CHAPTER 6 Health exams



Women with disabilities need health exams

Many people think a disabled woman's only health concern is her disability and that she needs no other health examinations. But this is not true. Checkups with a health worker every 2 to 3 years, even if you feel fine, are an important way for a woman to find health problems early, when they can best be treated.

Women with disabilities often have a hard time getting exams. You may not want to get exams because you have grown up feeling ashamed of your body. Or you may not want anyone to touch your body. Or you may already have had so many exams and operations that you do not want to see another health worker.

But because regular exams are just as important for women with disabilities as they are for all women, learn as much as possible about them from this book and other resources. Then you can ask local health workers—and demand of hospital directors and ministers of health—to make these services available to you and other women with disabilities.

This chapter has information about breast exams (see page 128) and pelvic exams (see page 130). Getting these 2 exams is important for any woman to stay healthy. For more information about other health tests, see page 135.

WHAT REGULAR HEALTH EXAMS CAN TELL YOU

Sometimes a person can be sick and not realize it until the problem has become very serious and difficult to treat or cure. But many health problems can be found by having regular health checkups. Some of the health problems that can be helped if they are found early are: anemia (weak blood), tuberculosis (TB), HIV/AIDS and other sexually transmitted infections, malaria, some cancers, high blood pressure, worms and other intestinal parasites, and diabetes. Any woman, whether or not she has a disability, can have these problems.

Bringing health exams to the community



Lizzie Longshaw knew that most disabled women in her community in Zimbabwe never got pelvic or breast exams. Clinics that were accessible were too far away and too expensive for disabled women. But she knew how important these exams were

for women with disabilities. Because exams were not easy to get, many women did not learn about their health problems until it was too late and many died from cancer.

Lizzie, who is herself disabled, called together a group of women with disabilities. Together, they learned as much as they could about cancer and other health problems, and about how exams can help all women by finding problems early. The group then persuaded a representative from the Ministry of Health to meet with them about the health problems disabled women face. They explained how disabled women had trouble traveling to clinics and paying for health services. The representative was so impressed with how much the women had learned, he arranged for the government to provide a free, mobile clinic once a month to provide cancer screening and family planning services for disabled women in that community.

Two of the most important regular exams a woman should get are breast exams and pelvic exams. Two common cancers women develop are in their breasts and cervix, and these tests can help identify and treat them early.

How to prepare for breast and pelvic exams

Will you please tell me how you

will examine my

breasts?

You can prepare for a breast or pelvic exam by knowing ahead of time what is going to happen. Ask the health worker to talk about each step of the exam and to explain

anything you do not understand. It may help to think in advance of questions to ask her.

As a woman with a disability, you may have different needs during the exams. If possible, take a friend or family member who can stay with you the whole time. Talk with the health worker

about your specific needs before the exam so she can do them in a way that is safer and easier for you.

If you are deaf or cannot hear well, bring a friend with you who can use sign language to help you communicate with the health worker.

If vou are blind or cannot see well, bring a friend to explain and describe the exams. Ask the health worker to carefully explain what she is doing and what you cannot see.

If you have a mobility-related disability or cannot walk well, bring a friend, or plan ahead how to enter the clinic or health center.

If you have trouble understanding or learning, and the breast or pelvic exam makes you frightened, nervous, or uncomfortable, ask for someone you trust to stay with you during the exam.

Family members and caregivers can help women who have disabilities that affect learning or understanding:

• Talk about the exams in advance. A family member or friend can explain the exams to a woman who has trouble learning. Help her understand that these exams are important for her to be healthy. Describe what will happen during the exams and answer her questions. If you can, tell her who will do the exams.



- Visit the clinic before the exams, if possible. The day before the exams, try to go with her to the place where the exams will be done.
- Have someone she trusts go with her. If she wants, a friend or family member can stay with her during the exams. If the health worker who does the exams is a man, make sure a woman she trusts stays with her the whole time.

Health workers can help:

- **Explain the exams again right before.** Explain what will happen before starting the exams and ask if she has any questions. She will probably be less afraid if she can ask questions before the exams start.
- Show her any instruments you will use, such as the speculum. Make sure she knows what the speculum is before the pelvic exam so that it does not surprise her, and let her touch it if she wants to.
- Talk to her during the exams. Explain what is happening at each step. Tell her what you need to do next. Ask her if she is ready and wait for her to agree. That way she has some control over what happens.

The breast exam

A regular breast exam is a good way to make sure you do not have any signs of breast cancer. Most women have some small lumps in their breasts. These lumps often change in size and shape during her monthly cycle. They can become very tender just before monthly bleeding. Sometimes—but not very often—a breast lump that does not go away can be a sign of breast cancer. Many women get breast cancer which, if not treated, can kill you. Regular breast exams ensure that cancer can be found and treated early, when it can still be cured.



A sister or friend can do a breast exam for you if you cannot.

A trained health worker should examine your breasts every time you have a regular check-up or pelvic exam. She will use the exam method described in this chapter.

Even though a health worker may examine your breasts every year or two, you can examine your own breasts more often.

If your breasts are large, divide them into 4 parts and examine them one part at a time. You can draw a picture like this and make a mark if you find a lump anywhere.

If you cannot do it yourself, someone you trust can do it for you. It is best to get the same person to help each time. That way, the person who helps will know if something changes.

Try to examine your breasts once a month on the same day during your menstrual cycle (see page 75). If possible, always do it 7 days after your monthly bleeding starts each month. If you can do it regularly, you will learn how your breasts usually feel, and you will be more likely to know when something is wrong. Also, try to examine your breasts when you have enough time to relax and do the exam well.

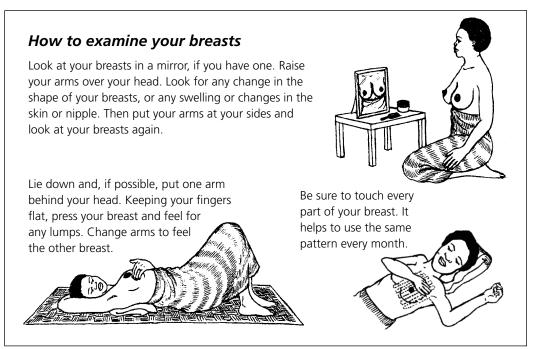
To help you remember how your breasts feel each month, make a simple drawing. Draw a large circle for the breast, and a smaller circle for the nipple. When you examine your breasts, if you feel any lumps, mark the place on the drawing. When you check again the next month, it will be easier to remember where any lumps were and if they are getting larger.

What to do if you find a lump

If the lump is smooth or rubbery, and moves under the skin when you push it, do not worry about it, but keep checking it each month. But if it is hard, has an uneven shape, and is painless or grows in size, keep watching it—especially if the lump is in only one breast and does not move even when you push it. See a health worker if the lump is still there after your next monthly bleeding. This may be a sign of cancer. You should also get medical help if there is a discharge from the nipple that looks like blood or pus.

Ask an experienced health worker to check **any** lump you find, whether it is smooth or uneven. **Continue having regular breast exams even after your monthly bleeding stops (menopause)**.

ONE WAY YOU CAN EXAMINE YOUR BREASTS



OTHER WAYS YOU CAN EXAMINE YOUR BREASTS



If you have weak muscles or your hands shake, you can use your other hand to guide your fingers. Or someone else can guide your hand. A helper can hold your hand up to your breast and keep your fingers in the right place.

Remember: If you get tired, take a break. You do not have to do the exam all at once.

The pelvic exam



If you cannot reach across your chest, you can use the hand that is closest to the breast.



If you cannot feel well with your fingers, you can use another part of the hand. You can use your thumb, your palm, or the back of your fingers. Be sure to feel all parts of your breast.

A pelvic exam can help you know if:

- you have any lumps, swelling, or sores, around your genitals. Some of these could be dangerous and may need treatment.
- you are pregnant.
- you have an infection in your womb, tubes, ovaries or vagina. Untreated infections are dangerous.
- you have cancer of the cervix, ovaries, or womb.
- you have other problems in the womb or the ovaries, such as fibroid tumors, endometriosis, or cysts that are not caused by cancer (see pages 81 to 82).

If you limp when you walk, or use a cane, crutch, or a wheelchair

If you have difficulty moving your body, you will know best how to move from one position to another. Ask your friend or the health worker to help. Before the pelvic exam begins, make sure you are well-balanced and feel safe and comfortable. (See pages 133 and 134 for some ideas.)

Before the exam, try to pass as much urine and stool as you can. The pelvic exam can easily make the muscles relax and cause urine and stool to come out. If you wear a catheter all the time, you do not need to remove it. It will not affect the exam. If you have a urine bag tied to your leg, remove it and place it either beside you or across your belly. Make sure the tube does not bend, and that it continues to drain properly.

Steps of the pelvic exam:

- 1. The health worker will look at your outer genitals for any swelling, bumps, sores, or changes in color.
- 2. Usually, the health worker will put a speculum into your vagina. A speculum is a small metal or plastic tool that holds the inside of the vagina open. She can then examine the walls of the vagina and the cervix for swelling, bumps, sores, or discharge. You may feel slight pressure or discomfort with the



speculum inside, but it should not hurt. The exam is more comfortable if your muscles are relaxed and your bladder is empty.

- 3. If the clinic has laboratory services, the health worker should do a Pap test for cancer and, if needed, tests for STIs. To do a Pap test, the health worker uses a small, rounded stick to scrape a bit of tissue off the cervix. This is not painful. You should feel only a little pressure. The sample of tissue is sent to a laboratory where it is checked for signs of cancer. If cancer of the cervix is found and treated early, it can almost always be cured.
- 4. After the health worker removes the speculum, she will put on a clean plastic glove and put two fingers of one hand into your vagina. She will press her other hand on your lower belly. In this way she can feel the size, shape, and location of your womb, tubes, and ovaries. This part of the exam should not be painful. If it is, tell her. It may mean something is wrong.
- 5. For some problems, the health worker may need to do a rectal exam. She will put one finger into your anus and one finger into your vagina. This exam can give the health worker more information about possible problems of the vagina, and of the womb, tubes, and ovaries. The rectal exam will be easier if you push against the health worker's finger when it first touches your anus—as if you are passing stool. This will relax the muscles around your rectum so the exam is less uncomfortable.

To the health worker:

In many clinics and hospitals, exam tables are high and hard to use for women who have difficulty moving their legs or holding them in place.

Tables closer to the ground are best for most women with disabilities. But you do not need to use a special table to do a pelvic exam. A health worker can do this exam on any clean, firm surface—even on a clean cloth on a clean floor.



A health worker at the clinic told me she could not do the exam because I could not get onto the table. So I asked her to do the exam on the floor. To examine someone on the floor, turn the handle of the speculum so it faces up when you put it into the woman's vagina. Otherwise the speculum will be hard to open. To

make sure the speculum does not touch the floor, put some folded cloth under the woman's hips to lift them a little.

Many women are frightened when they first see a speculum. They imagine that it must hurt them when it is put inside their vagina. When you examine a woman who has never had a pelvic exam before, show her a very small speculum, even if you plan to use a larger one. Make sure she is relaxed, touch her gently, and always explain what you are about to do. When the exam is finished, thank her for making it so easy for you to do the exam.

For more suggestions about making exams easier for women with different disabilities, see pages 133 and 134.

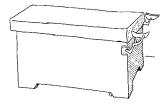
Take precautions to prevent dysreflexia (sudden high blood pressure with pounding headache)

Dysreflexia is common in people with spinal cord injuries. It is the body's reaction to something that would normally cause pain or discomfort, but which the person does not feel because of the injury.



During a woman's pelvic exam, dysreflexia can be caused by:

- a woman's body touching a hard exam table or surface (even if she cannot feel it).
- pressure in the vagina or rectum from the hands of the person doing the exam or from an instrument (such as a speculum), especially if it is cold.
- cold temperature in the clinic where the exam is being done.
- a urine tube (catheter) that has become bent or twisted.





A speculum can be used upside down to examine someone on the floor.

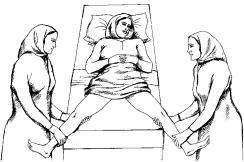
IMPORTANT If you examine a woman with a spinal cord injury, watch for signs of dysrelexia and be prepared to stop the exam. **Dysreflexia is a medical emergency.** The high blood pressure can cause seizures or bleeding inside the brain. Do not leave a person with dysreflexia alone. For signs and treatment of dysreflexia, see pages 117 to 119.

POSITIONS FOR A PELVIC EXAM

If you cannot separate your legs easily, this does not mean you cannot have the exam. Talk to the health worker about different positions that will work for your body. Here are some positions many women with physical disabilities use:



Women who have trouble with their hips may find this position easier. This position is good if there is no one to hold your feet, because many women can keep their legs in this position without tightening their muscles.



Some exam tables have places for a woman's feet to rest. Many women with disabilities do not use these footrests.



Some women use the footrests for support under their knees if they are unable to hold their knees up themselves.





This position works well for women who cannot move their legs on their own. It can also be good for women who have trouble bending their knees.

If you have stiff or tight muscles

Muscles can suddenly get tight and stiff during an exam. This happens mainly to women with a spinal cord injury or cerebral palsy. Sudden muscle spasms can happen when:

- you move onto an exam table.
- you are in an uncomfortable position.
- an instrument such as a speculum is put into the vagina.
- a health worker puts her fingers in the vagina or anus, as with a 'bimanual' or rectal exam.

If you have tight muscles, ask the health worker to go slowly so you have more time to relax. If a spasm happens during the exam, ask the health worker to stop and wait until your muscles are relaxed or soft again. Do not pull or push directly against the tight muscles. This will make the spasm worse. A friend can gently hold or support the affected place until the muscle is soft again.

The exam will be easier if you can find a comfortable position where you can relax and do not have to make your muscles tight to hold yourself in place. Or ask a friend or family member to help hold your body during the exam. If this is not possible, you can roll up blankets and put them underneath your knees.



A friend or family member can support your legs during the exam. Then you can relax your muscles, which makes the exam easier.



You can also roll up a blanket or use pillows to support your legs.

IMPORTANT Do not massage or rub spastic muscles. Massage will make the muscles tighter.

The pushing exercise

Women with cerebral palsy or spastic muscles often have a hard time relaxing their muscles. To help relax the pelvic muscles, you can practice a pushing exercise. First, practice pushing down as if you were trying to pass stool. Some women imagine they are laying an egg that comes out through the vagina. After a while, try taking a deep breath just when you start to push.

Practice this exercise before you have the exam. You can also do it again during the exam, especially before the health worker puts a finger or an instrument in your vagina. Once the health worker starts to examine you, it will help if you stop pushing and relax the muscles in your belly. If your muscles are tight, the health worker will not be able to feel inside you.

Other exams to stay healthy

All women can take better care of their own health when they know how to look for signs of illness. For example, you or a person you trust can use the information on pages 128 to 130 to check for signs of breast cancer.

There are other tests that can also be done at home by you, family members, or caregivers. But some tests are best done by a health worker in a clinic or hospital.

You can use a general health guide to learn to examine yourself, to learn the signs of different illnesses, or to learn more about the tests usually done in clinics. You can look at information in the books listed below: WWHND = Where Women Have No Doctor; MW = A Book for Midwives; and WTND = Where There Is No Doctor. All these books are available from Hesperian.

Exams that can be done at home:

- abdominal (belly) exam, to check for pain and unusual lumps (WWHND page 534)
- check for problems during pregnancy (MW pages 109 to 114)
- pulse check, to make sure the rhythm feels steady (WTND page 32 to 33)
- blood pressure (WWHND page 532) and temperature (WTND page 30)
- signs of anemia (WTND page 124)
- signs of hepatitis (WTND page 172)
- vision test (WTND page 33)

Exams that are done in a clinic or hospital:

- Pap test of the opening of the womb (cervix) to check for cancer
- tests for gonorrhea and chlamydia
- blood test for anemia
- blood test for syphilis
- blood test for HIV
- blood test for hepatitis A, B, or C
- blood test for malaria (especially important for pregnant women)
- urine tests for diabetes
- stool test for worms and parasites
- mucus (sputum) test for TB
- urine or blood test for pregnancy
- urine test for infection of the bladder or kidneys



Working for change

What women with disabilities can do

We can always ask to have breast and pelvic exams when we see a health worker. Also, we can get together as a group and study this and other health books to gather as much information as we can about the exams women should have. Then we can ask local

Learn as much as possible about health exams from this and other health books.



health workers, and also hospital and clinic directors, to make these services available to us. As a group we can tell the Ministry of Health how important these exams are to women with disabilities.

People First makes easy-to-understand health booklets

In 1997, several women with learning difficulties started a women's group, called People First Liverpool, so they could learn more about women's health care. They worked with a women's health clinic to produce several booklets that would make health exams easier to understand. To find out more about these booklets, see page 381.



Learning about sexuality and fertility

Kranti and Sabala are health workers in one of the poorest communities in India, where most women, with and without disabilities, are unable to get any health care.

They have taught women how to examine and understand their own bodies. They have looked at problems, such as unusual vaginal discharge, and



discussed fertility awareness and sexuality. They have focused on finding remedies to problems that the women can do themselves and that do not require lots of resources.

What families and caregivers can do

Friends and families of women with disabilities can help by talking with disabled women about how important it is for all women to get regular exams. Learn to describe what will happen during the exam and why the results are important to know. Encourage women with disabilities to share what they know about exams and the ware health workers can adout the average



Offer to go with me to get the health exam and stay with me if I choose.

Many women are

anxious or afraid the

first time they have

an exam, especially a pelvic exam.

the ways health workers can adapt the exams to their needs.

Also, talk about the barriers in clinics and hospitals that keep women with disabilities from getting exams, and what can be done to make getting exams easier.

As your disabled daughter grows from a girl into a woman, help her to not be afraid of exams. Together, you and your daughter can work to make sure clinics are accessible, health workers are trained, and transportation is available.

What health workers can do

Health workers can begin by talking with a woman before any exam. Explain what is going to happen, answer her questions, and tell her she can ask questions during the exam too.

Help women with disabilities understand why it is important for them to have health exams, including both pelvic and breast exams. You can explain why these exams are important for all women. Explain that a disabled woman can have these exams, even if it is hard for her to move her arms and legs. Explain that disabled women and their health workers have found many different positions women can use for these exams. Remember that the disabled woman understands her body better than anyone. So ask her to let you know how much she can move and if she will need another person to help.

Women are often taught not to touch their own bodies, and not to complain. Because of this, many women are uncomfortable doing the breast exam, or telling someone they have an unusual pain in the belly. Women are sometimes embarrassed to talk about sex or the sexual parts of the body. So it may be difficult for them to talk about a discharge from the vagina. Health workers can help by encouraging women in their communities to feel comfortable touching their bodies and talking about any problems they may have.

Always speak directly to the disabled woman and ask her about her health problem, even if there is someone else in the room assisting her. Talk with her as you do with other people, even if she has difficulty speaking with you.

When you examine a woman who is blind or cannot see well

For a blind woman, going to an unfamiliar place like a clinic can be confusing. She does not know where things are or where to go. Sometimes people treat blind women roughly or move them around. This is not very respectful.

When you guide a blind woman, do not take hold of her arm or hand. Many blind women rely on their hands to "see," by touching. Instead, offer her your arm and let her hold your arm or rest her hand on yours. Tell her where things are and where you are going. Then she will learn how to get around the space better on her own and will feel more comfortable during the exam.



When you examine a woman who is deaf or cannot hear well

For deaf women, going to a clinic can be very frustrating when no one there can use sign language. Sometimes, a deaf woman will bring with her someone who can



hear, and who knows her sign language and can interpret for her. If she does, make sure you look at the deaf woman and not at her interpreter when you speak to her and when she speaks to you. This includes when you listen to the interpreter. Look only at the deaf woman. The interpreter is there to help, but the deaf woman is the person who has come to you to receive health care.

When you examine a woman who has trouble learning or understanding

Women who have trouble learning or understanding should still get information about their health and should help make decisions about their bodies. You may need to take more time to explain things to a woman who has trouble learning. Instead of just asking her if she understands, ask her to tell you in her own words what she has learned.





I used to wait for disabled women to ask me about pelvic or breast exams. But most women with disabilities are surprised to find out they can have these exams, or they feel embarrassed to talk about them. Now I make sure to ask if they know about the exams all women should have.