Women First
Breast Health for Women with Developmental Disabilities

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About the Project

The *Breast Health for Women with Disabilities* project was made possible by a grant from the Wyoming Affiliate of the Susan G. Komen Breast Cancer Foundation. This project was designed to make information on breast health for women with disabilities accessible to health care providers, women with disabilities, and their families and loved ones. The project consists of the development of an annotated bibliography, the procurement of library materials on this topic, and the development of this handbook, *Women First: Breast Health for Women with Developmental Disabilities*.

Using This Guide

This guide has been developed specifically to help self-advocates learn basic breast health information. Care providers are encouraged to use this guide when working with women with developmental disabilities when discussing issues related to breast self exams, breast cancer, regular visits to their health care providers, and staying healthy in general.

Self-advocates should be encouraged to use this guide as a tool to help them be a part of their own health care. It has been designed to be placed in a notebook that may also serve as a single storage place for their personal health information and taken with them when they visit their health care provider. The calendar that has been included can be used to track monthly self exams and yearly visits with their personal health care provider. Additionally, the calendar can be photocopied and reused on an annual basis. Additional copies of this guide, as well as the calendar, can be downloaded from the Wyoming Institute for Disabilities web site at: http://wind.uwyo.edu/breasthealth/.

Important Notes

It was not possible to present every issue related to breast health and breast cancer in this handbook. However, it is hoped that it can be used as a starting point to introduce these topics and raise awareness of how important it is for women with developmental disabilities to be involved in their own health care. It is expected that care providers and women with developmental disabilities will engage in multiple conversations about these topics and breast health will become a regular part of every woman’s health regime.

It also should be noted that not all methods and techniques for conducting a breast self exam are presented in this guide. Therefore, to ensure that the breast self exam is being conducted correctly, a qualified health care provider should be consulted.

Availability

This handbook is available in alternative formats upon request and through the Wyoming Institute for Disabilities web site at: http://wind.uwyo.edu/breasthealth/.

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We are all women!
Being a woman is great!

Women can do so many things. And so can you! We can have fun, and spend time with our friends and family.

We have the right to make choices. We can say no to things we don’t like. We all like to have fun and to feel good.
Part of being happy and feeling good is being healthy! It is important for us to take care of our health.

We must take care of our bodies. We are special and it is the only body we have!

To stay healthy, we must eat right and be active. This is not always easy, but these are two things we need to do to stay healthy.

We must also take care of health problems. Women have different health problems than men.
Many people get cancer.

Getting cancer means part of our body is getting sick.

Some women get cancer in their breasts.

Sometimes breast cancer is found by seeing or feeling changes in our breasts.

All women can get breast cancer, including us.
How can we prevent breast cancer?
We can’t, but we can help find it.

What can we do to help find breast cancer?
We can do Breast Self Exams.

What is a Breast Self Exam?
A Breast Self Exam is when we check our own breasts ourselves. This means we look at and feel our breasts for changes.

If we do Breast Self Exams, we will get to know what our breasts feel like.

Then, if we find a lump or if there are other changes in our breasts, we will notice them.
It may sound scary, but we can do it!

It is easy.

It only takes a little while.

We only need to do it once a month.

By doing a Breast Self Exam, we will learn what our breasts usually look like. That way if we see or feel changes, we can see our doctor or nurse.

Let’s learn to do Breast Self Exams.
1. To see and feel your breasts, you must take all your clothes off above your waist.

2. Stand or sit in front of a mirror so you can see your breasts.

3. Look for any unusual changes in your breasts, such as color, shape or size. Also look for liquid coming from the nipples.
4. Now lie down or lean back comfortably.

5. Hold together the fingers of your hand. Feel one breast by pressing down firmly and moving your fingertips in small circles. Start at your nipple and do this all around the breast and under the arm.

6. Now, do this for the other breast. Feel the nipple, breast, and under the arm.
A Breast Self Exam is hard for many women to understand or do alone. That’s OK, we can ask someone else for help.

It is very important to ask a person you feel safe and comfortable with, like a friend or caregiver. If you do not have a person you are completely comfortable with, talk to a doctor or nurse.

Because we want to notice changes in our breasts, it’s best to have the same person do it every time.

It’s OK to ask the person questions or give the person instructions. This is your body!
If I can’t do my own, can anyone do the exam?
No. Only you can choose the person.

How often do I do Breast Self Exams?
Once a month.

What if I find a change in my breast?
If you or the person doing your exam finds a change in your breast, go to your doctor or nurse. They will tell you what to do next.

Will all changes in my breast make me sick?
No. Many changes are normal and most do not lead to cancer. But it is important to tell someone if you find any changes when you do your Breast Self Exam.

Checking our breasts once a month and working with our doctor or nurse are important ways women can take care of their bodies.
Some people only go to the doctor when they are sick.

But you should go to the doctor at least once a year, even if you do not feel sick.

When you go to the doctor, they will check to see if you are healthy. They will also examine your breasts, just like you do.

Some women feel embarrassed or just don’t want to go to the doctor. It is normal to be scared or nervous. If you feel this way, talk to a friend, your doctor or nurse about your feelings.
Go to your hospital or doctor’s office. You may go with a friend or caregiver.

You will need to check in at a desk.

You fill out some papers and then wait.

The nurse will call your name.

You will go to a small room and the nurse will ask you some questions about your life and health. The nurse will probably weigh you and measure how tall you are.

You will need to get undressed from the waist up, or totally undressed. If you need assistance with this, it is OK to ask for help.
Your doctor or nurse will come soon.

They will check on your health by listening to your heart, looking in your eyes and ears, and asking you to stick out your tongue.

Then they will do a breast exam. The steps are the same as the steps you do.

The doctor or nurse will look for changes in your breast such as size, shape, color, or lumps.

They are looking for anything that is different from the last time you visited.

They will feel both breasts, just like you do.
Will it hurt?
No. The doctor or nurse will just look at and feel your breasts. They will do the same things you do.

Do I have to get undressed?
Yes. Just like when you do your Breast Self Exam, you must take off clothing that could get in the way. Your doctor or nurse will probably give you a loose shirt to wear.

What is a mammography?
A mammography is like an X-ray of your breasts. It is another way to find hard lumps. Women usually start these at age 40. You can ask your doctor or nurse about them if you want to.

If I go to a doctor or nurse, do I still need to do my own Breast Self Exam?
Yes. Seeing a doctor or nurse does not replace a Breast Self Exam. You must still check your breasts once a month.

Do Breast Self Exams help?
Yes! Any woman can get breast cancer, but you can help find it early by doing a Breast Self Exam.
Taking care of our bodies is important, because we are important!

We all can get breast cancer, but we can all help find it.

We can do Breast Self Exams once a month. Breast Self Exams will help us find changes that may lead to breast cancer.

We can also see a doctor or nurse once a year.

These are important things we can do to keep healthy!
Isn’t it great to be a woman!
Women have fun.

We can make good choices.
We have control over our lives and health.

We can be happy and healthy.
Your Monthly Self Breast Exam Schedule

Use this calendar to help you do a Breast Self Exam once a month. Every time you do your exam, mark it on this calendar. You could write your name, make a check mark, or put a sticker on each month to show that you did your exam. An easy way to remember is by doing your exam at the end of your period each month. If you don’t have a period, be sure and do it on the same day of every month. And don’t forget to visit your doctor or nurse once a year!

Date of Yearly Doctor Visit: ____________________

Women First: Breast Health for Women with Developmental Disabilities
Tips for Care Providers

- Consider the whole woman. Just as every other woman needs preventative health care services such as screening for hypertension, diabetes, and breast cancer, women with disabilities need the exact same care.

- Accessibility has to be addressed both environmentally and behaviorally. Health care providers should look at the physical features of their facilities, as well as how people interact with and treat women with disabilities.

- Not only is it important to respect the feelings, opinions, and decisions expressed by women with disabilities, it is also critical to a woman’s health that she be encouraged to ask questions and express her own opinions.

- Always use people first language. This means to put the person first, disability second. (Ex. “person with a disability” not “disabled person”)

- Seek training and instruction in providing adaptive services in basic health care including breast examinations, mammograms, pelvic exams, and overall health screening techniques.

- Communication is critically important in providing good health care. When necessary, adapt how communication occurs. This may involve using interpreters, assistive technology, or restructuring the way questions are asked.

- Ask the person with a disability how they prefer to receive assistance and services. Every person is different, and although it is beneficial to be informed about disabilities in general, each person’s needs are unique.

- People with developmental disabilities are at a higher risk for abuse and violence than other individuals. Many times these crimes are committed by someone in the person’s life. Health care providers may want to privately screen for possible abuse.

Additional Resources

**Breast Health for Women with Disabilities:** Provides access to information on breast health for women with disabilities, especially developmental disabilities.
http://wind.uwyo.edu/breasthealth/

**Wyoming Institute for Disabilities:** Provides community outreach, training, education, and information dissemination services in the area of developmental disabilities.
Phone: 307-766-2761
Web Site: http://wind.uwyo.edu/

**WIND Resource Library:** Houses an extensive collection on developmental disabilities including many resources on breast health and accessible health care.
Phone: 307-766-2935
Web Site: http://wind.uwyo.edu/library/

**Women’s Health Source:** Provides a variety of services to assist women in receiving breast care, mammograms, breast cancer services and treatment.
Phone: 800-264-1296

**Wyoming Breast Cancer Resource Directory:** The web site contains a comprehensive directory of programs in Wyoming which provide breast cancer related services.
Web Site: http://wind.uwyo.edu/pathways/breastcancer/
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About WIND

The Wyoming Institute for Disabilities (WIND) has been a part of the University of Wyoming, College of Health Sciences since 1994. As a member of the national network of University Centers of Excellence in Developmental Disabilities Education, Research and Service, WIND provides teaching, research, information services, and technical assistance to both the University and Wyoming at large. Its major functions include teaching, research, information dissemination, and service in the broad area of disabilities, particularly in the area of developmental disabilities.

For More Information

More information about this project, as well as about people with developmental disabilities, please contact:

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