my family should consider?

SHOULD I UNDERGO GENETIC TESTING?

- What are the pros and cons of genetic testing? Medically? Emotionally?
- How would having a genetic mutation affect my risk for breast and ovarian cancer?
- Who in my family should ideally be tested first?
- If I test negative, what are the chances that someone in my family still might be a carrier, based on my family history?
- If I test negative, what would my risk for breast and ovarian cancer be?

WHAT DO I NEED TO KNOW ABOUT INSURANCE & LEGAL PROTECTIONS?

- How much will it cost me? Will my insurance cover it? If so, how much? If my insurance doesn't cover it or if I'm not insured at all, are there any financial assistance programs that I qualify for?
- If I test positive, could I be discriminated against? What are the legal protections against genetic discrimination when it comes to health insurance, employment or life insurance?

NOTES

This guide was authored in collaboration with Dina Roth Port, author of the book *Previvors: Facing the Breast Cancer Gene and Making Life-Changing Decisions*.

BRIGHT PINK is a national non-profit on a mission to save women's lives from breast and ovarian cancer by empowering them to live proactively at a young age. For more information or to get involved, visit BrightPink.org.

