

Tips for Women with Disabilities on Understanding Breast Cancer



Breast Cancer Awareness




Risk Factors for Breast Cancer



Clinical Breast Exams and Screening




Mammograms and Screening



Breast Cancer Diagnosis



Breast Cancer Treatments and Side Effects



Care During and After Breast Cancer Treatment



Insurance Coverage for Mammography

Additional copies of tip card packets
are available at
www.aahd.us

For more information, contact:

American Association on Health & Disability
110 North Washington Street, Suite 328J
Rockville, MD 20850

(301) 545-6140

www.aahd.us



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Susan G. Komen

1-877 GO KOMEN

(1-877-465-6636)

<http://ww5.komen.org>



Dear Friend:

Women often do not find time to take care of themselves. Women with disabilities face extra challenges--some lack time to attend to their routine physical health in addition to their disability. Or they may think "I won't get breast cancer because lightning can't strike twice."

Women with disabilities are as likely and sometimes more likely to get breast cancer as the general population due to having more risk factors than women in general. Because there's no sure way to prevent breast cancer, it's important to take care of yourself by having regular screenings to find breast cancer early, when breast cancers often respond well to treatment, and the chance for survival is high. These tip cards stress the importance of early screening and provide self awareness messages for you to follow. Also covered are diagnosis, treatment issues, and insurance coverage.

We hope this guide will inspire you to take charge of your breast health and be a self advocate. Getting early breast cancer screening can save your life!

Women with Disabilities and Breast Cancer Awareness and Screening

- ❖ Susan G. Komen reports that breast cancer is the most common cancer among American women, except for skin cancers.
- ❖ Women with disabilities are as likely to get breast cancer as the general population.
- ❖ Women with disabilities, including African-American and Hispanic/Latina women are less likely to get regular clinical breast exams (when a health care provider looks at and feels your breasts) and mammograms (x-rays of the breasts), which increases their chances of being diagnosed with larger tumors and more advanced tumors.
- ❖ Be sure to get screened and speak with your doctor about which tests are right for you.
- ❖ Have a mammogram every year starting at age 40, if you are at average risk.
- ❖ Have a clinical breast exam at least every 3 years starting at age 20, and every year starting at age 40.
- ❖ Know your risk, learn about your family history and talk to your health care professionals about your personal risk of breast cancer.

- ❖ Knowing what is normal for you will help you know when something has changed. If you notice any changes in your breasts, make an appointment with your health care provider right away.
- ❖ Make healthy lifestyle choices (keep a healthy weight, limit alcohol intake, limit post-menopausal hormone use and breastfeed, if you can).
- ❖ Early detection can save your life.

Women with Disabilities and Risk Factors for Breast Cancer

❖ Risk factors are things that can put you at high risk of breast cancer. If you have one or more of the following risk factors for developing breast cancer, as many women with disabilities do, talk to your health care provider about getting screened earlier and/or more often than recommended for women without risk factors:

- Gender--being female is biggest risk factor.
- Age--risk increases as you get older—this is second biggest risk factor.
- Family History--breast cancer risk is higher among women whose mother, sister, or daughter has had this disease.
- Personal History--a woman with cancer in one breast has increased risk of developing new cancer in other breast or in another part of same breast.
- Previous Chest Radiation--Women who received chest radiation as treatment for another cancer or disability are at increased risk for breast cancer.

- Higher amounts of estrogen in the blood are linked to an increased risk of breast cancer in women after menopause.
- Some inherited gene mutations (BRCA1, BRCA2 and others).
- Alcohol--linked to increased risk of developing breast cancer.
- Being overweight or obese—may increase breast cancer risk, especially after menopause.

Please visit

[https://www5.komen.org/BreastCancer/
BreastCancerRiskFactorsTable.html](https://www5.komen.org/BreastCancer/BreastCancerRiskFactorsTable.html)

to learn more about Breast Cancer Risk

Women with Disabilities and Clinical Breast Exams

- ❖ A clinical breast exam (CBE) is a physical exam done by a health care provider, who looks at your breasts and underarms and feels them while you are sitting up and then lying down.
- ❖ The CBE should be done as part of your regular checkup. If it is not offered by your health care provider, you should ask how often you should be getting one.
- ❖ Clinical Breast Exams:
 - Start at age 20.
 - Ages 20 – 39 and no risk factors: at least every 3 years.
 - 40 and older: every year.
 - If a health care provider has told you that you have other risk factors, follow his or her advice on how often to have clinical exams.

❖ If you have difficulty getting a clinical breast exam:

- Have your spouse, family member, friend, or caregiver come with you to give you physical and/or mental support.
- Tell your health care provider what makes you uncomfortable and what makes an exam more comfortable for you.
- Ask for help from your health care provider.

Women with Disabilities and Mammograms

- ❖ A mammogram is an X-ray that makes an image of the breast in order to find signs of breast cancer.
- ❖ Mammograms use very little radiation and can detect very small tumors that can't be felt during a breast self exam or even a clinical exam.
- ❖ Mammograms:
 - Start at age 40.
 - Have a mammogram every year, if your of average risk.
 - If a health care provider has told you that you have other risk factors, follow his or her advice on how often to have a mammogram.
- ❖ When calling to schedule a mammogram, tell staff about your disability and if you:
 - Use a walker, cane, wheelchair, or scooter.
 - Need help completing forms, dressing, positioning, sitting up, standing, moving your arms, and/or moving from your wheelchair or scooter to a chair if needed.

- Plan to bring someone to help you undress and dress and/or hold you during the mammogram if needed.
- Have movement or other physical issues that may cause the mammogram to take more time.
- ❖ Tell scheduling staff about physical access issues that concern you, which may involve the parking lot and outside of the building as well as the inside of the facility.
- ❖ During the mammogram:
 - Getting a clear X-ray makes a mammogram successful; find out what position is most comfortable for you and gets the best X-ray.
 - Write what position works for you so you can remember it for the next time. Ask the technologist to include it in your records, since staff might change.
 - To get close to the mammography machine, your wheelchair needs to have removable arms. Make sure the wheelchair you use that day has removable arms.

Women with Disabilities and Breast Cancer Diagnosis

- ❖ After your mammogram, the doctor will check the results for changes in your breasts by looking at the mammogram X-ray.
- ❖ Your doctor may then want to do one or both of these tests to better understand your breasts:
 - Ultrasounds: can tell the difference between types of lumps and do not hurt.
 - MRI: another way doctors take a picture of the breast, using a large magnet and radio waves.
- ❖ Since a test cannot prove for sure that an abnormal area is cancer, sometimes a biopsy (when a small amount of tissue is removed) is needed.
- ❖ If you need a biopsy:
 - Find out about access to and within the facility.
 - Tell staff beforehand about your needs.
 - Since biopsy tables are generally high and sometimes difficult for women with disabilities to get up on, ask before the biopsy if the staff has experience helping women with disabilities.

- Ask to bring someone to the biopsy to help you.
- ❖ After the biopsy, the doctor can tell if cancer is present and if it has spread by looking at the tissue under a microscope.
- ❖ When discussing your diagnosis with your doctor, ask questions if you do not understand.
- ❖ Bring a spouse, family member, friend, or caregiver with you to take notes and ask questions.
- ❖ If the doctor finds cancer, try not to be afraid.
 - There are more than three million breast cancer survivors alive today in the U.S.
 - The five-year overall survival rate for early stage breast cancer is 99%.
 - Women are leading full lives with breast cancer, due to earlier detection and improved treatment.
- ❖ From diagnosis through treatment, patient navigators can help women with disabilities get the services they need by helping identify barriers to care and resources to overcome those barriers.

Women with Disabilities and Breast Cancer Treatments and Side Effects

- ❖ Every woman diagnosed with breast cancer needs to talk to her oncologist (cancer doctor) when deciding on the best treatment for her.
- ❖ Find out before starting treatment about access to and within the treatment facility.
- ❖ Tell staff beforehand about your needs and ask if the staff has experience helping women with disabilities. Bring someone to the treatment facility to help you.
- ❖ There are many types of breast cancer and treatments; your doctor will discuss your options.
- ❖ The type of disability you have may or may not affect your treatment.
- ❖ Make sure you have reliable accessible transportation to complete a full course of chemotherapy or radiation treatment.
- ❖ It is important to have coordination between existing and new health professionals who provide you with healthcare.

- ❖ Make sure your oncologist and the pharmacist know of all of the medicines you are taking.
- ❖ Chemotherapy drugs may have side effects.
- ❖ Some people may experience no side effects of chemotherapy. Talk with your doctor about possible side effects and how they can be managed.
- ❖ Surgery can also result in side effects. Talk with your doctor about possible side effects and how they can be managed.
- ❖ Breast cancer treatment can cause new conditions, such as lymphedema, and women with disabilities may face extra challenges caused by other conditions they have as a result of their disability.
- ❖ Before starting breast cancer treatment, talk with your doctor about your disability and possible challenges with treatment.
- ❖ Remember, there are many medicines that help with side effects of treatment.

Women with Disabilities and Care During and After Breast Cancer Treatment

- ❖ It's now more important than ever to follow a healthy lifestyle during and after treatment. Lifestyle changes may help you cope with both your disability and the effects of breast cancer treatment:
 - Nutrition
 - If you're on a special diet for your disability, ask your doctor how to follow it if also dealing with eating problems caused by cancer treatment.
 - Try to eat healthy foods (ask your doctor about speaking to a nutritionist).
 - Consider eating 5 to 6 small meals or snacks each day instead of 3 big meals.
 - If you're not up to eating solid foods, try milkshakes, smoothies, juice, or soup.
 - If you have bowel/bladder issues due to your disability, discuss your diet with your doctor.
 - Fatigue
 - Try to take short naps or rest during the day.
 - Accept help from family or friends to do chores, run errands, and make meals.
 - Try to relax, engaging in meditation, yoga, or guided imagery.

- Physical Activity
 - Check with your health care provider to see how much exercise you should be getting during each stage of treatment.
 - A physical therapist can give you ideas about appropriate exercises that can be done from a wheelchair.
- Dental Care
 - Ask your health care provider for a mouthwash to help with symptoms.
 - Before you begin treatment, see your dentist and finish necessary dental work.
- Psychological Support
 - Get support from others who have breast cancer by joining a support group either in person or online.
 - Talk about your feelings with family members, close friends, health care provider, clergy member, and/or oncology (cancer) social worker.
 - Consider keeping a journal to record your feelings and thoughts. If it's hard to write, try speaking into a tape recorder.

o See friends and be socially active.

- ❖ Once you've had breast cancer, you have a higher risk for developing a new breast cancer than someone never having had the disease. That is why it is very important to see your doctor regularly.
- ❖ Continue regular screening--if cancer comes back, it can be found and treated early. Talk with your doctor about recommended screenings and follow up.
- ❖ Mammography screening after mastectomy (breast removal):
 - If you've had one breast removed, you will likely not need future mammograms on that breast. However, check with your doctor for guidance.
 - Ask your doctor how often you should get a mammogram on the remaining breast.
 - If you've had both breasts removed, you'll likely no longer need mammograms. Check with your doctor to see if you need other screening tests.
- ❖ If follow-up mammography screening involves going to a new facility:
 - When calling for an appointment, tell scheduling staff about your disability so mammography staff will be better prepared to help you.

- Ask the scheduling staff about access issues at the mammography facility that concern you.
- ❖ After finishing treatment, report the following symptoms to your doctor immediately:
 - Changes in remaining breast(s) and chest area.
 - Changes such as pain; or breathing, unusual visual, or digestive problems that don't go away.
- ❖ Continue to deal with treatment-related side effects the best you can and talk with your doctor for help.

Women with Disabilities and Insurance Coverage for Mammography

- ❖ The Affordable Care Act (health insurance legislation signed into law in 2010), expanded options for people with disabilities for their health insurance and beginning to make health insurance more affordable and accessible for everyone.
- ❖ The Affordable Care Act makes it illegal for insurers to deny coverage to women because they get sick. Insurers cannot refuse to cover women who get breast cancer and have other pre-existing conditions.
- ❖ The Affordable Care Act has made mammograms affordable for nearly everyone. If you have:
 - Insurance: mammograms and other preventive women's services are almost always covered at no cost.
 - Medicare: preventive services, including mammograms, are free on an annual basis for all women with Medicare aged 40 and over, with no co-pays for the women.
 - Medicaid: all state plus D.C. Medicaid programs will cover screening mammograms.

- ❖ The National Breast and Cervical Cancer Early Detection Program (NBCCEDP) run by the Centers for Disease Control and Prevention (CDC) provides breast and cervical cancer screening (including clinical breast exams and mammograms) to low-income, uninsured, and underserved women for free or at very low cost.
- ❖ Each state's Department of Health has information on how to contact the nearest CDC screening and early detection program in your area. Contact the CDC at 1-800-CDC-INFO (1-800-232-4636) or at www.cdc.gov/cancer.
- ❖ If you do not have health insurance and NBCCEDP does not work for you, try to find a center that offers low-cost or free mammograms. Contact the National Cancer Institute (1-800-4-CANCER), the American Cancer Society (1-800-ACS-2345), or your local hospital for assistance.

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