



HCP and patient portrayal

A Black Woman's Guide to "The Breast Cancer Talk" With Doctors

Talking with your doctor about a breast cancer concern can be very scary, especially for Black women like us.

Here is a guide with advice from Novartis advisor, Dr. Monique Gary, to help you with what to expect – and what not to accept – during your visit at the doctor's office. We also recommend bringing a loved one or care partner with you to your appointment for additional support.

What's Your Risk?

As an initial step to better understand your own breast health, you can use one of the following tools and share what you learn with your doctor*:

- [NIH Risk Assessment Tool \(The Gail Model\)](#)
- [Black Women's Health Study Risk Calculator](#)
- [Tyrer-Cuzick Risk Assessment Calculator](#)

Risk assessments are tools that predict your risk of developing breast cancer, based on information about your medical, reproductive, and family history. Even if you don't have a family history of breast cancer, there are other risk factors that you may not be aware of. The more you know about your risk, the more you can advocate for your care.

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Dr. Gary was compensated by Novartis Pharmaceuticals Corporation.

Did you know Black women are **41% more likely** to die from breast cancer than white women?¹

Considering this and many more unfortunate statistics, it's critical for Black women and their providers to have a strong trusting relationship.

Yet, only 3% of practicing oncologists are Black.²

So, it's quite likely you are working with doctors who may not share your background or culture. Dr. Gary shares that this may contribute to moments of miscommunication and create a barrier to access consistent, high-quality, and culturally competent care.

We hope this guide will help you have more productive and meaningful conversations with your care team.



Do you feel you have a trusting relationship with your doctor?

The standard-of-care should *feel like* your doctor is treating you as they would their respected friend or acquaintance. It doesn't mean treatment will be easy, but it means that you should feel confident in your team and the plan they have created from shared decision making with you. Here are some tips to help ensure you get the optimal care you deserve.

- **Make a list of key questions** to discuss with your doctor during your appointment and ask follow-up questions, if needed
- **Invite your doctor to view things from your perspective** (or your loved one's perspective. This might sound like: "What questions or concerns would *you* express if you were in place of my loved one here today?")
- **Mirror or repeat important topics from your discussion** with your doctor to help you better absorb what's being said during your appointment
- **Take notes or pictures** of what you discuss with your doctor, including their recommended care plan and next steps
- Ask your doctor if they have different considerations for **testing, treatment, and clinical trial enrollment based on data for Black women**
- **Bring a caregiver, loved one, or friend with you** for emotional support and to help capture anything you may miss during your appointment. Studies show that physicians spend more time explaining care and answering questions when an advocate is present³
- Ask your doctor for **resources to review after your appointment**



Musts at your doctor visit

If any of these steps aren't addressed, feel empowered to ask your doctor for them at your primary care visit:

1. A thorough breast exam

- If you have an unusual physical breast exam, your health care team should order a mammogram.
- If you are at a high risk of breast cancer, your provider should also order a mammogram and possibly other imaging tests, as indicated by NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®), which are evidence-based medical recommendations for the diagnosis, treatment, and supportive care for cancer patients.⁴
- The NCCN Guidelines® also recommend that women should begin annual screening mammograms at age 40 if they are at average risk.⁴

2. Family history/genetic testing discussion

- If you have family history of breast cancer, ask your doctor if genetic testing could be an option. Genetic testing can help detect gene variations that raise one's risk of developing breast cancer.⁵ However, if you don't have or are unaware of family history, you may still be at risk! Only 5-10% of all cancers are hereditary, so it's important to continue regular preventative measures.⁶

3. Ordering of additional imaging & testing (scans/3D imaging, ie, MRI, CT scan, etc)

- For women with extremely dense breasts, it is recommended that annual mammography screenings be paired with a supplemental screening. Supplemental screening should be considered for women with heterogeneously dense breasts.⁴
- Denser breasts can make it harder for doctors to see breast cancer on mammograms. This increases the risk that cancer could be missed, so a supplemental screening could give your provider a clearer picture to ensure you've been thoroughly and accurately examined.⁷
- If you have an unusual diagnostic breast exam (ie mammogram) your health care team should order a biopsy. Do your best not to let this overwhelm you; this is just another step in taking control of your breast health!

There may be conversations that seem invasive or uncomfortable. Here are some topics your doctors should discuss with you that may be important for your breast health care.

Breasts

The density of your breasts can determine the type of imaging you may need and be offered. Doctors should be having a conversation with you about breast density. If your breasts are very dense, you may need more frequent screening, or you may be prescribed a 3D mammogram, whole breast ultrasound, or possibly magnetic resonance imaging.^{7,8}

If you have dense breasts *and* a family history of breast cancer, you could be at increased or high risk for breast cancer.⁹ There are special programs to support you with risk reducing strategies. Talk to your doctor about determining your individualized risk, and if you haven't used a risk calculator, ask them to help you.

Overall Health

Your doctor should focus on your overall wellness including, but not limited to, weight. While it is standard for offices to record your weight and body mass index (BMI) as per medical guidelines, your doctor should also be asking about your daily practices, activity levels, and lifestyle habits you feel motivated to make. They may have resources like nutritional consultants, smoking cessation support, or weight management specialists to help you achieve your goals.

Family History

Doctors will often ask you about your maternal and paternal family medical histories. It's okay if you don't have access to that information. But it's crucial to ask your family, and there are resources available to help you navigate difficult conversations about family health history.¹⁰ If family members are inaccessible, you can ask your doctor about your options for genetic testing to help fill in those gaps.⁵



Time for Q and A

A follow-up plan

- You should also ask your team when to schedule follow-up imaging after receiving the results of your diagnostic imaging or biopsy. Do you return to annual screening or will short-term follow-up imaging be recommended?
- If something unusual has been found, ask for an explanation of whom you should consult next (ie, surgeon, oncologist, oncology nurse, nurse navigator) and how they will play a role in your care.

What if cancer is detected?

Take your time to process your feelings.

This is a time when you need people who love you around you. Think about whom you would like to be part of your care team and ask them to either come with you to your doctors' appointments or call them on speaker phone to help you capture what your doctor is saying.

The information you will receive about your diagnosis and treatment is important, which is why you should feel empowered to ask your loved ones for help capturing it all. Whenever possible, please bring a friend, family member or someone with you to your appointment for support and to help advocate on your behalf.



Some questions you can and should ask your care team if breast cancer is diagnosed

Please explain what you know about my diagnosis

- Your tumor stage. This may include information about its size, whether it has impacted lymph nodes or other organs, etc.
- Your tumor subtype: Is your tumor hormone-receptor positive or negative? Does it express HER2? Is it “triple negative”? What do these terms mean for your treatment?
- Ask your doctor about both genetic and genomic testing to help know more about your diagnosis and potential care.
 - Genetic testing can help identify inheritable genes, while genomic testing, once diagnosed with cancer, examines a sample of the cancer tissue to assess the activity of certain genes. This activity level can help predict the likelihood of the cancer growing and spreading, informing your long-term treatment plan.^{10,11}

What should I expect next in my care?

- Your doctor should provide a full care roadmap. Ask them to make it visual, so you can take pictures and refer back to it later. Ask your doctor to point you to available resources, including those developed by patient advocacy organizations.
- If there are discussions about surgery (ie, lumpectomy or mastectomy), ask your doctor about reconstructive surgery and how to integrate it into your care plan.
- Don't count yourself out — there are reconstructive options for breast conserving surgery that can include reduction, augmentation, and symmetry procedures, in addition to mastectomy reconstruction with implants or other tissue.¹² Explore your insurance coverage; it is possible that these procedures may be covered as part of your care plan.

Discuss treatment goals and priorities

- Ask your doctor about the proposed treatments and why they are being recommended to you. They can show you the guidelines that are the basis for their treatment recommendations to help you feel more confident in the plan.
- How can the treatment(s) control the disease?
- What can you expect in terms of side effects? Is there a way to manage them?
- Can they recommend any integrative therapies to support your nutritional, emotional, and physical well-being?
- If you have goals to start or continue a family, express that to your provider, and ask how you can take efforts in preserving your fertility before making treatment decisions so you can consider all of your options.

Is a clinical trial an option for you? Why or why not?

- Ask your doctor about clinical trials as a treatment option. Ask about how the process works, including informed consent, opt-out, and oversight.

Can they provide additional support, including:

- Contacts with other patients or with patient support groups?
- Help understanding your insurance coverage and determining which care is in or out of ‘network’?
- Patient navigation?
- Financial navigation?

Your doctor should graciously answer your questions, even repeat questions.



Questions to ask if you feel like your doctor is dismissing your concerns

- “Should we look at this further with imaging (scans, tests)?”
- “How can we be sure (that it is/is not a concern)?”
- “When can we have a follow-up exam or appointment?”
- “Is this included in the medical guidelines? Where?”
- “Are there any options to modify my treatment plan if I'm finding my side effects too hard to tolerate?”



Need more time?

At the end of your appointment, there should always be time for feedback, questions, and answers. While oftentimes doctors and other members of your health care team have several patients booked in a day, and they may also try to complete notes about your visit, you should not feel rushed. If you feel that your needs are not being addressed, here are some ways to ask for more time or clarity.

- **“Can you pause from your notes for a minute?”**
Then, ask your follow-up questions.
- **“Can you explain to me what I should expect between now and our next visit?”**
- **“What I’m hearing you say is…”** Then repeat what you are hearing in your own words.
- **“I need a little more time, can we schedule a follow-up?”**
- **“Does your office offer any assistance to locate support groups or more resources?”**
- **“Is there anyone on your team that could help me navigate my next steps after this visit?”**



Do you feel uncertain about your provider?

Unfortunately, there are times when a health care professional may not be the right fit for you. If something is making you feel uncomfortable, don’t be afraid to trust your gut. Your feelings are valid, and it’s okay to seek a second opinion or find a different doctor.

Here are some examples of red flags that may be a sign that you should seek a second opinion.

- **Insensitive comments**
- **Assumptions based on race or gender**
- **Expectations that you should be able to endure discomfort or pain**

About Novartis

We are committed to help improve patient outcomes in breast cancer care, including in the Black community, where there is significant unmet need. We work with leading multidisciplinary experts to raise awareness and create solutions to help Black patients, and their providers better navigate together through the continuum of breast cancer care.

To learn more, please visit novartis.com/us-en/MTJWPatient.

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