

Breast Health Resource Document

Table of Contents

- Discussing Your Breast Health with Your Provider
- Performing a Breast self-Exam
- Navigating Mammogram Coverage and Cost
- Screening Anxiety: Facts to Know
- Participating in Clinical Trials

If You Receive a Breast Cancer Diagnosis:

- Preparing Questions for Breast Cancer Appointment
- Breast Cancer Trials
- Where Can I find Support?
- Wellness Resources
- How to Support a Loved One

Discussing Your Breast Health with Your Provider

BEFORE THE APPOINTMENT DURING THE APPOINTMENT AFTER THE APPOINTMENT



CHOOSE A PROVIDER

Consider your values, goals, and priorities and choose your provider accordingly. The person in charge of your breast health can be a primary care provider, general practitioner, ob-gyn, etc.



MAKE AN APPOINTMENT

Meet with your provider in a timely manner to discuss your breast health and prevention strategies.



GATHER INFORMATION

Gather information about your breast cancer risk factors. For those in the WISDOM study, make sure to bring your screening recommendation letter, your responses to Breast Health Questionnaire (BHQ), genetic testing results (if you are in the personalized group), and Breast Health Decisions (BHD) tool (if applicable) to your appointment. If you are not in the WISDOM study, be prepared to discuss your family history of cancer, lifestyle choices, etc. Click [here](#) to see a potential list of questions your doctor might ask you.



PREPARE QUESTIONS

Write down questions you have about your breast health. You can ask your provider about different screening approaches, breast cancer prevention strategies, etc. Click [here](#) to see a potential list of questions you can ask to your breast health provider.



DISCUSS THE SCREENING RECOMMENDATION

Have a discussion with your provider about the risks and benefits of screening based on your level of risk. If you are a WISDOM participant, share your screening assignment letter with your provider.



DISCUSS GENETIC TESTING RESULTS/OPTIONS

The genetic testing can affect prevention strategies by revealing if you are at increased risk of breast cancer due to your genes. If you have genetic test results from the WISDOM study, discuss the findings with your provider. Otherwise, ask your provider about genetic testing to determine if it is applicable to your breast health decisions.



DISCUSS RISK REDUCTION MEDICATIONS

Endocrine risk reduction medications decrease the levels of estrogen in your body. This reduces the likelihood of developing the type of breast cancer that requires estrogen for growth. The risk reduction medications are recommended for women with high risk by [the United States Preventative Task Force](#). To decide whether these medications are right for you, have a discussion with your doctor and carefully consider the risks and benefits.



DISCUSS LIFESTYLE CHOICES

[Diet](#), [alcohol](#), and [exercise](#) have been shown to impact the risk of developing breast cancer. Talk to your doctor to learn more about how you can make healthy lifestyle choices.



FOLLOW THE SCREENING RECOMMENDATIONS

If you are in the WISDOM study, follow the screening recommendations provided in your letter. If not, follow the recommendations given by your provider.



NOTE UPDATES TO YOUR BREAST HEALTH

If there are changes to your breast cancer risk, (i.e., your family member got diagnosed with breast cancer), make sure to provide updates to the WISDOM study as well as your provider. Also inform your provider about any updates on your lifestyle, goals, or priorities. This is important since these changes might affect the screening recommendations. Seek additional help if your provider can no longer provide appropriate guidance.



PERFORM SELF-EXAMS

Continue to monitor your breast health by routinely performing [breast self-exams](#). If you notice anything suspicious, make an appointment with your provider.



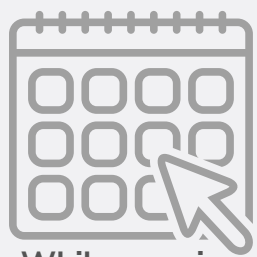
GET A SECOND OPINION

If you feel uncertain about the guidance provided by your provider or would simply like to get more information on your breast health, do not be afraid to get a second opinion.

Performing a Breast Self-Exam

The self-detection is one of the most common ways breast cancer is identified. In fact, 25% of breast cancer survivors detect breast cancer themselves. Therefore, you should know key physical signs of breast cancer and perform regular breast self-exams to inspect your breasts.

Examine your breasts on a monthly basis and keep track of changes in your breast health

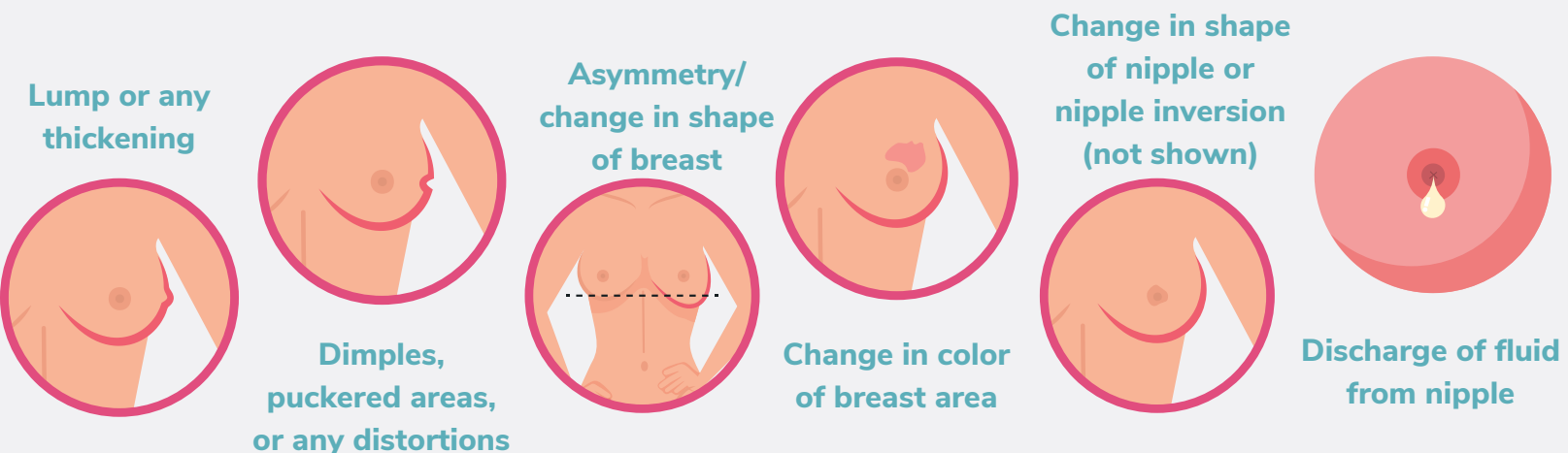


Once a month, preferably a week after the last day of your period, examine your breasts 1) in front of a mirror to look for visual changes, 2) in the shower with soapy hands to feel tactile changes, 3) while lying down when your breast tissue is spread out, making it more feasible to examine all areas. Inspect your breasts in a circular motion, from the nipple to outer regions of your breast.



While pressing on your breasts, alternate between applying low, medium and high pressure with pads of your fingers. This will allow you to examine all the tissues in your breast. Note any changes to your breast appearance.

What to Look for When Performing a Breast Self-Exam?



Also look for symptoms, such as pain, redness, itching, and rashes

Having one or more of these features on your breasts does not mean you have a breast cancer. However, if you notice something abnormal, make an appointment with your breast health provider and have your breasts examined by them.

NAVIGATING MAMMOGRAM COVERAGE AND COST

Information about Mammography Screening Coverage:

If you have insurance:

- The Affordable Care Act, passed in 2010, requires most health insurers to cover mammography screening at least biannually with no cost sharing under the Health Resource Services Administration guidelines.
- If you are concerned with whether your insurance covers your mammogram, please call your health insurance company to verify their specific policies.

If you don't have insurance:

- There are several resources if you do not currently have health insurance.
 - If you are currently uninsured, and your income is $\leq 250\%$ of the federal poverty level, and are between 40-64, you may qualify for free or low cost screenings in your state. Visit this [link](#) to learn more about services available in your area.
 - Other resources that offer financial assistance or access to free mammograms include but are not limited to:
 - [Susan G. Komen Foundation Affiliates](#)
 - [American Cancer Society](#)
 - American Breast Cancer Foundation
 - [Planned Parenthood](#): Can often refer you to low-cost imaging centers.
 - Other local organizations in your area

Screening Anxiety: Facts to Know

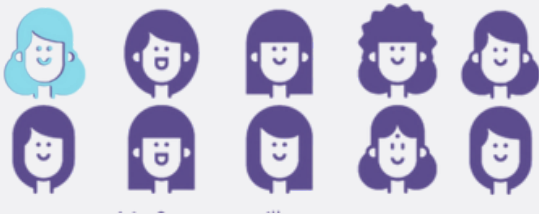
Breast cancer screening can cause anxiety, whether you're waiting for your results or if you are told to come back for additional testing. Luckily, most of these additional tests turn out to be benign, or false positive results. Here are few things you should know to help reduce screening anxiety.

1) How often do mammograms indicate an abnormality when there is really no cancer? Such a scenario is called a false positive result. The likelihood of a getting a false positive result is 61% with annual mammogram screening.

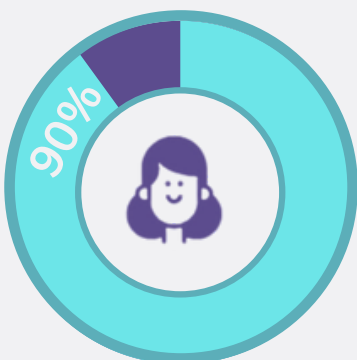
2) Why are you called in after your mammogram? This can be due to one of the reasons listed below:

- Blurry image (this can be caused by dense breasts)
- Calcifications or a mass (cyst or solid mass)

3) How often do women get called back for additional testing?



On average, about 1 in 10 women will be called in for further testing after a mammogram, but majority (>90%) of these women do not have cancer.



4) What additional tests are performed if you are called back? One or many of the tests listed below can be performed:

- Further imaging (i.e., diagnostic mammogram, MRI, ultrasound, etc) to obtain more detailed images of breast area
- Biopsy = removal of breast tissue to examine cells under microscope.

5) If I need biopsy, does it mean I have cancer? No, most women who have breast biopsy do not have cancer. This will be noted as a negative or benign result in your summary of the findings. The timing of results will depend on your facility (usually few days to more than a week).

6) What to do while waiting for results? The waiting period can be stressful. To help ease your anxiety, return to your daily activities, focus on other priorities, and spend time with your friends and family.

7) Good news! Your results are negative. What should you do to continue monitoring your breast health?

- Ask your doctor about next steps and follow the screening recommendations
- Be in tune with your body and perform routine breast self-exams

7) What should you do if your biopsy shows cancer? If you feel overwhelmed by your breast health update, talking to a patient navigator or a patient advocate in your medical facility can help. If this service is not available to you, reach out to the WISDOM Study. We will try our best to connect you to our patient advocates who will guide you through your concerns and help you communicate with your doctor.



Participating in Clinical Trials



"Clinical trials are tomorrow's treatment today" -
Dr. Laura J. Esserman, MD, MBA

What are clinical trials?

Clinical trials are **research studies** designed to find **safe and better ways** to prevent, find, diagnose, treat, manage symptoms, improve care and quality of life. We cannot **make a progress** and **learn something new** without conducting clinical trials.

Why are clinical trials important?

By participating in the clinical trial, you can 1) **contribute to the knowledge** about breast health and benefit future individuals or 2) receive an **innovative treatment** that might be better than the standard of care.

How do clinical trials work?

Who can participate in clinical trials?

- Healthy women
- Women diagnosed with cancer

How is participant safety ensured during the study?

- Clinical trials are reviewed by experts to ensure participants are protected
- Participants sign the consent form that explains risks and benefits of participating
- Participants receive close attention and follow-up

What types of clinical trials exist?

- Cancer Prevention
- Screening
- Treatment
- Supportive Care
- Quality of Life Studies

What are factors to consider before choosing a clinical trial?

- Eligibility, location, study format (in-person vs. virtual), cost of traveling, time commitment, etc.



To find a clinical trial for you/your loved one, please visit:

[breastcancertrials.org](https://www.breastcancertrials.org)

clinicaltrials.ucsf.edu

[clinicaltrials.gov](https://www.clinicaltrials.gov)

If You Receive a Breast Cancer Diagnosis

PREPARING QUESTIONS FOR YOUR BREAST CANCER APPOINTMENT



TOPICS TO CONSIDER



ORGANIZING YOUR QUESTIONS IN CATEGORIES IS HELPFUL!



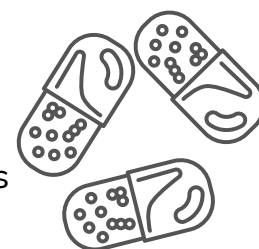
1) DIAGNOSIS

Discuss your diagnostic results, such as your pathology report and other test reports. This will help you learn about the specific type of breast cancer you have.

Example: Is my cancer hormone positive? Is my cancer fast-growing or slow-growing?

2) TREATMENT OPTIONS

Your breast cancer treatment may include several components, such as surgery, radiation therapy, systemic therapy (i.e., chemotherapy, endocrine therapy, immunotherapy), etc. Each of these procedures and treatments have options and the order in which they occur can differ from one patient to another. Asking about options and the sequence of therapies can help you make the best decision for yourself.



Example: Is chemotherapy recommended for me? Are there trials I can enroll in?

3) QUALITY OF LIFE



Before making a decision, discuss long term vs. short term side effects and symptom management with your doctors. Make sure to communicate your goals, hopes, and priorities to your providers.

Example: How can I manage hair loss? My son's graduation is in May. Will I be able to attend it with the current treatment regimen?

4) MEDICAL PERSONNEL

Discuss the roles and responsibilities of people involved in your care (i.e., surgeon, oncologist, radiologist, nurse, etc). If you do not feel comfortable with your care team, do not be afraid to get a second opinion and change your providers.



Example: Who can I talk to about managing symptoms? Who can I call in case of emergency?

Click [here](#) to view a list of example questions for your breast cancer care team!






BREAST CANCER TRIALS



[Breastcancertrials.org](https://breastcancertrials.org) helps women and men diagnosed with breast cancer learn about all their clinical trial options. Our national nonprofit offers the unique service of summarizing each clinical trial into easy-to-understand, patient-centered language. We provide free matching services to people with DCIS, stage I-III, and metastatic breast cancer. We strive to help everyone affected by breast cancer understand the variety of clinical trials available and what to expect if they choose to enroll.

Trial Matching in 3 Steps

-  **Enter your health history**
-  **Receive a personalized list of trials**
-  **View research site information**

Factors to Consider When Choosing a Trial

- Is the clinical trial a right match for your type of cancer?
- Are you eligible for participating in the study?
- What is the location of the study? Will you need to travel? If yes, what are the costs?
- What are the risks and benefits of participating?
- Will you need to take time off from the job?
- Will you need to make family arrangements (i.e., child care)?
- Will your insurance cover the cost of participating?

Please visit:

[Breastcancertrials.org](https://breastcancertrials.org)

Please contact:

Help-Desk@bctrails.org

Wisdom
thewisdomstudy.org

APPOINTMENT RESOURCES

QUESTION-LISTING HELP

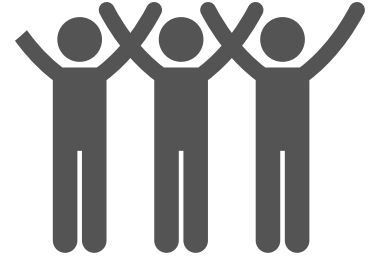
- **Open to Options:** (www.cancersupportcommunity.org/open2options)
- **The Cancer Support Community** offers a question-listing program available through the Cancer Support Helpline at 1-888-793-9355.
 - The phone consultation is offered in both English and Spanish and takes 45-60 minutes to complete.

SMARTPHONE APPS FOR RECORDING, QUESTION-LISTING

- **Appointment Buddy:** www.appointmentbuddyapp.com/
 - This free iPhone app allows you to record audio, take pictures, and write notes for your appointments. No need to register; simply download the app and begin organizing appointments. Recordings, notes, and pictures can be emailed to others in compressed files. The app does not help build question lists.
- **Medcorder:** <https://www.medcorder.com/>
 - This free app allows you to record, securely backup, transcribe, and share doctor consults with loved ones to make better medical decisions together. Automated transcriptions are free and processed immediately in-app for easy sharing.
- **Abridge** (on Apple Store and Google Play)
 - <https://apps.apple.com/us/app/abridge-record-doctor-visits/id1446432189>,
 - https://play.google.com/store/apps/details?id=ai.abridge.nativeclient.release&hl=en_US)
 - This free app allows you to record, replay, and share* recordings of doctor consults.
 - Recordings can only be shared in the app.
- **Rev Voice Recorder** (<https://www.rev.com/voicerecorder>)
 - This free app allows you to record and listen to audio, organize and share the recordings, and order voice-to-text human transcriptions at a rate of \$1/min. Available for iPhone and Android.
- **Temi Recording app** (<https://www.temi.com/>)
 - This free app lets you record, edit, and share audio. You can request automated transcriptions for \$0.10/minute. Available for iPhone and Android.

WHERE CAN I FIND SUPPORT?

COMMUNITY



- Support Groups
 - Talk to your care team, hospital social worker, and other survivors of cancer for local resources.
- Family and friends
- Spiritual services
- Online forums
 - **Living Beyond Breast Cancer** (<http://www.lbbc.org/>)
 - Offers information for newly diagnosed, for young women, LGBT women, African-American women, women with triple negative disease, women living with metastatic breast cancer, and many more.
 - **Smart Patients** (www.smartpatients.com)
 - An online community where patients and caregivers learn from each other about treatments, clinical trials, the latest science, and how it all fits into the context of their experience.
 - **EngagedPatients.org** (<http://engagedpatients.org/>)
 - A national campaign with the vision that all patients and their loved ones have free access to the tools and the resources they need to be fully informed and participating members of their health care teams
 - **The Cancer Support Community** (<https://www.cancersupportcommunity.org/find-support>)
 - Offers support and information in many formats.

PROFESSIONAL HELP



- Helplines
 - The Peer Support Program (<http://cancer.ucsf.edu/support/crc/peer-support>)
 - Can match you by phone to a cancer survivor who had a similar cancer diagnosis, treatment, or circumstances. 415-885-7210
 - The Toll-Free Cancer Support Helpline is open Mon-Fri 9 am- 9 pm ET 1-888-793-9355.
 - They have locations worldwide and have an online community Living Room.
 - **After Breast Cancer Diagnosis (ABCD)** (<http://www.abcdbreastcancersupport.org>)
 - Provides a helpline and one-on-one peer support to patients, families and friends by telephone. 1-800-977-4121
- Counseling
 - Call your insurance company or look at Psychology Today (<https://www.psychologytoday.com/us/therapists>) or Psychologist Locator (<https://locator.apa.org/>) to find providers
 - Learn more at: <https://www.cancer.net/coping-with-cancer/finding-social-support-and-information/counseling>
- **Psycho-oncology**: focuses on the emotional and social effects of a cancer diagnosis
 - Psycho-oncology services are tailored to help you cope with your diagnosis

WHERE CAN I FIND SUPPORT?

EVENTS



- Events provide a way to find trusted information on your diagnosis, treatment, how to take care of yourself, and more. These events can be tailored towards specific groups and types of diagnosis.
 - You can meet new people and community, and learn how to get more involved.
 - Talk to your care team, provider, or social worker to find local support groups and resources such as nutritional workshops, exercise groups and workshops, and educational webinars
- Check out these organizations for events and resources:
 - [FORCE](#), [Susan Love Foundation](#), [Share Cancer Support](#), [Sharsharet](#), [Tigerlily Foundation](#), [Touch the Black Breast Cancer Alliance](#)

GET INVOLVED

- Getting involved in breast cancer research and support can help you find people with the same passions and experiences as you.
- You can get involved by:
 - Volunteering
 - Share your story online with Living Beyond Breast Cancer
 - Find a local organization, online or in-person events, or volunteer on a helpline
 - Donating and fundraising
 - You can create your own fundraising event or join in on walks, bake sales, and more
 - Clinical trials
 - Learn more about clinical trials and how to find the right one for you below!





WELLNESS RESOURCES

MEDITATION AND RELAXATION

- **Headspace** (<https://www.headspace.com/>)
 - Two-week free trial for the general public. (Providers with a National Provider Identifier can sign up for free full access.)
- **Calm** (<https://www.calm.com/>)
 - Seven-day free trial. A meditation, sleep, and relaxation app that also provides resources specifically for coping with COVID-19 anxiety.
- **Stop, Breathe & Think** (<http://www.stopbreathethink.com/>)
 - Always free, and for kids too.
- **Insight Timer** (<https://insighttimer.com/>)
 - Always free. This is not a daily app, but rather a great library where you can search for various types of meditations and lengths by excellent teachers.
- **10% Happier** (<https://www.tenpercent.com/>)
 - Free and paid options available. Health care providers can use redemption code HEALTHCARE to unlock all content.
- **UCLA Mindful App** (<https://www.uclahealth.org/marc/ucla-mindful-app>) Free and has meditation by Diana Winston.

ANXIETY

- **Ginger** (<https://www.ginger.io/frontlines>)
 - Free behavioral health coaching for health care clinicians who are directly supporting COVID-19 patients (free through June).
- **Sanvello** (<https://www.sanvello.com/>)
 - Clinically validated techniques for reducing stress and treating anxiety and depression (free premium access during COVID-19 pandemic).
- **Happify** (<https://www.happify.com/>)
 - Some free content, including stress reduction and cognitive techniques to address anxiety.
- **MindShift CBT** (<https://www.anxietycanada.com/resources/mindshift-cbt/>)
 - Free content, including cognitive behavioral therapy strategies to address general worry, social anxiety, and panic.

ADDITIONAL APPS

- **Insomnia**
 - **CBT-i Coach** (<https://www.mobile.va.gov/app/cbt-i-coach>)
 - Free cognitive behavioral therapy for insomnia, available for iOS and Android.
- Interested in finding another high quality mental health app, but feeling overwhelmed by all the choices?
 - **PsyberGuide** (<https://psyberguide.org/>) is a helpful non-profit site developed by UCSF alum and UC Irvine professor Stephen Schueller, PhD, that provides expert reviews on mental health apps (both credibility and user experience) and offers solid recommendations.

HOW TO SUPPORT A LOVED ONE



OFFER HELP

Many people find it hard to ask, but offering to help with tasks such as: taking care of a child, feeding a pet, preparing a meal, and/or run errands will show your support.



CHECK-IN

Make time for a phone call to your loved one. Checking in regularly during the long haul will be very meaningful to them and shows how much you care.



LISTEN

Act as emotional support. Listening to your loved one and allowing them to express their feelings and emotions will show your support to them. Holding their hand and giving a hug also goes a long way.



EDUCATE YOURSELF

Learn about the diagnosis and the detailed information about treatments, side effects, concerns, etc. from the spouse or mutual friend in order to make sure you have the correct facts.



CHANGE TOPICS

Steer away from having conversations regarding the cancer as your loved one may need a break from talking about it. Instead, bring up topics such as interests, current events, etc.



KEEP THINGS NORMAL

Treat your loved one the same like you always have before the diagnosis. It is important to respect their wishes to do tasks prior to being diagnosed with the cancer, as it can help ease their mind.

HOW TO SUPPORT A LOVED ONE

SUPPORTING A LOVED ONE

- **Supporting a Loved One With Cancer** (<https://www.verywellhealth.com/tips-for-supporting-a-loved-one-with-cancer-2248966>)
- **What Can I Say to a Newly Diagnosed Loved One:** (https://www.cancercare.org/publications/104-what_can_i_say_to_a_newly_diagnosed_loved_one)
- **How to Support Someone with Breast Cancer:** (<https://breastcancernow.org/information-support/facing-breast-cancer/how-support-someone-breast-cancer>)
- **How to Be a Friend to Someone with Cancer** (<https://www.cancer.org/treatment/caregivers/how-to-be-a-friend-to-someone-with-cancer.html>)
- **Breast Cancer: Tips for Family** (<https://www.webmd.com/breast-cancer/guide/breast-cancer-tips-family>)
- **Supporting Friends Through Breast Cancer Treatment** (<https://www.umchealthsystem.com/medical-services/cancer-care/patient-education/supporting-friends-through-breast-cancer-treatment>)
- **Cancer Awareness: How to Support a Loved One with Breast Cancer** (<https://www.nwpc.com/cancer-awareness-how-to-support-a-loved-one-with-breast-cancer/>)

WEBSITES AND BOOKS

- **UCSF Patient Education:** (https://www.ucsfhealth.org/conditions/breast_cancer/)
- **BreastCancer.org** (<http://www.breastcancer.org/>)
 - A comprehensive online resource about breast cancer.
- **American Cancer Society** (<https://www.cancer.org/cancer/breast-cancer>)
- **National Cancer Institute** (<https://www.cancer.gov/types/breast>)
- **Medivizor** (<https://medivizor.com/>)
 - Provides personalized information and updates about research, treatment options, relevant clinical trials. Summarizes research articles (and provides full text).
- **Dr. Susan Love's Breast Book** (<https://www.drSusanLoveResearch.org/dr-susan-loves-breast-book-elibro-de-la-mama>)
 - Available on Amazon.
- **Aftershock! What to do when the doctor gives you – or someone you love – a devastating diagnosis** (<http://www.aftershockbook.com/>)
 - Jessie Gruman's book on how to cope with a life-threatening diagnosis. Available on Amazon.
- **What Do I Tell the Kids?** (<https://orders.cancersupportcommunity.org/>)
 - by the Cancer Support Community. Order online or available at the UCSF Cancer Resource Center.
- **The Empowered Patient** (<http://theempoweredpatient.com/>)
 - a book by Julia Hallisy with hundreds of life-saving facts, action steps and strategies you need to know



SOURCES

- <https://www.cancer.org/cancer/breast-cancer/screening-tests-and-early-detection/mammograms/what-does-the-doctor-look-for-on-a-mammogram.html>
- <https://www.cancer.org/cancer/breast-cancer/screening-tests-and-early-detection/mammograms/what-does-the-doctor-look-for-on-a-mammogram.html>
- <https://www.mayoclinic.org/tests-procedures/breast-exam/about/pac-20393237>
- [https://pubmed.ncbi.nlm.nih.gov/21675875/#:~:text=Women%20often%20detected%20breast%20cancers,%20by%20accident%20\(18%25\).](https://pubmed.ncbi.nlm.nih.gov/21675875/#:~:text=Women%20often%20detected%20breast%20cancers,%20by%20accident%20(18%25).)
- <https://knowyourgirls.org/resources/questions-to-ask-your-doctor-about-breast-health/#:~:text=Questions%20for%20your%20next%20doctor's%20visit&text=Would%20I%20benefit%20from%20a,to%20be%20screened%20more%20often%3F>
- <https://www.ucsfhealth.org/education/basic-facts-about-breast-health-nutrition-for-breast-cancer-prevention>
- <https://www.cancer.org/healthy/cancer-causes/diet-physical-activity/alcohol-use-and-cancer.html#:~:text=Breast%20cancer%3A%20Drinking%20even%20small,their%20risk%20of%20breast%20cancer.>
- <https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/breast-cancer-medications-for-risk-reduction>
- <https://www.breastcancer.org/managing-life/exercise>
- <https://www.verywellhealth.com/find-free-or-low-cost-mammograms-429861>
- <https://www.cdc.gov/cancer/nbccedp/screenings.htm>
- <https://www.cdc.gov/cancer/nbccedp/screenings.htm>