



Breast Health Toolkit for Women with Disabilities

About this Toolkit

The American Association on Health and Disability developed this *Breast Health Toolkit for Women with Disabilities* to educate women with disabilities and providers on the importance of breast health and screening. It is intended to provide users with informative and practical resources to understand the importance of breast cancer screening, risk factors, treatment, health disparities, and survivorship. This toolkit contains tools, tips, and insights to be used in screening preparation and understanding breast health for women with disabilities.

In this Toolkit...

Letter from AAHD Executive Director Roberta Carlin, MS, JD

Breast Health Screening Recommendations

Risk Factors for Breast Cancer and Women with Disabilities

Health Disparities, Breast Cancer and Women with Disabilities

Continuum of Care Upon Diagnosis

Additional Resources for Women with Disabilities

Additional Resources for Healthcare Providers

Dedicated to better health for people with disabilities through health promotion and wellness



American Association on Health & Disability

110 N. Washington Street Suite 328-J Rockville, MD 20850

T. 301-545-6140 F. 301-545-6144 www.aahd.us

Dear Colleague,

This *Breast Health Toolkit for Women with Disabilities* was developed by the American Association on Health and Disability (AAHD).

Over the past decade, AAHD has been committed to raising awareness in women with disabilities about the importance of maintaining their breast health and raising awareness of health care providers about the importance of accessibility of health care facilities. While women with disabilities have the same chance of getting breast cancer as women without a disability, data from the Centers for Disease Control and Prevention and other sources, indicate that women with disabilities, especially those with significant physical challenges, receive mammograms less often than women without disabilities, and may be of higher risk of late – stage breast cancer and higher mortality. We also have learned through our work, that the barriers, whether attitudinal, cultural, environmental or physical, often present challenges for women with disabilities when seeking preventive and routine screening, as well as for treatment and follow up care.

AAHD has designed this toolkit to provide information for both women with disabilities and health care providers. The toolkit was developed with the goal of creating a user-friendly, informative, and relevant product for women with disabilities and health care providers who want to increase their knowledge about breast health screening recommendations, risk factors, health disparities, treatment, follow up, and survivorship for women with disabilities.

You will find a variety of components that you can mix and match from fact sheets to on-line training videos. Many of the documents in the toolkit were developed with funding from the Susan G. Komen Foundation, which has been a fantastic partner of AAHD for the last decade. The board and staff of AAHD are very appreciative of Susan G. Komen's ongoing support over the years.

We look forward to continuing to expand this toolkit by offering more materials and resources. Please send any updates to contact@aaht.us. We appreciate your role in spreading the word about the toolkit, but most importantly, we hope you find the toolkit useful for you, your friends and colleagues.

At any time, please contact me with any questions about the *Breast Health Toolkit for Women with Disabilities*.

Warm regards,

Roberta S. Carlin, MS, JD
AAHD Executive Director

Dedicated to better health for people with disabilities through health promotion and wellness



Breast Health Screening Recommendations

Dedicated to better health for people with disabilities through health promotion and wellness



Breast Health Screening Recommendations

There are several recommendations and guidelines distributed by different organizations. These are some examples of reputable sources that put out guidelines.

American Cancer Society

Offer screening mammography between 40 and 44 years and begin at 45, then continue to be screened every year between ages 40-54, then every 2 years at or over age 55

- <https://www.cancer.org/latest-news/special-coverage/american-cancer-society-breast-cancer-screening-guidelines.html>

American Cancer Society Recommendations for the Early Detection of Breast Cancer
Guideline for women at *average risk* for breast cancer

Age Group	Screening Recommendation
Ages 40 – 44	Woman should have the choice to start annual breast cancer screening with mammograms if they wish to do so.
Ages 45 – 54	Woman should get mammograms every year.
Age 55 and older	Women can switch to mammograms every two years, or can continue yearly screening. Screening should continue as long as a woman is in good health and is expected to live 10 more years or longer.

©2017 American Cancer Society, Inc. All rights reserved. The American Cancer Society is a qualified 501(c)(3) tax-exempt organization and donations are tax-deductible to the full extent of the law.

National Cancer Institute

Does not issue screening guidelines but follows the USPSTF recommendations

- <https://www.cancer.gov/types/breast/patient/breast-screening-pdq>

Susan G. Komen Foundation

Follows these guidelines presented by three major health organizations

- <https://ww5.komen.org/BreastCancer/BreastCancerScreeningforWomenatAverageRisk.html>

Dedicated to better health for people with disabilities through health promotion and wellness



Figure 3.1: Breast cancer screening recommendations for women at average risk

American Cancer Society	National Comprehensive Cancer Network	U.S. Preventive Services Task Force
Mammography		
<p>Informed decision-making with a health care provider ages 40-44</p> <p>Every year starting at age 45-54</p> <p>Every 2 years (or every year if a woman chooses to do so) starting at age 55, for as long as a woman is in good health</p>	<p>Every year starting at age 40, for as long as a woman is in good health*</p>	<p>Informed decision-making with a health care provider ages 40-49</p> <p>Every 2 years ages 50-74</p>
Clinical Breast Exam		
<p>Not recommended</p>	<p>Every 1-3 years ages 25-39</p> <p>Every year starting at age 40</p>	<p>Not enough evidence to recommend for or against</p>
* Breast tomosynthesis (3D mammography) may be considered.		

Dedicated to better health for people with disabilities through health promotion and wellness



American College of Radiology (ACR)

Start at age 40 then continue to be screened every year

“The ACR recommends annual mammographic screening beginning at age 40 for women of average risk. Higher-risk women should start mammographic screening earlier and may benefit from supplemental screening modalities. For women with genetics-based increased risk (and their untested first-degree relatives), with a calculated lifetime risk of 20% or more or a history of chest or mantle radiation therapy at a young age, supplemental screening with contrast-enhanced breast MRI is recommended. Breast MRI is also recommended for women with personal histories of breast cancer and dense tissue, or those diagnosed by age 50. Others with histories of breast cancer and those with atypia at biopsy should consider additional surveillance with MRI, especially if other risk factors are present. Ultrasound can be considered for those who qualify for but cannot undergo MRI. All women, especially black women and those of Ashkenazi Jewish descent, should be evaluated for breast cancer risk no later than age 30, so that those at higher risk can be identified and can benefit from supplemental screening.”

- <https://www.acr.org/Advocacy-and-Economics/ACR-Position-Statements/Breast-Cancer-Screening-in-Women-at-Higher-Than-Average-Risk>
- [http://www.jacr.org/article/S1546-1440\(09\)00480-3/fulltext](http://www.jacr.org/article/S1546-1440(09)00480-3/fulltext)

U.S. Preventive Service Task Force (USPSTF)

Start at age 50, however, make screening an individual decision between 40-49, then continue to be screened every 2 years regardless of age

- <https://www.uspreventiveservicestaskforce.org/Page/Document/RecommendationStatementFinal/breast-cancer-screening1>
- Update of the 2009 U.S. Preventive Services Task Force (USPSTF) recommendation on screening for breast cancer: <http://annals.org/aim/fullarticle/2480757/screening-breast-cancer-u-s-preventive-services-task-force-recommendation>

Dedicated to better health for people with disabilities through health promotion and wellness



Recommendation Summary

Population	Recommendation	Grade (What's This?)
Women aged 50 to 74 years	The USPSTF recommends biennial screening mammography for women aged 50 to 74 years.	B
Women aged 40 to 49 years	<p>The decision to start screening mammography in women prior to age 50 years should be an individual one. Women who place a higher value on the potential benefit than the potential harms may choose to begin biennial screening between the ages of 40 and 49 years.</p> <ul style="list-style-type: none"> For women who are at average risk for breast cancer, most of the benefit of mammography results from biennial screening during ages 50 to 74 years. Of all of the age groups, women aged 60 to 69 years are most likely to avoid breast cancer death through mammography screening. While screening mammography in women aged 40 to 49 years may reduce the risk for breast cancer death, the number of deaths averted is smaller than that in older women and the number of false-positive results and unnecessary biopsies is larger. The balance of benefits and harms is likely to improve as women move from their early to late 40s. In addition to false-positive results and unnecessary biopsies, all women undergoing regular screening mammography are at risk for the diagnosis and treatment of noninvasive and invasive breast cancer that would otherwise not have become a threat to their health, or even apparent, during their lifetime (known as "overdiagnosis"). Beginning mammography screening at a younger age and screening more frequently may increase the risk for overdiagnosis and subsequent overtreatment. Women with a parent, sibling, or child with breast cancer are at higher risk for breast cancer and thus may benefit more than average-risk women from beginning screening in their 40s. <p>Go to the Clinical Considerations section for information on implementation of the C recommendation.</p>	C
Women aged 75 years or older	The USPSTF concludes that the current evidence is insufficient to assess the balance of benefits and harms of screening mammography in women aged 75 years or older.	I
All women	The USPSTF concludes that the current evidence is insufficient to assess the benefits and harms of digital breast tomosynthesis (DBT) as a primary screening method for breast cancer.	I
Women with dense breasts	The USPSTF concludes that the current evidence is insufficient to assess the balance of benefits and harms of adjunctive screening for breast cancer using breast ultrasonography, magnetic resonance imaging, DBT, or other methods in women identified to have dense breasts on an otherwise negative screening mammogram.	I

These recommendations apply to asymptomatic women aged 40 years or older who do not have preexisting breast cancer or a previously diagnosed high-risk breast lesion and who are not at high risk for breast cancer because of a known underlying genetic mutation (such as a *BRCA1* or *BRCA2* gene mutation or other familial breast cancer syndrome) or a history of chest radiation at a young age.

[Return to Table of Contents](#)

Dedicated to better health for people with disabilities through health promotion and wellness



Risk Factors for Breast Cancer and Women with Disabilities

Dedicated to better health for people with disabilities through health promotion and wellness



Links to resources from AAHD on risk factors:

- Risk Factors
 - <https://www.aahd.us/wp-content/uploads/2012/10/BreastCancer-RiskFactors.pdf>
- Self-Awareness Messages
 - <https://www.aahd.us/wp-content/uploads/2012/10/BreastCancer-SelfAwareness.pdf>

Centers for Disease Control and Prevention article:

- CDC – “Women with Disabilities are Less Likely to Have Received a Mammogram During the Past Two Years”
 - <https://www.cdc.gov/ncbddd/disabilityandhealth/breast-cancer-screening.html>



WOMEN WITH DISABILITIES AND RISK FACTORS FOR BREAST CANCER

Risk factors are things that can put you at high risk of breast cancer and determine how often you should get tests to check for cancer. All women should know what risk factors they have, especially women with disabilities.

Having a risk factor for breast cancer, or even several, doesn't mean you'll get breast cancer. But, if you have one or more of the following risk factors, 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.

Most women who develop breast cancer have NO risk factors.

Here are some overall risk factors for developing breast cancer

- Age: your risk increases as you get older.
- Birth Control Pill Use: Current or recent use of birth control pills slightly increases risk of breast cancer.
- Early Menstruation (Periods): women starting menstruation early (before age 12) is linked to a small increase in breast cancer.
- Gender: being a woman is the most important risk factor.
- Genes: inherited gene mutations have been linked to breast cancer (BRCA1, BRCA2, p53, CHEK2, ATM, PALB2).

- Late Menopause: women going through menopause later (after age 55).
- Menopausal Hormone Therapy (MHT): Estrogen plus progestin increase risk of both developing and dying from breast cancer.
- Personal History: a woman with cancer in one breast has an increased risk of developing a new cancer in the other breast or in another part of the same breast.
- Previous Chest Radiation: women who received chest radiation as treatment for another cancer or for a disability are at increased risk for breast cancer.
- Race: African-American women are slightly less likely to develop breast cancer than White women but are more likely to die of this cancer.
- Women who give birth to first child at age 35 or younger tend to have a protective benefit from pregnancy.



source: www.Thinkstock.com

Here are some risk factors that are related to how you live and your lifestyle

- Alcohol: linked to increased risk of developing breast cancer

continued.....

continued.....**some risk factors that are related to how you live and your lifestyle**

- Being overweight or obese: found to increase breast cancer risk, especially after menopause
- Birth Control Pill Use – current or recent birth control pills slightly increases risk of breast cancer.
- Family History – Breast, ovarian or prostate cancer. A mother, father, sister, or daughter with breast cancer or a mother, sister daughter with ovarian cancer, increases the risk of breast cancer. A father or son with prostate cancer may increase risk of breast cancer.
- Lack of physical activity - regular exercise appears to lower breast cancer risk by about 10-20 percent.
- Hormone therapy after menopause: used to help reduce menopause symptoms and prevent osteoporosis (thinning of bones). This can also increase the risk of getting breast cancer and the chances of dying from breast cancer.

Women with disabilities need to be concerned about breast cancer because they may have these risk factors

- Early menstruation
- Previous chest radiation/or radiation
- Never having children
- Obesity & overweight
- Physical inactivity
- Being a woman

REMEMBER—know your breast cancer risk factors and talk about them with your health care provider. To learn about factor that affect breast cancer risk, visit:

ww5.komen.org/AboutBreastCancer/RiskFactors/FactorsAffectingBreastCancerRisk/FactorsAffectingBreastCancerRisk.html.



American Association on Health and Disability
www.aahd.us

susan g. komen.
877-465-6636 (hotline)
ww5.komen.org

For more information, please contact AAHD Komen Project Director at 301-545-6140 x203 or visit our website at www.aahd.us

This publication was made possible by a 2016-2018 grant from Susan G. Komen®.

© 2016 American Association on Health & Disability

American Association on Health and Disability (AAHD) provides the materials and links for general information, education and awareness purposes only. Although every effort is made to assure that information is accurate and current, knowledge in the field of disability and medicine is changing often, and all data is subject to change without notice. AAHD makes no representations or warranties and assumes no responsibility or liability as to the accuracy, completeness, reliability or usefulness of any information contained in this document. Neither AAHD nor any parties, who supply information to AAHD, make any warranty concerning the accuracy of any information in this document.



WOMEN WITH DISABILITIES AND BREAST SELF-AWARENESS MESSAGES

If you're a woman with a disability, you're just as likely to get breast cancer as other women. Having a disability doesn't keep you from getting breast cancer — breast cancer can happen to you!

To find breast cancer early,

Know your risk

- Talk to both sides of your family to learn about your family health history.
- Talk to your provider about your personal risk of breast cancer.

Get screened

- Ask your doctor which screening tests are right for you if you are at a higher risk
- 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
- Sign up for a screening reminder at www.komen.org/reminder

Know what is normal for you and see your healthcare provider if you notice any of these breast changes:

- Lump, hard knot or thickening inside the breast or underarm area
- Swelling, warmth, redness or darkening of the breast
- Change in the size or shape of the breast
- Dimpling or puckering of the skin
- Itchy, scaly sore or rash on the nipple
- Pulling in of your nipple or other parts of the breast
- Nipple discharge that starts suddenly
- New pain in one spot that doesn't go away

Make healthy lifestyle choices

- Maintain a healthy weight
- Add exercise into your routine
- Limit alcohol intake
- Limit postmenopausal hormone use
- Breastfeed, if you can

Breast Self-Awareness Message Videos

Susan G. Komen has produced breast self-awareness videos. Breast self-awareness materials and translated materials, including American Sign Language, are found at ww5.komen.org/translations.html.

Breast Self-Awareness Message Cards

Breast self-awareness message cards in different languages are available at ww5.komen.org/translations.html.



American Association on Health and Disability
www.aahd.us




877-465-6636 (hotline)
www5.komen.org

For more information, please contact AAHD Komen Project Director at 301-545-6140 x203 or visit our website at www.aahd.us

This publication was made possible by a 2016-2018 grant from Susan G. Komen®.

© 2016 American Association on Health & Disability

American Association on Health and Disability (AAHD) provides the materials and links for general information, education and awareness purposes only. Although every effort is made to assure that information is accurate and current, knowledge in the field of disability and medicine is changing often, and all data is subject to change without notice. AAHD makes no representations or warranties and assumes no responsibility or liability as to the accuracy, completeness, reliability or usefulness of any information contained in this document. Neither AAHD nor any parties, who supply information to AAHD, make any warranty concerning the accuracy of any information in this document.





Health Disparities, Breast Cancer and Women with Disabilities

Dedicated to better health for people with disabilities through health promotion and wellness



Health Disparities

- Women with Disabilities and Health
 - <https://www.cdc.gov/ncbddd/disabilityandhealth/women.html>
- The Double Burden of Women with Disabilities and Breast Cancer
 - <https://www.aahd.us/wp-content/uploads/2012/03/BreastCancer-SecondaryConditionsTreatments.pdf>
 - <https://mic.com/articles/134979/women-with-disabilities-are-more-likely-to-die-of-breast-cancer-here-s-why>
- Disparities Among Mammography Screenings of Individuals with Disabilities
 - <https://mic.com/articles/134979/women-with-disabilities-are-more-likely-to-die-of-breast-cancer-here-s-why#.XotBhwhNY>
- Breast Cancer Action – “Disparities and Breast Cancer”
 - <https://bcaction.org/site-content/uploads/2013/11/Disparities-in-Breast-Cancer-Through-the-Breast-Cancer-Care-Continuum.pdf>
- Race and Ethnicity and Breast Cancer
 - <https://ww5.komen.org/BreastCancer/RaceandEthnicity.html>
 - <http://www.communityscience.com/knowledge4equity/HealthDisparitiesChartBook.pdf>

Dedicated to better health for people with disabilities through health promotion and wellness

WOMEN WITH DISABILITIES, SECONDARY CONDITIONS AND BREAST CANCER TREATMENTS

Women with disabilities face many challenges, including the management of secondary conditions as a result of their primary disabilities. Breast cancer treatments can make these challenges more difficult, since treatment may cause short-term and long-term side effects. However, there are strategies to help monitor the impact of breast cancer treatment side effects that may affect disability and secondary conditions.

What is a secondary condition caused by a primary disability?

- A physical, medical, cognitive, emotional or psychosocial condition directly caused by an existing medical condition or disability.
- Researchers and healthcare professionals believe that some secondary conditions can be prevented or decreased by a combination of health maintenance practices, eliminating environmental barriers, and improved healthcare access. However, other conditions are part of having a specific disability and can be managed but not prevented.
- In one study of women with physical disabilities, the average number of secondary conditions was 13 per woman, 5 of which were rated as severe or chronic. Secondary conditions are very common in people with disabilities and need to be managed while undergoing treatment for breast cancer.

Examples of common secondary conditions that happen because of a disability may include:

- Arthritis
- Cardiovascular conditions
- Depression
- Fatigue
- High blood pressure
- Joint pain
- Learning disabilities
- Obesity/weight gain
- Pressure sores
- Respiratory infections
- Social isolation
- Urinary tract infections

A secondary condition can be temporary or permanent. It can be acute or chronic.



source: www.Thinkstock.com

Secondary conditions and breast cancer treatments

Before you start breast cancer treatment

- Tell your health care provider about all your health conditions, whether or not you think they are related to your disability. Your health care provider needs to understand your medical status so he/she may properly manage your breast cancer treatment.
- Your healthcare provider will consider how your disability and secondary conditions can influence the treatment options available to you.
- Your healthcare provider will develop a treatment plan based on your disability, risk factors, secondary conditions and possible treatment side effects.

American Association on Health & Disability

110 N. Washington Street • Suite 328-J • Rockville, MD 20850

T. 301-545-6140 F. 301-545-6144 www.aahd.us

Why breast cancer treatment may affect my disability and secondary conditions

- Breast cancer treatment often causes side effects. Some women have very few side effects of treatment and some have many more. The degree of side effects has no relation to whether or not the treatment is working.
- Side effects occur because cancer cells can grow and divide quicker than normal cells. Many anti-cancer drugs (chemotherapy) are made to kill growing cells. Chemotherapy can also affect normal and healthy cells that grow quickly. Damage to normal cells can cause side effects.
- Some side effects can worsen some secondary conditions, such as fatigue.

What are some examples of breast cancer treatment side effects that may affect my disability and secondary conditions?

- Women going through breast cancer treatment may be more tired than normal, more nauseous, have tingling in their toes and fingers, joint pain, swelling in the arm(s), and experience a variety of other symptoms specific to the drugs they are taking. While you are going through chemotherapy, you will receive ongoing blood tests to make sure your body is handling the treatments.
- Radiation is usually given daily for about 6 weeks, so the skin may become sore towards the end of the treatment. Women getting radiation treatment may need special creams to help maintain their skin so it does not break down or become infected. With the right creams, the skin will look just like it did before the radiation treatment. It is important for you and your healthcare provider to take care of your skin during treatment.

What are aromatase inhibitors?

- Drugs (daily pill) that some women often take for up to five years after they finish breast cancer treatment. If you are taking an aromatase inhibitor (Tamoxifen, Arimidex) after finishing either radiation or chemotherapy treatment, you may have additional side effects, such as increased joint pain and elevated cholesterol. It is important that you tell your healthcare provider about any additional symptoms you are having. These symptoms may affect your health and your disability.
- Since aromatase inhibitors and chemotherapy may cause loss of bone mass, it is important to have a bone density test. This painless test to check for bone loss is a very important follow up test for women with disabilities, who may already be experiencing bone loss due to their original disability and secondary conditions. There are medicines you can take to help prevent bone loss.

REMEMBER--Be sure and ask your health care provider about how to manage the symptoms related to cancer treatment. Let your healthcare provider know about any changes you have in managing your disability, secondary conditions, or your general health.

For more information, please contact Komen Project Coordinator at 301-545-6140 x203 or visit our website at www.aahd.us

This publication was made possible by a 2011-2012 grant from Susan G. Komen for the Cure®



© American Association on Health and Disability



© 2012 American Association on Health & Disability

American Association on Health and Disability (AAHD) provides the materials and links for general information, education and awareness purposes only. Although every effort is made to assure that information is accurate and current, knowledge in the field of disability and medicine is changing often, and all data is subject to change without notice. AAHD makes no representations or warranties and assumes no responsibility or liability as to the accuracy, completeness, reliability or usefulness of any information contained in this document. Neither AAHD nor any parties, who supply information to AAHD, make any warranty concerning the accuracy of any information in this document.



Continuum of Care Upon Diagnosis

Dedicated to better health for people with disabilities through health promotion and wellness



Upon Diagnosis:

- Steps for Women with Disabilities and Breast Cancer Diagnosis
 - <https://www.aahd.us/wp-content/uploads/2012/10/BreastCancer-Diagnosis.pdf>
- Importance of Social Support Systems from the Susan G. Koman Website
 - <https://www5.komen.org/BreastCancer/WhatIsSocialSupport.html>

Survivorship:

- During and After Treatment
 - <https://www.cancer.org/treatment/survivorship-during-and-after-treatment.html>

WOMEN WITH DISABILITIES AND BREAST CANCER DIAGNOSIS

After your mammogram, the doctor (radiologist) will check the results for changes in your breasts by looking at the mammogram X-ray. The changes may or may not be signs of cancer.

Changes in the breasts sometimes found by mammograms can include

- Calcifications, which look like small white spots on the mammogram and may or may not be caused by cancer
- A mass, which can be
 - ✓ a cyst (a fluid-filled non-cancerous sac) or
 - ✓ a solid tumor that may or not be cancer

Your health care provider may want to perform further tests to get a better understanding of your breasts. He/she may want to do one or both of the following

- **Ultrasound:** an ultrasound can tell the difference between types of lumps. Ultrasounds do not hurt and help health care providers find out about size, shape, and thickness of lumps.
- **MRI:** another way for doctors to take a picture of the breast by using a large magnet and radio waves.

You may need a biopsy after your screening test

- After your mammogram, ultrasound, or MRI, your doctor may recommend you get a biopsy afterward to prove for sure that an abnormal area is cancer.
- A biopsy is when a small amount of tissue is removed from the breast.

Tips for getting a better biopsy – Inquire about accessibility

- Before getting your biopsy, find out about accessibility to and within the facility.
- Tell staff beforehand about your needs.
- Since biopsy tables are generally high and sometimes hard 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.



source: National Cancer Institute
Author: Bill Branson (Photographer)

What happens after the biopsy is done?

- After the biopsy, the doctor can tell if cancer is present and if it has spread by looking at the tissue under a microscope.
- Depending on the results of the physical exam and biopsy, additional tests may also be needed.

If the doctor finds cancer, try not to be afraid. It might help you to know

- The chance of a woman getting breast cancer is one in eight women over a lifetime. Breast cancer happens more than you think, and you are not alone!

continued.....

continued...

If the doctor finds cancer, try not to be afraid. It might help you to know

- There are about 3.1 million breast cancer survivors alive today in the U.S.
- Most recent statistics available from Susan G. Komen state the five-year overall survival rate for early stage breast cancer is 99%.
- Women are leading full lives with breast cancer. This is due to:
 - ✓ Earlier detection (finding cancer early) through screening tests or exams
 - ✓ Improved treatment

Tips for getting better care from diagnosis through treatment

- When discussing your diagnosis with your doctor, ask questions if you do not understand.
- You should bring a spouse, family member, friend, or caregiver with you to take notes and ask questions.
- It is especially important for women with disabilities to use the services that patient navigator programs provide. These programs give information and support to those with breast cancer.
- From the point of diagnosis through treatment, patient navigators can help make sure that women with disabilities get the services they need. Navigators help identify barriers to care and resources to overcome those barriers.
- Always discuss any accessibility challenges with your doctor when discussing your diagnosis and treatment plan.

REMEMBER--after being diagnosed with breast cancer, get as much information as possible about your condition and the suggested treatment options.



American Association on Health and Disability
www.aahd.us



877-465-6636 (hotline)
ww5.komen.org

For more information, please contact AAHD Komen Project Director at 301-545-6140 x203 or visit our website at www.aahd.us

This publication was made possible by a 2016-2018 grant from Susan G. Komen®.

© 2016 American Association on Health & Disability

American Association on Health and Disability (AAHD) provides the materials and links for general information, education and awareness purposes only. Although every effort is made to assure that information is accurate and current, knowledge in the field of disability and medicine is changing often, and all data is subject to change without notice. AAHD makes no representations or warranties and assumes no responsibility or liability as to the accuracy, completeness, reliability or usefulness of any information contained in this document. Neither AAHD nor any parties, who supply information to AAHD, make any warranty concerning the accuracy of any information in this document.





Additional Resources for Women with Disabilities

Dedicated to better health for people with disabilities through health promotion and wellness



- List of FDA Mammography Sites
 - <https://www.accessdata.fda.gov/scripts/cdrh/cfdocs/cfMQSA/mqsa.cfm>
- ScreenABLE
 - “The Program for Healthcare Justice and the ChicagoCHEC present ScreenABLE a brief video about access to mammography for women with disabilities”
 - <https://www.youtube.com/watch?v=JXlkzwbG2-0&t=40s>
- State Programs for Breast Health for Women with Disabilities
 - OR: <https://www.ohsu.edu/xd/research/centers-institutes/oregon-office-on-disability-and-health/resources/breast-cancer.cfm>
 - NY: <https://www.health.ny.gov/publications/0953/>
 - FL: <http://fodh.phhp.ufl.edu/cdc-funded-module-projects/module-b-the-right-to-know/>
 - MT: http://mtdh.ruralinstitute.umt.edu/blog/?page_id=1235
 - OH: <https://www.ohsu.edu/xd/research/centers-institutes/oregon-office-on-disability-and-health/resources/upload/CDC-Women-with-Disabilities-Breast-Cancer.pdf>
 - NH: <https://www.dhhs.nh.gov/dphs/cdpc/bccp/index.htm>
 - <http://mtdh.ruralinstitute.umt.edu/blog/wp-content/uploads/Responsive-Practice-Providing-Mammography-to-Women-with-Disabilities.pdf>
 - RI: https://ww5.komen.org/uploadedFiles/Komen/Content/What_We_Do/In_the_Community/Assisting_Community_Health_Needs/Rhode%20Island%202015%20Community%20Profile%20Report.pdf
- Center on Research for Women with Disabilities
 - <https://www.bcm.edu/research/centers/research-on-women-with-disabilities>
- Breast Screening Reminders
 - komen.org/reminder
 - <http://apps.komen.org/Subscriber/new-user-registration.aspx?unauth=1&ecid=vanityurl:114%3E>
- Tips for Women with Disabilities on Understanding Breast Cancer (laminated tip cards)
 - https://www.aahd.us/wp-content/uploads/2012/10/KomenTipSheets_06092016.pdf
- Project Accessibility USA – - <https://www.aahd.us/initiatives/project-accessibility-usa/>
 - Project Accessibility USA Training Video
 - <http://www.project-accessibility-usa.org/Home.htm>
 - Project Accessibility USA Mammography Facility Assessment
 - <https://www.aahd.us/wp-content/uploads/2012/10/Facility-Assessment-5-20-13-.pdf>

Dedicated to better health for people with disabilities through health promotion and wellness



Additional Resources for Healthcare Providers

Dedicated to better health for people with disabilities through health promotion and wellness



Additional Resources for Healthcare Providers →

- Frequently Asked Questions about Mammography and the USPSTF Recommendations: A Guide for Practitioners
 - https://www.sbi-online.org/Portals/0/downloads/documents/pdfs/Detailed_Response_to_USPSTF_Guidelines-12-11-09-Berg.pdf
- Breast Cancer Screening (PDQ®)–Health Professional Version from the National Institute of Health
 - <https://www.cancer.gov/types/breast/hp/breast-screening-pdq>
- *Project Accessibility USA* – Working with Women with Disabilities – On-line Course for health professionals to understand and educate themselves about working with people with disabilities
 - <http://www.project-accessibility-usa.org/Home.htm>
- Quick Guide to Interacting with People with Disabilities
 - <https://www.aahd.us/wp-content/uploads/2012/10/Quick-Guide-To-Interacting-7-2-13.pdf>
 - Tips for Women with Disabilities on Understanding Breast Cancer (laminated tip cards)
 - https://www.aahd.us/wp-content/uploads/2012/10/KomenTipSheets_06092016.pdf
- Removing Barriers for Women with Disabilities – Improving Accessibility (Power Point)
 - <https://www.aahd.us/wp-content/uploads/2012/10/RemovingBarriersWomenDisabilities-ppslides.pdf>
- Guide to Disability for Healthcare Insurance Marketplace Navigators
 - <https://nationaldisabilitynavigator.org/wp-content/uploads/Materials/Disability-Guide.pdf>
- Disability and Health- Healthcare Providers from the CDC
 - <https://www.cdc.gov/ncbddd/disabilityandhealth/hcp.html>
 - *Project Accessibility USA* – - <https://www.aahd.us/initiatives/project-accessibility-usa/>
 - Project Accessibility USA Training Video
 - <http://www.project-accessibility-usa.org/Home.htm>
 - Project Accessibility USA Mammography Facility Assessment

Dedicated to better health for people with disabilities through health promotion and wellness



© • <https://www.aahd.us/wp-content/uploads/2012/10/Facility-Assessment-5-20-13-.pdf>

- New Hampshire's Disability & Public Health Project's training for mammography technologists – This service is available free of charge at this link:
 - <https://iod.unh.edu/projects/new-hampshire-disability-public-health-project/responsive-practice-healthcare-providers>

For more information, please visit:
<https://www.aahd.us/>

Dedicated to better health for people with disabilities through health promotion and wellness